



**SEXUAL AND REPRODUCTIVE HEALTH (SRH) NEEDS OF ADOLESCENTS  
GROWING WITH PERINATALLY ACQUIRED HIV AT MZUZU CENTRAL  
HOSPITAL**

**MSC (CHILD HEALTH NURSING) THESIS**

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## **Declaration**

I, Thom George Ngwira, the undersigned declare that this thesis is my own work. To the best of my knowledge this thesis has never been presented for the award of any academic certificate within institutions of higher learning. Citations and acknowledgements have been made where other peoples work has been used.

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**Legal full name**

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**Date**

**Certificate of Approval**

The undersigned hereby certify that this is Thom George Ngwira’s own work and has been submitted with my approval.

Signature.....Date.....

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## **Dedication**

This work is dedicated to my wife Eunice and our three children Latoya, Lincoln and Lingalithu for the time they endured while I was in school and their moral support.

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I thank God the Almighty for keeping me healthy, His ever protection and for the provision of knowledge and wisdom whilst studying in Cape Town and Blantyre. Am also indebted to the following individuals and institutions;

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The opinions expressed and the conclusions arrived at in this paper are those of the researcher and not attributed to my research supervisors.

## **Abstract**

**Introduction:** Adolescents with perinatally acquired HIV are growing up to adulthood. Data from the Rainbow Clinic in 2015 indicated that there were 94 adolescents growing up with perinatally acquired HIV accessing services at the hospital. Provision of the services at the Clinic is ill-equipped to address the specific age-appropriate sexual and reproductive health needs of adolescents growing up with HIV. This is complicated in adolescents with perinatally acquired HIV who have both psychological and physiological problems. This study sets up to explore the SRH needs for adolescents growing up with perinatally acquired HIV from the service providers and the adolescents themselves.

**Methodology:** This study was qualitative in nature that used an exploratory design to understand the SRH needs for adolescents growing up with perinatally acquired HIV. Qualitative data was collected from seventeen adolescents growing up with perinatally acquired HIV and five service providers using semi structured interview guides and focus group discussion for a period of approximately four weeks. The thematic content analysis was used to manage and analyse data manually.

**Results:** Study results revealed that a generalised lack of knowledge on sexual and reproductive needs among adolescents growing up with HIV accessing services at the clinic. The clinic also is not yet integrated to provide a full range of sexual and reproductive health services together with HIV services. Access to information on SRH is limited as adolescents are not adequately provided with this information. However adolescents suggest practical strategies to improve SRH service delivery.

**Discussion and conclusion:** Adolescents growing up with HIV need age appropriate services that are comprehensive as to assist them with the challenges they face as they grow up with HIV in order to improve their quality of life. The need for adolescents to access

services under one roof ensures that adolescents living with HIV can have an easy access to both HIV and SRH services rather than HIV treatment and care alone.

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### **List of Abbreviations**

<b>AIDS</b>	:	Acquired Immune Deficiency Syndrome
<b>ART</b>	:	Antiretroviral Therapy
<b>COMREC</b>	:	College of Medicine Research Committee
<b>HIV</b>	:	Human Immunodeficiency Virus
<b>SRH</b>	:	Sexual and Reproductive Health
<b>SSA</b>	:	Sub-Saharan Africa
<b>YFHS</b>	:	Youth Friendly Health Services
<b>UNAIDS</b>	:	The Joint United Nations Program HIV/AIDS
<b>UNFPA</b>	:	United Nations Population Fund
<b>UNICEF</b>	:	United Nations Children Fund
<b>WHO</b>	:	World Health Organization

## **Definition of Terms**

**Child:** The UN Convention on the Rights of the Child defines a child as everyone less than 18 years unless, "under the law applicable to the child, majority is attained earlier."

**Adolescents:** The World Health Organization (WHO) defines adolescents as those people between 10 and 19 years of age. The great majority of adolescents are, therefore, included in the age-based definition of "child", adopted by the Convention on the Rights of the Child, as a person under the age of 18 years.

**HIV/AIDS:** The human immunodeficiency virus (HIV) is a retrovirus that infects cells of the immune system, destroying or impairing their function. As the infection progresses, the immune system becomes weaker, and the person becomes more susceptible to infections.

**Perinatally Acquired HIV:** Perinatally acquired HIV (human immunodeficiency virus) is transmitted from mother to child during pregnancy, labour and delivery and breastfeeding.

**Service providers;** Service providers refers to a health professional working in the study area at the time of data collection and having certification to work in health service institutions in direct care of adolescents growing with HIV.

**Sexual and Reproductive Health:** Sexual and reproductive health is a state of complete physical, mental and social well-being in all matters relating to the reproductive system.

**Sexual and Reproductive Health needs:** SRH needs of adolescents with perinatally acquired HIV includes access to promotion of sexual health, provision of high-quality services for family planning, information and negotiating skills on safer sex, combating sexually transmitted infections among those receiving antiretroviral therapy and issues relating to self esteem, worries as well as experiences of sexual and physical violence.

# CHAPTER 1

## Introduction and Background

### Introduction

Globally, children with perinatally acquired HIV are growing up to adolescence. An estimated 2.1 million adolescents aged 10–19 years are HIV positive worldwide (UNAIDS, 2013b). In the Sub-Saharan region including Malawi, there is a growing population of adolescents with perinatally acquired HIV infection (Pettitt 2014, Birungi, Obare, Mugisha, Evelia, & Nyombi, 2009). WHO (2014) defines adolescents as young people between the ages of 10 and 19 years who make about 20% of the world's population. Adolescence is a specific developmental phase between childhood and adulthood, characterized by physiological, social, and behavioural changes; sexual maturation, increasing independence and evolving legal capacity (Hodgson, Rossa, Gitau-Mburua, & Choolwe, 2012). Adolescents may be curious and sometimes be under the influence of peers and/or substances which may make them fall prey to sexual activities. Jobson (2014) noted that as part of the transition from childhood to adolescence, adolescents growing with HIV experience sexual feelings. Some adolescents act on these feelings by having sexual intercourse or may masturbate, some may engage in anal intercourse or oral sex (World Health Organization, 2014). This is complicated in adolescents with perinatally acquired HIV who have both psychological and physiological problems as they grow up to adulthood. Psychologically, they face a lot of behavioural and mental disorders due to denial as they fail to accept that they are infected by their parents and are in shock and disbelief. Physiologically, HIV infection that was acquired perinatally evolves from a fatal childhood illness to a chronic medical condition of the adolescence. The chronic medical condition normally alters the experience and timing of developmental milestones for the adolescents. It also alters the interactions among biologic and HIV-related stressors such as sero-status disclosure, medical

treatment adherence, illness stigma that can negatively influence both physical and sexual development of adolescents with perinatal HIV.

Poverty normally prompts adolescents to engage in sex as a source of income and puts them at risk of trafficking and/or sexual exploitation by adults (UNICEF, 2007). This becomes more challenging to adolescents who are growing with HIV, are poor and have lost their parents to HIV. Malawian women begin sexual activity 1.7 years before Malawian men with the median age at first sexual intercourse for women age 25-49 is 16.8 years, compared to 18.5 years among men age 25-49 (MDHS, 2016). With young people engaging in sex as early as 16 years, addressing the sexual and reproductive health needs of this unique population is therefore critical. As such, practical-and-age-appropriate HIV interventions in sexual and reproductive health are needed to reduce secondary HIV transmission among adolescents and to promote optimal sexual and reproductive health outcomes.

## **Background**

Worldwide, more than three million children were infected with HIV and approximately 90% of these HIV-infected children lived in sub-Saharan Africa, including Malawi (Idele, et al. 2014). The situation puts the Sub-Saharan Africa almost facing same challenges when it comes to adolescents growing with HIV (Beksinska, et al., 2014, Mburu, et al., 2014, Birungi, et al., 2009 and Godia et al., 2013). The growing population of adolescents with perinatally acquired HIV infection living within this region presents with unprecedented challenges and opportunities to learn about the pathogenesis of HIV infection (Lowenthal, et al. 2014). Adolescence is the period when many people begin to explore their sexuality as a result, access to sexual and reproductive health information and services becomes increasingly important (Idele, et al. 2014). In Malawi, almost half of the children living with HIV are on treatment making it even worse as the other half is not on treatment (UNAIDS 2016). There is an increasing number of perinatally-infected children who are

growing into adolescence and are becoming sexually active. Early sexual debut in Malawi (before 15 years of age) provides more opportunities over time for adolescents to be exposed to HIV, especially where higher risk partners or multiple partners are involved and condom use is less likely. This brings more concerns about both secondary sexual transmission and third generation mother to child HIV transmission as they grow to young adulthood (Lowenthal, et al. 2014). A global level analysis indicates that adolescents (aged 10-19 years) are the only age group where AIDS-related deaths are not decreasing but deaths among other age groups declined by more than 40 per cent between 2005 and 2014 (UNAIDS, 2015). This indicates that adolescents are growing up with HIV are dealing with chronic illness. In addition to dealing with chronic illness, HIV-infected adolescents have to confront psychosocial issues, maintain adherence to drugs, and learn to negotiate sexual relationships, while undergoing rapid physical and psychological development (Lowenthal, et al. 2014). It is therefore, imperative that HIV care should integrate practical-and-age-appropriate sexual and reproductive health and psychological, educational, and social services. Adolescents growing with perinatally acquired HIV are generally perceived to be in good health and their sexual and reproductive health needs are often overlooked. Sexual and reproductive (SRH) needs of adolescents growing with perinatally acquired HIV includes access to promotion of sexual health, provision of high-quality services for family planning, information and negotiating skills on safer sex. Combating sexually transmitted infections among those receiving antiretroviral therapy and issues relating to self esteem, worries as well as experiences of sexual and physical violence are also part of the SRH needs (Birungi., et al. 2009, Hodgson., Rossa., Gitau-Mburu., & Choolwe., 2012, Dorrell & Katz, 2014, Lowenthal. et al., 2014). Nonetheless, because adolescents are central to the HIV/AIDS pandemic, adolescent sexual reproductive health deserves careful attention. Efforts to improve SRH in adolescents with perinatally acquired HIV should focus on gaps in service delivery rather

than education and information activities alone as is currently the case at Mzuzu Central Hospital. What can be found in the literature is limited and ultimately inadequate to represent the evidence base in this area (Idele. et al., 2014). While it is possible that there may be SRH needs of adolescents with perinatally acquired HIV much does not appear in the literature.

Service providers encourage adolescents perinatally infected with HIV to refrain from or postpone sexual initiation (Birungi. et al., 2009). Nonetheless, adolescents begin to explore their sexuality and engage in sexual relationships as such there appears to be a significant disconnect between service providers and adolescents (Albright & Fair, 2014). This implies that, firstly, service providers seem un-prepared to find out whether their clients are sexually active in order to provide age appropriate information and services on prevention of pregnancy and other STIs, re-infection and secondary transmission of HIV. Secondly, sexually active adolescents living with HIV are left un-prepared and unable to negotiate contraceptive use or access contraceptive methods and other preventive services (Jobson., 2014, Pettitt, Greifinger, Phelps, & Bowsky, 2014). This puts them at risk of engaging in sexual practices that may lead to further transmission of HIV or unwanted pregnancies.

Although Malawi has made significant strides in reducing HIV infections, statistics showed that there were 66,000 new infection occurring annually especially among adolescents aged 15-24 (UNAIDS, 2013a). In 2016 it was estimated that 90,000 adolescents were living with HIV and over 90% were children growing with perinatally acquired HIV (UNICEF report 2016). There was also limited literature that had focused on sexual and reproductive needs of these adolescents in Malawi. In this context, UNICEF/UNAIDS (2013) report urged all stakeholders to increase scaling up access to treatment, psychosocial support and adoption of safe sexual behaviour such as abstinence and use of condoms for adolescents with HIV. UNICEF (2014 pp 15), further observes that research and experience showed that adolescents were somehow a “forgotten group” when it came to HIV/AIDS prevention and

services. This was supported by Pettitt, et al, (2014) who believed that the clinical, psychological, social, and reproductive health needs of adolescents growing with HIV remain poorly understood and efforts to mobilize and advocate for their treatment, care, and support had been inadequate. Yet most of the adolescents living with HIV were believed to have reached puberty in Malawi which is the time in life when a young person starts to become sexually active (Baryamutuma & Baingana, 2011). Hodgson, et al, (2012) concludes by noting that living with HIV magnifies the need for effective support in this developmental phase, particularly as HIV-positive adolescents begin sexual relationships, assume greater responsibility for treatment adherence, and prepare for adult life. Therefore, it was against this background that this study sought to focus on adolescents growing with perinatally acquired HIV.

### **Statement of the Problem**

An escalating number of adolescents with perinatally acquired HIV globally, continue to grow up to adulthood including in Malawi. Slogrove, et al, (2018) notes that there are 38,000 adolescents living with perinatally acquired HIV and 79% are living in sub-Saharan Africa. According to the National AIDS Commission (NAC) (2009), it was estimated that 10% of children and young people in Malawi had HIV, and over 90% of these had acquired HIV perinatally. As for Mzuzu Central Hospital, data in 2015 at indicated that there were 94 adolescents growing with perinatally acquired HIV accessing ART services but with minimal provision of SRH services. As adolescents are growing up, they start indulging in sexual activities. In 2015, out of 94 adolescents, seven adolescents were treated with sexually transmitted diseases, four of them became pregnant and 71 were accessing condoms. This data signifies that as adolescents with perinatally acquired HIV are growing up, they are engaging in unprotected sexual activities which may result in transmitting HIV to their sexual partners or babies and/or re-infecting themselves with a different trait of HIV. However, SRH

outcomes among these adolescents, their sexual and reproductive health needs and how they are met remain poorly understood since the services provided at the clinic are designed around adult care. For instance, the services that are being provided to adolescents concentrate much on education on prevention of sexually transmitted diseases, family planning rather than actual provision of SRH services during teen club meetings. However, there is no literature to indicate that SRH needs for adolescents growing with perinatally acquired HIV were identified at the Clinic in the Northern region of Malawi. Therefore this study focused on the SRH needs for adolescents growing with perinatally acquired HIV.

### **Significance of the Study**

The study explored the SRH needs of adolescents growing with perinatally acquired HIV from the perspectives of the adolescents themselves. To add value to the study, the service providers were also interviewed to triangulate SRH needs from the service providers' perceptions. Adolescents growing with HIV are regarded as the "insiders" which means their narratives provide the "insider view" of the adolescents SRH needs. As research is a catalyst for change, it provides information that will be used for interventions aimed at improving the services at the Rainbow Clinic. This information is intended to provide insights to health workers to provide practical-and-age-appropriate SRH services and quality care to the adolescents. It would also act as a basis for further research in SRH needs for adolescents growing with perinatally acquired HIV and improve service providers' understanding of this unique group and their SRH experiences in Malawi hence promoting their optimal SRH outcomes. Furthermore, the findings will have implications on the quality of care and patient experiences. The implication to practice, theory or policy, is that standards of care will be considered and a more holistic focus adopted in order to meet the SRH needs for adolescents who acquire HIV perinatally.

## **Objectives of the study**

### **Broad objective.**

The broad objective was to explore the SRH needs for adolescents growing with perinatally acquired HIV at Mzuzu Central Hospital.

### **Specific objectives.**

- To identify SRH needs from the perspectives of the adolescents growing with perinatally acquired HIV.
- To establish adolescents perceptions' on the SRH services offered at Mzuzu Central Hospital.
- To determine service providers' perceptions of SRH needs of the adolescents growing with perinatally acquired HIV.

## CHAPTER 2

### Review of Literature

#### Introduction

According to Brink, Walt and Rensburg (2014), literature search and review is a crucial element of the research process. It frequently means the difference between a focused, thorough and well-designed study and one that is fragmented, incomplete and poorly planned. Burns & Groove (2011) states that a literature review is an organized written presentation of what has been published by scholars. The purpose of the review is to convey to the reader what is currently known regarding the topic of interest.

The literature review was conducted using multiple search databases to ensure coverage of research deriving from multiple disciplines related to this topic. The electronic search databases included Ebscohost, Google Scholar, PsycINFO, PubMed (includes MEDLINE) CINAHL and Google and employed keywords and various combinations of search terms as follows: perinatally acquired HIV, adolescent, SRH Needs, Malawi, Africa. The decision to choose articles published between 2009 and 2017 was made to ensure that current literature was used and 72 articles were downloaded and analysed for this review. Health research is a fundamental prerequisite to the evolution of solutions to health problems. Specifically, research is essential to identify needs and priorities, demonstrate effectiveness, and reveal an understanding of specific social and cultural issues that should guide health policies and clinical practices (Powell et al., 2014). This literature review overview is based on published literature and has been organised into four main parts. Firstly, the prevalence of HIV among adolescents growing with HIV and their SRH needs globally. Secondly the prevalence of HIV among adolescents growing with HIV and their SRH needs in Sub-Saharan Africa. Thirdly the prevalence of HIV among adolescents growing with HIV and

their SRH needs in Malawi. Literature review will also present whether service providers view the services they provide do meet the needs of the adolescents.

The literature review in this chapter will be guided by study objectives. The first objective was to identify SRH needs for adolescents growing with perinatally acquired HIV at Mzuzu Central Hospital. The SRH needs of adolescents with perinatally acquired HIV as defined by this study include access to promotion of sexual health, provision of high-quality services for family planning, information and negotiating skills on safer sex, combating sexually transmitted infections among those receiving antiretroviral therapy and issues relating to self esteem, worries as well as experiences of sexual and physical violence.

### **Prevalence of HIV among Adolescents Growing with HIV**

Worldwide, more than three million children are infected with HIV and approximately 90% of these HIV-infected children live in sub-Saharan Africa (Idele. et al., 2014). In 2016, UNAIDS reported that the trend in new HIV infections among adults (aged 15 years and older) had remained static between 2010 and 2015 at 1.9 million new infections per year (2015 range of 1.7 million–2.2 million). In 2017, however, UNAIDS estimates show a slightly different trend: new adult infections are estimated to have declined by 8% between 2010 and 2015, and by 11% between 2010 and 2016 (UNAIDS, 2017). However a global level analysis indicates that adolescents (aged 10-19 years) are the only age group where AIDS-related deaths are not decreasing but deaths among other age groups declined by more than 40 per cent between 2005 and 2014 (UNAIDS, 2015). AIDS-related deaths among adolescents have tripled since 2000 from 18,000 to 41,000 in 2015 which can be largely attributed to a generation of children infected with HIV perinatally that are growing into adolescence with delayed or without access to life-saving interventions. WHO, (2016) attributes this to the fact that complications from pregnancy, childbirth, and unsafe abortion are a leading cause of death for young women aged 15 to 19 because when girls give birth

before age 18, there is also increased risk of death or disability to their newborn. As such, Save the Children (2016) recommends that global health indicators highlight the need to have a greater focus on adolescents growing with HIV.

UNICEF, (2011) notes that these adolescents are now expected to survive or already surviving into adolescence and will face the potential consequences of prolonged HIV infection. According to WHO (2016) global findings indicate that many adolescents are sexually active and are at risk of adverse reproductive health outcomes that subsequently affect achievement of life goals and optimum contribution to national development. Many adolescents initiate sexual intercourse early, have multiple partners and often do not use condoms for protection during sex which can lead to sexual and reproductive ill-health and HIV. The importance of linking sexual and reproductive health (SRH) and HIV responses has to be overemphasized. UNAIDS (2013b), notes that sexual and reproductive health programmes such as family planning (FP), maternal and newborn health (MNH), promotion of sexual health, prevention and management of gender-based violence, prevention of unsafe abortion and management of post-abortion care need to be improved in context of growing with HIV. Therefore adolescents growing with HIV are vulnerable due psychological and physiological problems need life skills to enable them make informed choices on sexual and reproductive health in order to maximize their potentials.

In the Sub-Saharan region, the UNAIDS Gap report (2015) contributes that AIDS related illnesses are the most leading cause of death among adolescents in Africa and the second most common cause of death among adolescents globally. UNAIDS (2014) notes that percentage of people living with HIV who are not receiving antiretroviral therapy has been reduced from 90% in 2006 to 63% in 2013. Among adolescent girls, aged 15–19 years, in sub-Saharan Africa, a higher percentage of girls (13%) than boys (9%) have had sex before the age of 15 years (Idele et al., 2014). While treatment access among African children still

lags behind that of adults, in some areas over 40% of perinatally HIV-infected children in need of antiretroviral therapy are now receiving it (Shriver, 2012). As the HIV epidemic matures and antiretroviral treatment is scaled, children with HIV are reaching adolescence in large numbers (Lowenthal. et al., 2014). Dealing with such a macroscopic problem needs concerted effort to mitigate the problems adolescents face as they grow with HIV.

Adolescents growing with HIV develop sexual needs and desires. Yet their sexual and reproductive health (SRH) needs have not been fully addressed within the service provision and HIV/AIDS programs (Obare, Birungi, & Kavuma, 2010). Chronic illness affects adolescent development which in turn can impact the course of the illness itself. The short- and long-term consequences of these adverse effects in the setting of the rapidly evolving hormonal, metabolic and psychosocial milieu of adolescence are unknown (Shriver, 2012). Lack of awareness and other social pressures and power imbalances among adolescents can put their health at risk. The growing population of adolescents with perinatally acquired HIV infection living within this region presents with unprecedented challenges and opportunities to learn about the pathogenesis of HIV infection (Lowenthal. et al., 2014). Lowenthal et al., (2014) indicates that HIV infection that was acquired perinatally when the immune system was not well developed normally results in chronic clinical complications that cause severe morbidity. Despite this, Mofenson & Cotton, (2013) contributes that success in the prevention, access and treatment of paediatric HIV infection has changed the face of the HIV epidemic in children from a fatal illness to that of a chronic illness. In addition, to dealing with chronic illness, HIV-infected adolescents have to confront psychosocial issues, maintain adherence to drugs, and learn to negotiate sexual relationships, while undergoing rapid physical and psychological development (Lowenthal. et al., 2014). Adolescents growing with HIV are at high risk of re-infecting others with HIV or themselves getting re-infected. It is imperative that their needs have to be understood and be addressed.

Additionally, while the mortality of HIV in children in sub-Saharan Africa is very high in the absence of treatment, approximately 13-17% of perinatally HIV-infected children have slow HIV progression and will survive to over 10-15 years of age without treatment (Shriver, 2012). Progress has been dramatic in stopping new HIV infections among children. These successes pose new management challenges as perinatally infected children are surviving into adolescents (Mofenson & Cotton, 2013). This demands an improvement in sexual and reproductive health service delivery as adolescence is a time of risk-taking behaviours including substance use and early initiation of sexual activity, which carry particular concerns for transmission of HIV.

In a study conducted in Uganda, Atuyambe et al., (2015) found that the various adolescent Sexual and Reproductive Health (SRH) needs that were reported ranged from condoms, teenage medical centres and post abortion care services, the need for condoms to be put in accessible places at no cost and the need for a youth counsellor. The other need included post abortion care services as a great need that was not catered for. However, in a study that was conducted in Botswana, Schaan et al., (2012) found that there was a potential for HIV-positive young women to experience lack of information, misinformation, and possible discrimination when seeking SRH services at ART clinics. While overall, the knowledge, attitude and practice (KAP) of respondents were adequate and positive, many still lacked facts about contraception, pregnancy risks, and the association between HIV and hold attitudes which can alienate HIV-positive women from seeking SRH services. In another study conducted in Zambia, it was revealed that awareness levels of HIV and SRH among adolescents varied widely. While respondents were aware of how HIV spreads, and use of condoms to prevent transmission, other SRH knowledge was less prevalent (Hodgson 2012).

A study in South Africa revealed that adolescents have a relatively high risk of contracting HIV. George & Sprague (2011) adds that HIV prevention programmes that

address both the behavioural and structural drivers of HIV risk are therefore critical.

However, given the already high HIV prevalence in this population, and the high risk of HIV infection faced by adolescents, care and support of the adolescents with HIV need increased attention. In another study in South Africa, Beksinska, Pillay, Milford, & Smit, (2014) observed that participants noted that services were often isolated in terms of having contact with other adolescents who were also HIV positive.

In a study conducted in Ghana, Dako-Gyeke & Ntewusu (2012) observed that while some adolescents accessed the services, they as well engaged in risky sexual practices due to factors such as poverty. The findings also revealed that adolescents utilizing the SRH services reported poor knowledge and usage of contraceptives, high fertility rates and high incidence of HIV among adolescents. Since these adolescents are sexually active, it has important implications for consequential prevention of HIV infection hence there is need of groundbreaking intervention programs offering age-appropriate reproductive health education and services. In Uganda a study by Birungi et al. (2008) showed disconnect between the information the service providers give to the young people, their actual needs and desires. The promotive services that were explored in the study from Uganda were information, family life education, communication, counselling and contraceptive use. During the interviews, the key informants provided explanations, which indicated that these services, utilized by adolescents, had contributed to an improvement in their sexual and reproductive health. An important aspect of the service provision was the creation of a peer group where adolescents could not hide their HIV status. Some also reported that some health workers give adolescents medicines to take home in case they want to abort or even help with illegal abortions (Atuyambe et al., 2015). Therefore services that target should be tail made in line with the goal of improving their welfare and quality of care.

Nearly half of the HIV-positive adolescents desire to have sex and many have had sex or intend to have sex in future (Bauermeister, Elkington, Robbins, Kang, & Mellins, 2012). In a study on Sexual and reproductive health needs of adolescents living with HIV in Kenya Birungi & Obare, ( 2011) found that more than half of the adolescents living with HIV felt that someone living with HIV should have sex and a similar proportion have had sex. Among those who have had sex, about two-thirds had consensual first sex. Besides, among those who have never had sex, nearly nine-in-ten intend to have sex in future with most (three-in-four) of them planning to wait until marriage before having sex. Most of the HIV-positive adolescents have ever been in a relationship; many are in or intend to be involved in relationships. And that about eight-in-ten of those who have never been in a relationship intend to be involved in relationships in future while among those who are not married or living with someone, a similar proportion intend to marry in future. With all these surveys from other African countries, with who Malawi shares most characteristics, research should also be conducted and bring country specific interventions to adolescents growing up with HIV.

While in Malawi with an estimated population of 16.7 million people, half of the population is under the age of 18, making it one of the youngest populations in Southern Africa (UNAIDS, 2014). However Malawi's HIV prevalence is one of the highest in the world, with 8.8% of the population living with HIV. It is noted that 4.5% of young females and 2.7% of young men are growing with HIV in Malawi (UNAIDS, 2013b). MDHS,(2016) reports that knowledge of contraceptive methods is almost universal in Malawi, with 98% of women and nearly 100% of men age 15-49 knowing at least one method of contraception. Nearly eight-in-ten of the adolescents surveyed know of a contraceptive method and similar proportions know of a place to get a method (WHO b, 2014). MDHS,(2016) reports that about 6 in 10 married women age 15-49 use a method of family planning—58% use a

modern method and 1% use a traditional method. Injectables are the most popular modern method (30%), followed by implants (12%), and female sterilisation (11%). Contraceptive injections accounts for most of women's contacts with providers and were generally administered at outreach clinics or at providers' or women's homes by low-cadre health care providers in Malawi (Nandini, Dasgupta, Zaba, & Crampin, 2015). This indicates that as a country Malawi has a huge burden of adolescents growing with HIV who know about contraceptive methods and yet they do not utilise them.

In general, adolescents growing with HIV are unlikely to seek health services, and when they do they are likely to get inadequate services (Ministry of Health, 2015). Despite the increasing numbers of perinatally HIV-infected adolescents with growing access to antiretroviral therapy as well as survival of youth with slowly progressive perinatal infection, Shriver (2012) notes that there is a scarcity of data about perinatally-infected adolescents in settings like Malawi. This situation presents Malawi with the challenge to ensure that this large group of young people stays safe and become useful citizens of the country in the near future (UNICEF, 2014).

Due to high levels of poverty in Malawi, the tendency among young female adolescents to have sexual intercourse with older men who can cater for the financial needs is becoming apparent. As such, adolescents have to survive all the economic and social hardships that come with abject poverty. HIV/AIDS also remains one of Malawi's major social and economic problems compounding the problems adolescents face when growing up to adulthood. HIV prevalence among young people is estimated at 6 per cent. Infection rates among females 15 -24 years of age are over four times as high (9.1 per cent) as among males in the same age group (2.1 per cent) leaving the girls more vulnerable than boys. UNICEF (2014), reported that 43 per cent of children aged 11 – 14 years in Malawi demonstrated a desirable level of knowledge on HIV/AIDS and sexual and reproductive health, suggesting

that this age group has been relatively neglected with regards to HIV/AIDS and SRH education and services. But this is in contrast to Munthali, Chimbiri & Zulu, (2004) who observed that nearly all adolescents aged 15–24 reported knowledge of at least one method of family planning in the 2000 DHS. The government of Malawi believes that the country has come a long way in responding to the HIV and AIDS pandemic and recognises that the national HIV and AIDS response is mature and must continue to receive increased support and commitment from all stakeholders (Department of Nutrition, HIV and AIDS, 2013).

Idele et al. (2014) reported that in most low- and middle-income countries, early sexual debut is common—almost 30% of adolescent girls aged 15–19 years in Malawi reported having first sexual intercourse before they were 15 years old. Early sexual debut in Malawi (before 15 years of age) provides more opportunities to high risk behaviours over time for adolescents to be exposed to HIV, especially where higher risk partners or multiple partners are involved and condom use is less likely. Nonetheless, only about two-in-ten of those who had consensual first sex used a preventive method that first time. In addition, among those who have ever had sex, slightly more than half have ever used a method while less than half reported current use of a method. There are also tendencies from older men who choose to have sex with younger girls to avoid HIV infection due to the belief that younger girls are likely free of HIV infection known as *chidyamakanda* which can result into pregnancies. This brings more concerns about both secondary sexual transmission and third generation mother to child HIV transmission as they grow to young adulthood (Lowenthal et al., 2014). In conclusion, there are diverse SRH needs for adolescents' growing with HIV in the globally, in Sub Saharan Africa and Malawi in particular.

Baryamutuma & Baingana, (2011) observes that in many developing countries, HIV/AIDS programs and services are designed around paediatric and adult care services and are not adolescent specific. The sexual and reproductive health needs of young people

perinatally infected with HIV remain largely unaddressed by existing HIV/AIDS programs mostly because, such programs encourage young HIV positive clients to refrain from or postpone sexual activity (Hodgson, Ross, Gitau-Mburu & Choolwe 2012; Lowenthal, 2014). According to Atuyambe et al. (2015) adolescents are quite explicit about what they want from service providers. Contrary to this, SRH issues discussed during ART clinics of young HIV-positive clients and service providers tend to be about refraining from or postponing sexual initiation (Birungi, et al., 2009). If this link between service providers and adolescents is not addressed then the quality of care provided will be compromised. Therefore there is another need to design programs that are age appropriate for the adolescents.

Comprehensive services for HIV-positive adolescents in low- and middle-income countries such as Malawi are underdeveloped despite the importance of the adolescents (UNICEF, 2010). Birungi et al., (2009) noted that there is need to recognize that adolescents growing with perinatally acquired HIV are sexually active or anticipate being so in future. Thus, both sexually active and non-sexually active young adolescents require information and services on prevention of unwanted pregnancies as well as avoiding infecting their sexual partners with HIV and re-infecting themselves. WHO (2014) stipulates a number of elements that stimulate adolescents to seek healthcare which include: confidentiality, provision of required information and services, accepting adolescents as they are, considering and respecting adolescents' opinions, allowing adolescents to make their own decisions, ensuring that adolescents feel welcome and comfortable, being non-judgmental, and provision of services at a time that adolescents are able to come. However, Fair et al., (2013) notes that most health workers concentrate on teaching adolescents growing with perinatally acquired HIV on condom use, abortion, pregnancy prevention rather than reducing the risk of re-infection and family planning. Consequently there is need to devise ways of responding to these needs which should include emphasizing the disclosure of HIV status to the partner as

well as the need to accompany such disclosure with consistent condom use (Birungi, et al, 2009).

Birungi & Obare, ( 2011) also observed few of the HIV-positive adolescents belonged to a support group which suggests that many do not access the kind of support services that groups can offer which include peer support, life skills training, and psychosocial support. This implies that many adolescents might not benefit from critical sexual and reproductive health information for HIV-positive young people which can be channelled through the groups. In a study conducted by Birungi & Obare (2011) in Kenya and Uganda, they found out that there were programmatic gaps in addressing the sexual and reproductive health needs of HIV-positive adolescents. Key informant interviews with service providers showed that there was limited service orientation, lack of provider training in SRH counselling for HIV-positive adolescents, inadequate financial and human resources, and the difficulty of dealing with adolescent sexuality in general. These findings also corroborate Reddy, Fleming and Swain's (2002) findings that there is a strong positive correlation between a youth-friendly environment and sexual and reproductive health service utilization by adolescents. Service providers normally encourage young people perinatally infected with HIV to refrain from or postpone sexual initiation. In order to provide effective HIV care to HIV-positive adolescents. In a study about addressing the sexual and reproductive health needs of young adolescents living with HIV in South Africa, (Beksinska et al., 2014) it was observed that the provision of HIV treatment and care services to HIV positive adolescents is a relatively neglected issue in the South African response to the HIV epidemic as is the case in Malawi.

The survival of the children to adolescents has therefore necessitated the need to improve sexual and reproductive health services. Providing developmentally appropriate services for HIV-positive adolescents is an important, but neglected, aspect of the response to the HIV epidemic in Malawi. The provision of comprehensive adolescent specific HIV

services can assist adolescents in learning to manage their HIV infection, and in dealing with the challenges of going through adolescence with HIV. There is little known evidence that promote the choices of sexual practices and behaviours in adolescents growing with HIV. Atuyambe et al.,(2015) observes that adolescents have real SRH issues that need to be addressed such as unwanted pregnancies, sexually transmitted infections (STIs), defilement, rape and substance abuse.

However there are some studies that were conducted in Malawi worth emulating. Mwalabu, Evans, & Redsell, (2017) in a study titled factors influencing the experience of sexual and reproductive healthcare for female adolescents with perinatally-acquired HIV: a qualitative case study found that young women reported having little control over negotiating safer sex or contraception. The same study also find out young people's priority was preventing unwanted pregnancies yet several of the sample already had babies, and transfer to antenatal services created major disruptions in their HIV care. In contrast, caregivers and nurses regarded sexual activity from a clinical perspective, fearing onward transmission of HIV and advocating abstinence or condoms where possible which closed down possibilities for discussion about sexual matters and prevented young women from accessing contraception (Mwalabu et al., 2017).

### **Service Providers' Perceptions of SRH needs of the Adolescents Growing with HIV.**

Godia et al., (2013) reported that the majority of service providers were aware of the youth friendly service concept but that they lacked competency in providing SRH services to young people especially regarding counselling and interpersonal communication. The results also showed that service providers were conservative with regards to providing SRH services to young people particularly contraception. In a study conducted in Swaziland Mngadi, Faxelid, Zwane, Höjer, & Ransjo-Arvidson, (2015) observed that the majority of the health providers face problems when providing SRH services which include that they had

no contraceptives in stock at the health facility, that adolescents were reluctant to come for contraceptive services, that their religious beliefs and personal values did not allow them to provide contraceptives and that they had never received any special training in relation to adolescents' SRH needs. The service providers also reported being torn between personal feelings, cultural and religious values and beliefs and their wish to respect young people's rights to accessing and obtaining SRH services. This confirms that there are existing gaps in provision of services and needs of adolescents growing with perinatally acquired HIV. Such gaps include, stigma and discrimination in schools, nutritional and psychosocial services, poor flexibility of clinic opening hours, staff shortages limited resources, lower than expected quality of life and factors located within and beyond adolescents themselves were found to negatively influence adolescents' experiences (Mburu et al., 2014, Enimil et al., 2016).

There is also need to highlight SRH needs which would be solved by establishing adolescent friendly clinics with sexuality information, friendly health providers and a range of good clinical services such as post abortion care. It is therefore imperative for service providers to understand that adolescents growing with perinatally acquired HIV face challenges that are more complex considering the relationship that exists between sexual activity and HIV transmission (Marfatia & Naswa, 2010). Since most adolescents are unwilling to disclose their sexual activities to service providers at health facilities, making sexual and reproductive health services available at different types of outlets is useful. Adolescents living with HIV would require support to cope with sex and sexual needs, through full integration of individualized SRH services into the HIV services received. Service providers need to appreciate the individualistic nature of health problems of adolescents living with HIV and address their health care from this holistic perspective. A 'one-size-fits-all' approach for designing SRH programmes for adolescents living with HIV would not be appropriate (Oluwatoyin Folayan, Harrison, Odetoyinbo, & Brown, 2014).

The SRH needs and practices of adolescents living with HIV may differ from that of other adolescents and that of adults living with HIV. Therefore there is need to objectively design interventions that are age-appropriate and will help improve the quality of lives of adolescents growing with HIV, including reducing their risk for sexually transmitted infections and the chances of HIV re-infection. Adolescents are more likely to patronize the services of adolescent friendly outlets because they get opportunities to express themselves freely (WHO, 2016). In a study titled health workers' attitudes toward sexual and reproductive health services for unmarried adolescents in Ethiopia it was found out that some the health workers had a positive attitude toward provision of sexual and reproductive health services to unmarried adolescents but a minority of them displayed negative attitudes (Tilahun, Mengistie, Egata, & Reda, 2012). This ambiguous behavior by service providers presents a significant barrier to service utilization by adolescents to reduce sexually transmitted infections and unwanted pregnancies among adolescents. Morris & Rushwan, (2015) argues that addressing the global challenges of adolescent health, service providers should be equipped to provide accurate, balanced sex education, including information about contraception and condoms so that adolescents have the means to protect themselves, provided within a context of healthy sexuality, without stigma or judgment. There are many health and social challenges that adolescents face and efforts need to be directed to providing youth-appropriate services which are comprehensive, evidence-based that raises the capacity of service providers and adolescents so that healthcare workers move from being part of the problem to part of the solution. Service providers are also well placed to influence policy and ensure service provision for adolescents to receive early and tailored prenatal services to address their high risk and specific problems of anemia, malaria, HIV, and other STIs, as well as giving them special attention during obstetric care, given that they are most at risk of complications and death (Morris & Rushwan, 2015).

In conclusion, literature supports that there are complex yet interrelated gaps in understanding the sexual and reproductive health needs of the adolescents growing up with HIV both globally, in Africa and in Malawi in particular.

## **CHAPTER 3**

### **Methodology**

#### **Introduction**

This chapter will describe the research methods that were used to explore the SRH needs of adolescents growing with perinatally acquired HIV at the Rainbow Clinic, Mzuzu Central Hospital. The chapter is divided into subsections. The study design was to inform the reader with the nature of the research and has been followed by a description of the study site. The study population and the sampling technique will then be defined. Then there is a description of the research sample. To collect data, semi-structured interviews and focus group discussions were used as data collection instruments. Data analysis is discussed at the end.

#### **Study Design**

The research design was exploratory qualitative in nature that was used to understand the SRH needs for adolescents growing with perinatally acquired HIV. The researcher wanted to understand the processes and the full nature of the sexual and reproductive needs experienced by the adolescents as they grow with HIV. Qualitative research is a method of research designed for discovery rather than verification (Brink, Rensburg & Walt, 2014). The researcher seeks to explain process rather than to verify a cause and effect. It is used to explore little-known or ambiguous process like in this case, the SRH needs for adolescents with perinatally acquired HIV. Concepts that are important to health care professionals often are difficult to reduce in a quantitative way. To understand the SRH needs for the adolescents growing with HIV a qualitative study was therefore desirable. The study explored the SRH needs for adolescents growing with perinatally acquired HIV and how service providers perceived the adolescents' SRH needs. This was important as strategies were to be developed to promote optimal sexual and reproductive health outcomes among adolescents.

## **Study Site**

The study was conducted at the Rainbow Clinic, Mzuzu Central Hospital. The Clinic is an HIV and AIDS service provision centre which was opened in 2004. There are 4776 patients registered at the Clinic, out of which 94 adolescents are growing with perinatally acquired HIV. A range of services that are offered at the Rainbow Clinic include ART provision, counselling, collection of dry blood samples, management of related HIV symptoms, registration for ART, follow up of patients who default and conducting awareness campaigns in PMTCT. In terms of SRH, the clinic provides condoms and STI syndromic management. The clinic also works with other stakeholders through HIV linkages to support youth that are in primary schools through sports and recreation, nutritional supplementation and economic empowerment. The clinic has six nurses, two clinicians, one data entry clerk, six support staff and two peer educators. Home follow ups are rarely done due to inadequate financial resources and shortage of staff. They also facilitate teen club meetings where adolescents are trained on prevention of secondary HIV infection, sharing of experiences and are educated on HIV management. Guardians or parents with children who are less than 13 years and those with other problems like growth retardation are requested to escort their children as they attend the teen club meetings.

## **Study Population**

Participants were adolescents growing with perinatally acquired HIV accessing services at the Rainbow clinic and service providers working at the same Clinic. Subjects were recruited based on their interest and availability to participate in the research. The sample was derived from a population of adolescents aged between 13 to 18 years and five service providers who have been providing services at the Rainbow clinic for not less than six months.

## Sample Size

This study utilized purposive sampling technique. Purposive sampling is a non-probability sampling method that is characterized by a deliberate effort to gain samples by including groups or typical areas in a sample (Burns & Groove 2011). Purposeful sampling is a strategy that adds credibility to a sample when the potential purposeful sample is larger than one can handle. As for the Rainbow Clinic, there are ninety four adolescents growing with perinatally acquired HIV. Purposeful sampling utilizes small sample sizes, thus the goal is credibility, not representativeness or the ability to generalize. This reduces judgment within a purposeful category, because the cases are picked randomly and without regard to the outcome. Often in qualitative research, the researcher refers to the redundancy criterion: that is when no new information is forthcoming from new sampled units. That is when data collection stops, considering the amount of time it costs to do and transcribe the interviews. The sample would be determined by the informational needs. The researcher suggested 15-20 participants as ideal but it would dependent on data saturation. The numbers might change by either increasing or decreasing depending on data saturation. When data saturation is reached then sample size will be considered complete (Polit & Beck 2010). The researcher with the assistance of the service providers invited the adolescents to participate in the study. Information about the study was provided to the participants by the researcher and his assistant. The researcher interviewed seventeen participants because initially data had not saturated yet as most of the adolescents were only giving information about sexual health. This was as a result that most of them did not have any children or gotten pregnant to understand their reproductive health needs. Whitehead & Annells (2007) suggest that a common range in qualitative research is usually between eight and 15 participants but this can vary depending on data saturation. The small sample size is suitable because of the potentially detailed data that can be generated from each participant (Polit & Beck 2010).

WHO (2016) adds that in addition, because of the in-depth nature of these types of studies and the analysis of data that is required should have at least 10 participants in a qualitative study. This means that the sample size was within the recommended sample sizes appropriate to meet the objectives of the study.

Seventeen adolescents (seven males and ten females) growing with perinatally acquired HIV and five service providers who have worked in the department for over six months were interviewed. The service providers with over six months experience had a better understanding of the adolescents and the SRH services that are provided at the Clinic. One focus group interview with six to ten adolescents (four females and two males) growing with perinatally acquired HIV was also conducted at the clinic in order to explore the perceptions, attitudes and opinions of participants. According to Brink, Walt & Rensburg (2014) focus group interviews are interviews with groups of about five to 15 people whose opinions and experiences are requested simultaneously. This was done in order to elicit the sexual and reproductive health needs from the perspective of the adolescents and service providers who the researcher perceived to be knowledgeable on the subject matter. The participants were engaged as soon as the required ethical approval was obtained from COMREC and permission from the hospital was granted.

#### **Inclusion criteria.**

The inclusion criteria included the following;

- Adolescents growing with perinatally acquired HIV accessing SRH services at Rainbow clinic.
- Only those that were willing to participate in the study after giving in consent and assent
- Adolescents aged between 13 to 18 years
- Confirmed to have acquired HIV at birth through hospital records

- Adolescents less than 18 years whose parents had assented for them to participate.
- Service providers with 6 months or more work experience at the clinic

### **Exclusion Criteria.**

The exclusion criteria included the following;

- Adolescents that were less than 13 years.
- Adolescents not willing to participate in the study
- Adolescents with behaviourally acquired HIV as confirmed through hospital records
- Adolescents above 18 years.

### **Data Collection Procedure**

Semi structured interview guide was used to collect data from the adolescents accessing ART and SRH services at the Rainbow clinic. Data was collected through interviews for a period of approximately four weeks by the researcher using interview guides to ensure that data collected was relevant. For the focus group discussion, the researcher conducted the interviews. A tape recorder was also used to record information. The instrument was pre-tested at Rumphi District hospital where they offer similar services, in order to identify problems with the data collection tool and rectify them before the beginning of data collection. A friendly atmosphere between the researcher and the participants was created by identifying a quiet, undisturbed and familiar room within the Rainbow clinic to ensure that the participants are relaxed. Notes were taken during the interview and questions and responses were audio taped after getting permission to audio tape the interview.

### **Data Collection Instruments**

Semi-structured interview guides (Appendix 6 and 7: Semi structured interview guide in English and Chichewa for Adolescents), (Appendix 10 and 11: Semi structured interview guide in English and Chichewa for Service Providers) and focus group discussions (Appendix 8 and 9: Focus Group interview guide in English and Chichewa for Adolescents) were used

to collect data. This was done in order to gain more in-depth information from the participants (Brink et al., 2014). Neale & Boyce, (2006) describes semi-structured interviews as a qualitative research technique which involves asking questions to individual with a small number of respondents to explore their perspectives on a particular idea, or situation. Webb (2013) continues to describe interview as the main technique used in qualitative methods to explore the meaning of certain experiences to individuals. A semi-structured interview guides the interviewer in the areas that are needed to be covered during the process of data collection. Additional unplanned questions were asked in order to clarify some points stated by interviewees, or to clarify any other related points.

### **Data Analysis**

Data analysis was done manually as soon as data was collected using the thematic analysis. Thematic analysis is a conventional practice in qualitative research which involves searching through data to identify any recurrent patterns. A theme is a cluster of linked categories conveying similar meanings and usually emerges through the inductive analytic process which characterises the qualitative paradigm. Qualitative methods are invaluable for exploring the complexities of health care and patient experiences in particular. The objectives are focused and the researcher will work with structured interviews to elicit and manage data. This enables the researcher to explore data in depth while simultaneously maintaining an audit trail, which enhances the rigour of the analytical processes and the credibility of the findings. Burnard et.al (2008) describes thematic analysis as a method used to analyze data which involves analysing transcripts, identifying themes within data and gathering together examples of those themes from the text. A process of content thematic analysis involves the researcher identifying themes that will emerge from data. This was done while the interaction with the subjects was still fresh so as to record thoughts and reactions as accurately as possible. The first step in the data analysis was to transcribe the data collected word for word

to derive codes and eventually capture key thoughts and concepts. Transcriptions were detailed capturing characteristics of the interviewee, how fast or slow the interviewee responds to the questions, tone of voice and any pauses made before responding to the questions (Bailey, 2008). Secondly data collected was translated. The translation procedures described in qualitative nursing research are verbatim or word for word translation. Then data was translated in the original language which is English, and then analysis of content from the data. Bailey (2008) continues to observe that this involves presentation of audible data into written form so that the data can easily be studied and linked to the one that was hand written and to allow for easy coding. This allows the researcher to draw meanings from such features which leads to the data being enriched.

The researcher collected all words and phrases together into a clean set of pages which helped to delete all duplications and reduce categories. Next, the categories were synthesized to develop themes. The researcher then read through each transcript thoroughly in order to understand and draw meaning from them. Notes were made in the margins of words known as open coding. After transcription the data was coded according to relevant concepts and themes from the interviews. Codes were then sorted into categories based on how different codes were related and linked (Gale, Heath, Cameron, Rashid, & Redwood, 2013). Open coding offers a summary of statement or word for each element that is discussed in the transcript. The researcher discovered these themes in interview transcripts and attempt to verify, confirm and qualify them by searching through the data and repeating the process to identify further themes and categories.

The themes were examined and initial definitions were put in place. This phase of trawling back through the data examines how information was assigned to each theme in order to evaluate its current meaning. Thereafter the texts were reexamined carefully for relevant incidents of data for each theme. This second process of trawling back through the

data is also called coding. Taking each theme separately and re-examining the original data for information relating to that theme is a vital stage in the analytic process because human perception is selective and the relevance of data can be easily overlooked.

The researcher then worked on each transcript and data fitting one category was marked with same colour. The name, definition and supporting data were re-examined for the final construction of each theme, using all the material relating to it. This stage of re-contextualisation focuses more closely on the underlying meaning of each theme. Then the final construction of each theme was formed. The themes and subthemes that emerged were the results of the study. Lastly each theme was reported and finalized by writing the name of each theme, its description and illustrated with a few quotations from the original text to help communicate its meaning to the reader. Participants were asked to identify practical strategies to improve SRH service delivery for adolescents with perinatally acquired HIV. It was noted from the participants if they describe any of the following; reception by staff, refusal to offer services by service providers, lack of privacy and confidentiality, bad reception by staff, if they were well received, if they were being provided with more information, the opening times were convenient, services were free of charge, there were no drugs and commodity shortages, there were no long waiting times and lengthy lunch breaks, the lack of information and explanations given by providers, and short consultation time. Recommendations were then put in place for management and stakeholders to consider them. Factors pertaining to the quality of the healthcare service were also noted.

### **Trustworthiness of Data**

Trustworthiness is a way of demonstrating credibility and integrity of the qualitative research process (Moule & Goodman, 2009). The background, qualifications and experience of the investigator and the supervisors enabled this research to be trustworthy. Different

methods of data collection were employed. Three concepts, that of credibility, confirmability and transferability were used to describe the aspects of trustworthiness in the study.

### **Credibility.**

Credibility enables those reading the study to believe that the data presented is the true representation of the participants view, experience or belief (Moule & Goodman, 2009). It also shows how similar are the findings with certainty. To ensure credibility of the data, the researcher confirmed what the participants meant by posing probing questions, observation and repeating the responses to them so that they should verify their responses to ensure that the facts have not been misconstrued (Brink, H et al., 2014).

Clarification of the research questions was done during the interview to ensure that adolescents understand the questions before responding. There was a focus group interview and individual interviews, which formed the major data collection strategies for much qualitative research. Apart from getting information from adolescents, other information was from the service providers who also contributed to the data for this research. The researcher read and re-read the transcripts to understand the SRH needs of adolescents with perinatally acquired HIV.

### **Confirmability.**

As a means of verification, confirmability of the study was achieved when findings of a study reflected from what the participants of the study reported. The researcher provided a clear account of the actual procedures used for access and recruitment of research participants, data collection and analysis and to make sure that data speaks for itself, and is not based on biases and assumptions of the researchers. In order to separate views from the researcher and that of the participants', the researcher audio taped the interviews. In addition, during the interviews the researcher listened actively and was paraphrasing the participants' responses so as to get appropriate information. Furthermore, the researcher asked an assistant

fluent in both English and Chichewa languages to spot check his interpretations of the data. The researcher took these steps to demonstrate that findings emerged from the data and it was not his own predispositions. Given (2008), indicates that in qualitative research, the actions and perceptions of participants are analyzed for their expressions of meaning within a given context and not that of the researcher. Consistent with the practices of the selected qualitative methodology used, the researcher then interpreted the participant expressions through a coding or meaning-making process. Polit & Beck (2010), suggest that in this coding process, the researcher is looking for messages that were consistent with, confirm, or expand on current knowledge and theory. From these insights, the researcher was then able to make statements about the context under study.

### **Transferability.**

Moule & Goodman (2009), refers transferability as the extent to which research findings can be transferred from one context to another by providing a thick description of the data as well as identifying sampling and design details. In order to assess the point to which findings may be accurate of people in other settings, similar projects employing the same methods but conducted in different environments could well be of great value. So it is hoped that this research can be replicated in other central hospitals. This does not involve broad claims, but invites readers of research to make connections between elements of a study and their own experience. A diverse sample of adolescents from urban areas was selected. These included male and female 13-18 year adolescents growing with HIV to gain in-depth knowledge of a wider group.

### **Ethical Consideration**

Ethical consideration for this study was undertaken as follows. Ethical approval was obtained from the College of Medicine Research and Ethics Committee (COMREC) before data was collected. A written permission was sought from Director of Mzuzu Central

Hospital and District Health Officer from Rumphi District to conduct the actual study and pretesting of the tool respectively. An explanation about the study was provided to participants for them to understand the aim and objectives of the study (Appendix 1 and 2: Participants Information Sheet in English and Chichewa). Informed consent is a fundamental requirement in research participation. Participants willing to participate in the study signed a consent form or put a thumb-print for those who cannot write (Appendix 3 and 4: Consent Form in English and Chichewa) or assent form (Appendix 6 and 7: Assent Form in English and Chichewa for adolescents aged less than 18 years) for the parents to sign and show their agreement for the adolescents to be interviewed. Informed consent must be voluntarily obtained to avoid coercion. Folayan et al., (2015) argues that decisions on when an individual has adequate capacity to give consent for research most commonly use age as a surrogate rather than directly assessing capacity to understand the issues and adolescents participating in research are more likely to be coerced and may therefore not fully comprehend the risk they may be taking when engaging in research to make an informed decision on whether to participate in research or not. Due to the nature of HIV and considering that adolescents are young people and vulnerable group comprehensive information was provided to adolescents, their guardians in their own language for better understanding about the study.

It was made known to the adolescents and service providers that this study posed no physical risks to them. Though psychological risk is quite high to adolescents growing with HIV with these kinds of interviews, explanation about the study was provided to participants prior to the interview. Informed consent from the adolescents and service providers and guardians/parents was obtained before involving them in the study. Participants were not subjected to coercion in any way. Confidentiality was addressed so that no personal data collected from respondents was used for other means except for research purposes. Anonymity was addressed by use of codes and that no names were used. As for privacy, a

room within the rainbow clinic where interviews were to be conducted was sought. The field notes and the recorder were locked in the drawer of the researcher and access to the data was by the researcher only.

To achieve the above ethical aspects of the study the following aspects were taken into consideration;

**Respect.**

Respect for persons articulates that there is need to treat individuals as autonomous. The researcher should not use people as a means to an end but should allow people to choose for themselves. The researcher believes that some adolescents may have limited autonomy and have an inability to choose for themselves. As adolescents may be considered as minors, proxy consent was sought from their parents for them to participate in the study and make their informed choices. As such what will happen is that they will be given information about the research. Then they were asked whether they want to participate or not and make their own choice. They were informed that their privacy will be protected. If they have things that they do not want to be shared with others, the researcher ensured that it was not shared through the process of confidentiality.

**Beneficence.**

The Principle of beneficence states that the researcher should act kindly to all human beings. This study ensured that no participant was subjected from harm, prevented from evil and promoted good. This is really going out of our way in order to do good things for other people. From the principle of beneficence, the researcher has obligations that are familiar to the nursing profession. Participants were given adequate information about the study purpose, benefits and risks so that the participants should voluntarily, intelligently and clearly give informed consent which was in a written form. Furthermore, participants were informed that the study did not have any harmful effects, their participation in the study was voluntary and

that they would withdraw from the study at any time without giving any reasons. Participants were assured that withdraw or refusal to participate in the study could not affect their access to HIV services at the clinic. Participants were asked to voluntarily sign the consent form after showing their willingness to participate in the study. The participants were also assured that their responses would be handled in a confidential manner in order to protect their identity. The researcher refrained from invading participants' privacy by respecting their views in case of refusal to disclose personal information. Gathered information was stored by the researcher, and after data analysis the data collection materials were destroyed by burning.

### **Justice.**

The principle of justice gives the researcher the idea that people are treated fairly and that there should be a fair sharing of the burdens and benefits of research. The researcher should not burden one group with the risk of research in order to give another group the benefits of research. The purpose of this research was for the adolescents who are growing with HIV to benefit from the results. Therefore there was equitable selection of research subjects who will inform the service providers on how best they can be cared for. Privacy was maintained throughout the research process and that information collected remained anonymous and confidential. Names were not be used, and participants' information was not available to anyone except the researcher and his supervisor in order to protect their privacy and confidentiality.

The interview guides contained no any degrading, discriminating or any other unacceptable language that could be offensive to any members of the sample group. The interview guides were designed to collect information directly related to the research objectives, and no private or personal questions were asked from respondents. Works of other researchers and authors used in this research are referenced using APA 6<sup>th</sup> Edition

referencing system. To ensure that these standards have been followed, approval to conduct study was sought and gained from College of Medicine Research Council (COMREC) and the Management of Mzuzu Central Hospital where the study was conducted.

### **Limitations of the Study**

The study was conducted at one site due to financial constraints as the study was a requirement for the fulfilment of a Master Degree in Child Health. However, the results from the study would have been generalized and enriched if the study was conducted in more sites. As such there will be need to replicate the research in other institutions.

### **Research Dissemination**

Results will be disseminated to health professionals at the hospital and national level through meetings and conferences. The study results will possibly be published as a journal article where it may be accessed by health professionals in practice, research and education. The thesis will be submitted to Kamuzu College of Nursing Library and Mzuzu Central Hospital Library.

## CHAPTER 4

### Research Findings

#### Introduction

This chapter describes the findings of a study conducted at the Rainbow Clinic, Mzuzu Central Hospital. A pre-test study was conducted at Rumphi District Hospital. Data collection was carried out from the 4<sup>th</sup> to the 16<sup>th</sup> December 2016. The broad objective was to explore the SRH needs for adolescents growing with perinatally acquired HIV at Mzuzu Central Hospital. An interview guide containing a set of open ended questions was used so as to understand the SRH needs for adolescents growing with perinatally acquired HIV. Analysis of the data was conducted through a framework thematic content analysis approach. Themes were developed and grouped based on the transcribed field notes in order to identify recurrent themes and patterns. This was done in order to gain more in-depth information from the participants.

The findings in this chapter will be presented as a narrative. Demographic characteristics for adolescents and service providers with tables will be presented and the information will be synthesised in the research findings. Each objective will be presented with the three themes that emerged from the data that was collected. The first theme was preferred SRH needs of the adolescents which had the following subthemes; need for youth friendly services, access to a variety of family planning methods, informational needs and access to SRH services. The second theme was the perceived challenges to service provision. Subthemes that emerged included; poor infrastructure, SRH service provision and drug stock outs. The third theme that emerged was the sexual behaviour of the adolescents and the subthemes namely early sexual debut, HIV status disclosure to sexual partners and feeling of stigmatisation and abandonment. Citations from the interviews have been used to represent

the SRH needs for adolescents growing with perinatally acquired HIV at Mzuzu Central Hospital.

### **Demographic Characteristics for Adolescents and Service Providers**

Demographic characteristics for adolescents living with HIV have been segmented into sex, age, marital status, tribe, occupation and educational level. Other demographic characteristics include adolescents' living conditions, age they knew to be HIV positive, their age at menarche, when they first engaged in sex and if they are using contraceptives. For the health workers demographic data has been segmented into age, cadre, sex and number of years experience and whether they are trained in youth friendly health services.

**Table 1: Demographic Characteristics (Health Workers)**

<b>Cadre</b>	<b>Age</b>	<b>Experience in Years at the clinic</b>	<b>Qualification</b>	<b>Youth Friendly service Provider?</b>
Nurse 1	41	7 years	Dip. Nursing	No
Nurse 2	36	6 months	Dip. Nursing	No
Nurse 3	43	5 years	Dip. Nursing	No
Clinical Officer 1	52	16	Dip. C. Med	No
Clinical Officer 2	44	12 years	Dip. C. Med	No

**Table 2: Demographic Characteristics (Adolescents)**

<b>Demographic characteristics of adolescents by sex</b>		
Female	10	
Male	7	
<b>Demographic characteristics of adolescents by age</b>		
Age	13-15	3
	16-18	14
<b>Demographic characteristics of adolescents by marital status</b>		
Married	0	
Single	17	
<b>Demographic characteristics of adolescents by tribe</b>		
Chewa	2	
Tumbuka	5	
Tonga	1	
Ngonde	2	
Yao	2	
<b>Demographic characteristics of adolescents level of education</b>		
None	0	
Primary level	2	
Secondary level	15	
Tertiary level	0	
<b>Demographic characteristics of adolescents' age range they knew to be HIV positive</b>		
8-13 years	13	
14-18 years	4	
<b>HIV sero status notification by</b>		
Nurse	14	
Clinical Officer	3	
<b>Age range for sexual debut</b>		

Female	10-13 years	4
	14-18 years	6
Male	10-13 years	1
	14-18 years	4
<b>Demographic characteristics of adolescents sex before menarche</b>		
Female		3
Male		0
<b>Demographic characteristics of adolescents' living conditions</b>		
	Male	Female
All parents alive	0	0
One parent alive	2	1
Living with relatives	5	5
Living alone/with siblings	0	4
<b>Demographic characteristics of adolescents' using contraception</b>		
Male		0
Female		0
<b>Demographic characteristics of adolescents' ever engaged in sex</b>		
Female		10
Male		5
Not yet		2
<b>Partners notified before sex during first intercourse</b>		
Female		0
Male		0
<b>Demographic characteristics of adolescents' who ever impregnated or got pregnant</b>		
Age	Male	Female
11-14	0	1
15-18	0	4

## **Findings from the Qualitative Data**

This section presents qualitative data that was collected and it is presented using the study objectives and the themes that emerged. The findings of the study will answer the three objectives of the research if they were achieved or not. From the study findings, three themes and subthemes emerged. The first theme was preferred SRH needs of the adolescents. With this theme the following subthemes emerged; need for youth friendly services, access to a variety of family planning methods, informational needs and access to SRH services. The second theme was the perceived challenges to service provision. Subthemes that emerged included; poor infrastructure, SRH service provision and drug stock outs. The third theme that emerged was the sexual behavior of the adolescents and the subthemes namely early sexual debut, HIV status disclosure to sexual partners and feeling of stigmatisation and abandonment. The results also revealed that there was corroboration between the service providers and the adolescents growing with HIV. Most of the themes that emerged from the service providers were similar to the ones from the adolescents which were that they needed youth tailored services, informational needs despite that they were disinterested with family planning methods. Then the next presentation will be finding out on the way adolescents and service providers perceive service provision at the clinic. Data that emerged from focus group discussion had a similar pattern to the one that emerged during interviews hence the subthemes that emerged from the focus group discussion included; Informational needs, SRH service provision and the need for youth friendly services. A deliberate effort will be made to analyze whether the services are meeting the needs of the adolescents. If not why and if yes how? What are adolescents' preferences and what needs to be improved in terms of SRH service provision?

## **Preferred SRH needs of the Adolescents**

Three subthemes emerged on the preferred SRH needs of the adolescents. These were; need for youth friendly services, access to a variety of family planning methods, informational needs and access to SRH services.

### **Need for youth friendly services.**

The researcher wanted to find out from the adolescents the services adolescents growing with HIV wanted to be offered at the clinic. The findings revealed that adolescent wanted young service providers and fellow adolescents to provide the services to them. They reported that they wanted to be assisted by fellow teenagers because it was easier to communicate with them than older service providers with whom they became shy. They were of the view that they needed doctors who are friendly towards them and those who can understand them better.

*“We want teenagers to assist fellow teenagers because we are not free to say what we want to the service providers that are older than us because we get shy...that is why some teenagers do not access the services here. So for us who get information can ably assist other teenagers”.*

Contrary to the above need for young service providers, few adolescents also needed the older service providers to give them proper information and direction so that they could inform other teenagers the truth about SRH.

*“Because we also need information from the older service providers for us to give proper information to fellow teenagers. If the older service provider gives us information, this gives us the effort to tell the other teenagers the truth”.*

*“But we also need the adults providers to teach and direct us so that we can teach others”.*

They were also of the opinion that the hospital should bring in organizations that can assist the teenagers.

*“The hospital should bring in organizations that can assist the teenagers”.*

Another revelation that emerged was the relationship of the adolescents with the service providers. The adolescents felt that their relationship with the service providers was not good enough as they preferred providers who are youth friendly. It was revealed that the adolescents growing with HIV need adolescent specific clinics and services. The researcher also wanted to find out from adolescents growing with perinatally acquired HIV what SRH services do they get, services that they needed and services that they preferred from the clinic. Instead of concentrating on service provision, adolescents dwelt much on the relationship with the service providers. This information was important for the researcher to determine the perceptions of adolescents growing with perinatally acquired HIV on the SRH services offered at the clinic. Adolescents revealed that they preferred that services be opened earlier by young service providers' and in a place that provides privacy. Most of the adolescents growing with perinatally acquired HIV were of the view that they need service providers with a dedicated youth friendly mission, who are young and can easily interact and understand their problems as compared to older service providers who they perceive that they do not understand their problems. This was ably summarized by one participant.

*“We need young doctors who we can easily communicate with. We are mostly afraid interacting with the older doctors as we are afraid to tell them the problems we face”.*

The need for the youth friendly health services was hatched after the adolescents observed that most health workers are harsh towards them and yet they do not really understand the problems they are facing.

*“I can say that service providers are harsh and they should be more helpful to the young people living with HIV”.*

*“Adolescents face a lot of problems ....we need the service providers who are our mentors to help us whenever we are in problems”.*

Adolescents were of the view that older service providers are difficult to interact with hence the need for adolescents themselves to be providing the information with guidance from the older service providers. It was also noted that they needed other services to be provided by fellow peers who can be trained by the older service providers. They were of the view that there should be groups of adolescents who can easily discuss their problems as peers. This should be done by having nurses and doctors who are friendly. From the results from the characteristics dimension of the service providers, it was noted that their age range was from 36 years to 50 and probably the reason why the adolescents would like providers who can match their feelings and understanding.

*“I think they need to introduce a peer system where we have peers educating fellow peers. There should also be more peer service providers because most teens shy away because the providers are older people. If they are older people they think they can reveal this to their parents. If it is a fellow peer it is much easier to approach and easier to access the services. Lastly the health workers should improve the services towards youth friendly”.*

This poses a challenge as the adolescents do not to get the condoms because everyone notices that they are getting them. Adolescents do not get the condoms for fear of reprisals as they are afraid that elderly people who access similar services, like getting the condoms, would report them to their parents.

*“Being mixed with older people we (adolescents) think they (older people) can reveal this to our relatives. But if we are mixed with fellow peers it is much easier to approach and easier to access the services”.*

They also would love to have friendly health care workers and reduction in waiting time at the health facilities. They also wanted to be closer to the service providers so that they could get information and that they should be free to ask the service providers whenever we are not feeling fine. They also wanted to receive proper education in order to reduce pregnancies from young service providers”.

*“The challenges that we face are that clinicians are harsh, the environment is not conducive and service providers start working very late and it takes long time for us to get the drugs”.*

Despite the fact that there were a few service providers but that they were mostly harsh towards the adolescents. Adolescents felt that the service providers should be kind to the young people living with HIV. These young people know that they have the disease, they leave their homes and this shows that they are committed to improve their health. If a health worker shows a kind of bad attitude, they feel demotivated to get the services at the clinic.

*“At times they should be talking to us not in a harsh way. If they talk to us harshly, we think that they are not prepared to tell us the information we want to hear”.*

Participants from this study felt that they needed providers who were kind to them and were treating them with due respect as not doing so was demotivating the adolescents from getting the required services and that the service providers were reporting late for work.

*“They should not discriminate and be harsh to us by choosing their friends first when we are on the line”.*

### **Access to variety of family planning methods.**

Despite adolescents growing with perinatally acquired HIV in this study revealed that they need a variety of family planning methods it was revealed as previously noted that none of them was on any contraceptives. Nonetheless they noted that they normally get condoms only at the Rainbow Clinic. While few had ever used contraceptives, all of them were not on contraceptives as they stopped using any contraceptives at the time of interviews. One female adolescent had ever been infected with a sexually transmitted disease and got treatment together with her partner. Findings showed that they were not aware that as a condom it can also play the role of a contraceptive. Despite that they get these condoms, they said that the problem was that they are not taught how to use them.

*“We are just given condoms and yet they do not tell us how to use them but we also need male circumcision at the clinic”.*

*“They teach us about using family planning methods such as condoms as anyone can use them at any age but not much emphasis on other family planning methods”.*

However it was difficult for them to get the condoms since they are put at a place where everyone notices that they are getting the condoms.

*“There is no privacy at the clinic and also the room is too small such one cannot be able to get the condoms freely”.*

Furthermore all the participants new about condoms use representing a total knowledge use but few would access them. Very few participants felt that other contraceptives are not offered at the clinic except for the condoms and they wanted a wide variety of contraceptives from the clinic.

*“I would prefer if they offered family planning services the way Banja La Mtsogolo does whereby they have enough space and other family planning methods”.*

Despite attending the clinic, two adolescents did not know about contraceptive use because they were not menstruating yet and had no desire to have sex.

*“I have not started menstruating yet, so I don’t know anything about on any family planning methods”.*

They also felt that contraceptives were only given at the family planning clinic and not at the ART clinic hence branding this clinic as not providing a wide range of contraceptives.

*“...I have just seen older people and not young people having access to family services in other clinics and not at the Rainbow clinic. We only get condoms here. I would have loved if most young people should have access to all the family planning methods because most of them shy out just because they don’t know where to start from ...”*

### **Informational needs.**

Adolescents growing with perinatally acquired HIV in this study showed different understanding about SRH the information they got and what information about SRH they needed from the Rainbow Clinic. When asked what information about SRH do they get and what information about SRH they needed from the clinic, most of these adolescents did not know what SRH information was being given and equally did not know what information about SRH they needed to be offered at the clinic. Information on reduction on or to reduce the number of sexual partners, adherence to ARVs and HIV were the topics which adolescents reported to have received at the clinic. This included information about STI and HIV transmission, symptoms of STIs, and the use of condoms to prevent infection. Information about other SRH issues such as menstruation or puberty, sexuality, sexual debut and relationships was very limited. The adolescents also reported that they had received

information about STIs and HIV, but comprehensive education about condoms was lacking.

The most commonly identified need was for information about sexuality and relationships. Girls reported that they needed more information about how to avoid unwanted pregnancies. Information about prevention of pregnancy and family planning was quite relevant for the adolescent girl than a boy. Adolescents also needed information that is correct and honest as they perceived that the information they get at the clinic was incomplete. Most of the participants only expressed that they only get information about family planning services but did not know what information about SRH they needed as they are not taught about these services. This, they claimed was as a result of having nowhere to get this type of information. Some felt that they only get information on how they can improve their health and how to protect themselves.

*“What I require is full information on sex education since we were not taught in primary schools and most people just hear about other information and yet we do not know what it is all about. We need full briefing about these services”.*

The adolescents were of the view that they need information on how to improve their health and also how to information about sexual relationships.

*“Some service providers are shy to tell us the whole information as such we do not get all the information that we need from the clinic. The hospital needs to get professionals who can teach us the real information”.*

Adolescents believe that service providers need not only provide information but also make knowledge of SRH a life-skill for the adolescents. By doing so service providers will meet the SRH needs for the adolescents that will enable them to address SRH in ways that are meaningful for adolescents and help them build life skills to challenge the problems they face.

*“Adolescents face a lot of problems especially when we start engaging ourselves with boyfriends and we need the service providers who are our mentors to help us with information and life skills whenever we are in problems”.*

However despite the adolescents revealing their needs, it was also noted that they had their own preferences in terms of SRH provision. Adolescents generally preferred services to be provided where there was enough space with service providers that are friendly to them and those that have also been trained in youth friendly and they should understand that they are human. They were also of the view that the service providers should be targeting older adolescents for SRH services. They would also prefer a wide variety of family planning methods that are longer lasting. For their nutritional aspects, they would prefer if the hospital would provide them with food supplements that can make them healthier and strong to improve their reproductive health needs. This is how two of the adolescents summed up their preferences;

*“I would love that the health workers should target older adolescents about family planning and sexual issues. We also need people who are youth friendly and those that have also been trained in youth friendly and they should understand that we are human as well”.*

*“I would prefer if they offered family planning services the way Banja La Mtsogolo does it whereby they have enough space”.*

#### **Access to SRH Services.**

When it came to service provision, adolescents growing with perinatally acquired HIV in this study revealed that there were several problems they had when accessing services at the clinic. From the findings it was noted that the clinic had two Clinicians who were not working on full time basis and four Nurses that were providing services on daily basis. Most of the adolescents felt that there were few service providers at the clinic which had a big

impact in terms of service provision. It was also noted that there are a few staff working at the clinic and that the adolescents tend to stay long to access services at the clinic. Sometimes there are no clinicians at the clinic and the adolescents have to access services in the other cubicles within the outpatient department. This makes the adolescents not to seek the services and they go back home because they do not want to move around the hospital. They observed that they were very few service providers at the clinic making access to services difficult.

*“There should be enough service providers and the services they offer at this facility”.*

This meant that the adolescents were waiting for long to be attended to by harsh service providers. The service providers were also reporting late for duties.

*“There are always long queue at the clinic and service providers start working very late and it takes long time for us to get the drugs”.*

For this reason they tend to stay at the clinic very long hours and this makes some teen not to visit the clinic. The majority of the adolescents were concerned about long queues that were present at the clinic and reported being impatient and wanting to be assisted quickly rather than being moved within the hospital departments. They were of the view that government needs to employ more staff to man the clinic so that they get the services faster.

*“As such I think there should be full staff at the clinic and management need to employ more service providers”.*

They also needed more time with the service providers but could not get their intended interaction with staff because the staff was more overwhelmed with their work. So that the staff would advise them professionally on how to live a positive life rather than being harsh to them

*“We want more time to be with the service providers so that we interact with them but we understand that they are very few at the clinic”.*

Compounded with the challenge of few service providers, the adolescents also felt that drugs and other commodities were also in short supply at the clinic.

*“At times there are drug shortages such that we are given dosages for very young kids. On availability of drugs, the health workers should ensure that all drugs are available. If the drugs are not available most teenagers feel that they should stop taking the drugs. So the supply should always be there”.*

Generally all adolescents felt that service providers have a negative attitude towards them hence feel stigmatized both within the hospital and outside the hospital by the service providers. This then makes the adolescents shy away from getting the necessary services at the clinic.

*“we find that the people that are mentoring us are also the ones training us because they are the nurses or because they are councilors not knowing that behind our backs they go to the communities and tell people that I met so and so at that place mmmmm ....they were saying she is pregnant but knows her status and we don't know what she is thinking”.*

Despite facing a lot of challenges, adolescents growing with HIV have future plans which include going back to school, getting married and having children. They also need support from the service providers so that they can protect themselves to have a bright future.

*“I want to go back to school and ....we plan to get married when he comes back from South Africa.”*

## **Perceived Challenges in Service Provision**

Another theme that emerged was that adolescents also noted some challenges with the SRH service provision both at the clinic, teenage clubs and community support as they grow with HIV. These challenges are outlined below.

### **Poor infrastructure.**

Adolescents felt that the Rainbow Clinic where the services are provided was too small to accommodate the large numbers of adolescents and adults accessing the services. This congestion therefore leads to lack of privacy for the adolescents and as such they cannot freely express their feelings. Structurally, the department is located within the out-patient department of the Mzuzu Central Hospital. Patients access both specialized and primary HIV care according to their presenting complaints. When walking into this department it is well known that you are either getting a test for HIV or you are accessing treatment at the clinic. Adolescents believed that the area is too small compared to the numbers that access the services at the clinic. The researcher also found out that the service providers did not provide enough privacy to the adolescents growing with perinatally acquired HIV. This information was provided by all adolescents who were interviewed using interview guides and those that participated in the FGD. This information was important because if the service providers did not provide enough privacy to the adolescents then they (adolescents), would shun away from getting the services making them vulnerable from pregnancies and/or sexually transmitted diseases.

*“There is no privacy at the clinic and also the room is too small such one cannot be able to get all the needed services”.*

Initially the clinic was meant to provide ART services only and not SRH services. The clinic is structured in such a way that all patients have all to be weighed at a single area where they are also given health talks. Then they have all to go to a registration area. After

registration they either meet a nurse or a clinician in their rooms. Then they are given their drugs and condoms.

*“There is no privacy at the clinic such that when people are discussing you can hear them and also the room is too small such one cannot be able to get good services”.*

As such the area lacks privacy and they were of the view that they need a more spacious area where their privacy can be guaranteed. They wanted a place whereby space was enough for both the service providers and the adolescents. There is unfinished building at Mzuzu Central Hospital which was meant to be an ART clinic. Most of the adolescents were of the view that management should put in mechanisms to finish the building.

*“We need a special space as more people are not comfortable coming at this clinic because it is small and too open”.*

Whatever conversations that are done within the rooms are overheard from outside and this makes them shy away and opt out of the services provided at the clinic. Some said they are still getting the services as they do not have options not to do so. Not only that there were few service providers, these service providers lacked privacy when dealing with the adolescents.

*“There is no privacy at the clinic and also the room is too small such that someone cannot get good services. You can actually hear what they are discussing in the other room”.*

The adolescents felt that the clinic itself was small to accommodate the numbers that attend to the clinic making the environment not conducive to service provision.

*“The environment should be free and without any disturbances and that most of us fail to collect condoms since the area where they provide the condom is too open”.*

As such they felt that they need a place where they would interact with the service providers that could not offer any disturbances and where they would get other services such as for the SRH.

*“We want to be closer to the service providers so that we get information and we should be free to ask the service providers whenever we are not feeling fine... in order to reduce pregnancies”.*

On the other hand, service providers believed that the adolescents need enough space and providers who were trained in youth friendly health services and who are young than themselves.

*“I would wish that they have their own separate place to get ARVs so that this place is used by older patients. I think they should make it that they finish the new building that is outside the hospital and that they are provided with people trained in youth friendly health services”.*

### **SRH Service Provision.**

When the adolescents were asked about the services they get from the clinic, the participants equally had no clear response to the question. One participant felt that there were no SRH services being provided at the clinic but was of the view that they also needed information on how to delay pregnancies and post-abortion care.

*“Wait I don’t understand. There are no other services apart from getting condoms and information that are provided at this clinic...but I understand that if a girl is young and falls pregnant, she may damage her own internal organs in the abdomen. So it is better that they get information that tells the adolescents to delay sex until when they are a bit older or above 18 years old. But if they are young they need to*

*come to the hospital to be assisted by the professionals where their ovaries can be removed”.*

The researcher wanted to find out what services do adolescents growing with HIV need from the clinic. The participants were also not so sure about what the services they needed from the clinic. Only one participant thought you need to visit the professionals when you have a medical problem.

*“If you know that you cannot protect yourself, it is better that you visit the professionals on the dangers of falling pregnant when young so that you can be helped with information”.*

The researcher wanted to find out from the adolescents the services they would prefer to get from the clinic. There were conflicting views about preference of the services that are offered at the Rainbow clinic.

*“We need right information especially when you are pregnant and young. Because you can get STIs or Cancer of the cervix so that you can survive rather than die. It is not good to get pregnant while young but when you are pregnant before 18 years you need to get professional advice. It is so because some young teenagers deliver at home rather than at the hospital which is very dangerous”.*

While one participant wanted some organisations to come in and assist with SRH services as we also have sexual feelings, the other participant wanted information about management of pregnancies and its complications. Others did not have an idea about the services that are offered at the clinic thereby failing to come up with suggestions.

*“As adolescents we need organizations that can assist us with SRH services as we also have sexual feelings because we are getting older though we are HIV positive”.*

Adolescents were asked to mention the challenges they encounter at the clinic and make suggestions on how some of the challenges they had identified could be addressed. Both boys and girls mentioned problems accessing and use of contraception including condoms. Adolescents growing with HIV took note of the need to address SRH needs that have age-appropriate information and greater interaction with service providers.

*“We need services that are provided by the youth. Because we are not shy with fellow youths”.*

Of importance was also the need to improve the capacity of service providers to improve service provision. As previously noted, information was normally lacking but it should be important and critical to the adolescents growing with HIV. Information provided to these adolescents need to be consistent so as to make sure that adolescents are not offered with contradictory messages to improve communication and information sharing.

Adolescents generally also wanted more accurate SRH information especially from the service providers. The adolescents also need service providers who are not harsh in any way as they are perceived not prepared to enlighten the adolescents the information they need to get which is crucial when sharing experiences with fellow teenagers.

*“When the hospital forms various support groups for adolescents care, we can have trips so that we can also share information and experiences with other fellow teenagers”.*

Noting staff shortages, adolescents growing with HIV believed that they need more staff and time with service providers.

*“When I enquired, they said there are a few staff working at the clinic and we tend to stay long on the line. As such I think there should be full staff at the clinic. Sometimes there are no clinicians so you have to go back to the cubicles. Most teens will go back home because they do not want to more around the hospital”.*

## **Sexual Behaviour of the Adolescents**

The last theme that emerged was the sexual behaviour of adolescents which had these subthemes namely early sexual debut, HIV status disclosure to sexual partners and feeling of stigmatisation and abandonment.

### **Early sexual debut.**

Demographic characteristics of the adolescents revealed that adolescents' age range was from 13 to 18 years. Seven males and ten females who were interviewed were all not married but most of them had already engaged in sexual activity despite knowing that they were all HIV positive.

*“When I was pregnant since I was very young, I was advised to use family planning methods when I had the urge for sex so that I could not get pregnant again”.*

Disclosure of HIV status was mostly done at the hospital by nurses and very few by the clinicians at different ages. Two knew that they were HIV positive between ages of 6 to 10. Five knew it when they were between 11 and 15 years old while ten knew about their status when they were between sixteen and eighteen years. Despite knowing their HIV statuses, most of the adolescents were already engaging in sexual activities that were consensual and risky citing having sex just like any adolescent or due to financial problems.

*“I had sex at 17 years because I was staying with my stepbrother and his friend used to help me and we fell in love as he was the one supplying me with money as they had sold a plot and he had money. I lost my parents when I was young. This boy was very close to me and it just happened that we had sex then we just got close to each other”.*

Another reason for having sex was that these adolescents are heading households and need to support other siblings as noted below.

*“I started having sex due to the problems that I was experiencing at home. I had nobody to assist us at our house. My parents died and I am responsible for taking care of my two sisters. I wanted to assist them since I am the older one”.*

### **HIV status disclosure to sexual partners.**

The results show that about half of the adolescents who ever engaged in sex did disclose to their partners and the rest were not disclosing to their partners citing fear to be beaten as reasons for nondisclosure.

*“I had only one boyfriend who is in college now and we are still going out together. I did not tell him initially tell him that I was HIV positive because I was afraid of him but now he knows”.*

### **Feeling of stigmatisation and abandonment.**

It was difficult for them to understand why they are HIV positive unlike their other adolescents. This made them to hate their parents as they knew the source of their infection. There was no adolescent who had all parents alive while three had one parent alive. Ten of them were living with relatives while four got pregnant and were living as single parents and/or with their siblings. They had a sense of abandonment as they were living as single parents due to the fact they were abandoned by their boyfriends.

*“When they are stigmatised they feel not stable and start to indulge in sex as they do not have support from their real parents. If I had a stable family I believe I would not have found myself in this situation”.*

### **Adolescents’ Perceptions on the SRH Services**

The second objective of the study was to find out from adolescents growing with perinatally acquired HIV what their perceptions on the SRH services offered at Mzuzu Central Hospital. It also emerged whether the services met or did not meet their needs. From the research findings, most of the adolescents did not understand the SRH services that are

offered at the clinic. From the objective, the following three themes emerged; infrastructure that provides privacy, met and unmet SRH needs and problems with access to the services. Adolescents growing up with perinatally acquired HIV in this study revealed that they normally get condoms at the Rainbow Clinic. However it was difficult for them to get the condoms since they are put at a place where everyone notices that they are getting the condoms. This poses a challenge as the adolescents do not to get them because everyone notices that they are getting the condoms. They do not get the condoms for fear of reprisals as they were afraid that people seeing them getting the condoms would report them to their parents.

### **Infrastructure.**

As already highlighted, adolescents felt that the place where the services are provided inadequate for the service users who include adolescents and adults. Adolescents from this study revealed that they wanted a place where they would call it their own rather than sharing with adults and smaller children. Moreover the place is congested, the rooms are tiny and close to one another which leads to provision of services that does not allow for privacy. Every adolescent who was interviewed and participated in the focus group discussion was not satisfied with this type of set up. This information was provided by all adolescents who were interviewed using interview guides and those that participated in the FGD.

*“Here the place is small and we need our own space where we can freely discuss our own issues and getting services here is problematic”.*

*“There is no privacy at the clinic such that when people are discussing you can hear them and also the room is too small such one cannot be able to get good services”.*

### **Few but harsh service providers.**

Most of the adolescents felt that there were few service providers at the clinic which had a big impact in terms of service provision. They observed that there were very few service providers at the clinic. For this reason they tend to stay at the clinic very long hours and this makes some teens not to visit the clinic. They also needed more time with the service providers but could not get their intended interaction with staff because the staff was more overwhelmed with their work.

*“When I enquired, they said there are a few staff working at the clinic and we tend to stay long on the line. As such I think there should be full staff at the clinic. Sometimes there are no clinicians so you have to go back to the cubicles. Most teens will go back home because they do not want to more around the hospital”.*

Despite that there were a few service providers but that they were mostly harsh towards the adolescents. The service providers were also reporting late for duties. Participants from this study felt that they needed providers who were kind to them and were treating them with due respect as not doing so was demotivating the adolescents from getting the required services and that the service providers were reporting late for work. This meant that the adolescents were waiting for long to be attended to by harsh service providers.

*“The service providers should also be kind to the young people living with HIV. These young people know that they have the disease, they leave their homes and this shows that they are committed to improve their health. If the health worker shows a kind of attitude it kind of demotivated them”.*

### **Stock out of drugs and commodities.**

Compounded with the challenge of few service providers, the adolescents also felt that drugs and other commodities were also in short supply at the clinic.

*“At times there are drug shortages such that we are given dosages for very young kids. On availability of drugs, the health workers should ensure that all drugs are available. If the drugs are not available most teenagers feel that they should stop taking the drugs. So the supply should always be there”.*

### **Met and unmet SRH needs.**

A deliberate effort was made to analyze whether the services are meeting the needs of the adolescents. Service providers also believed that they are meeting some of the needs that the adolescents require and yet some of their needs are not met. Service providers believe that the needs adolescents included ongoing information, counseling on how to cope with stress, behaviour change lessons and education on SRH issues. Some of the needs that are met included adherence, psychological and nutritional needs.

*“I believe that psychological support, adherence mmmmmh nutritional and medical support are being met”.*

Nonetheless, the some service providers also believe that some of the adolescents needs are not met.

*“.....but on career development, life skills and behaviour change I think we are losing out”.*

### **Service Providers’ Perceptions of SRH needs of the Adolescents**

To determine service providers’ perceptions of SRH needs of the adolescents with perinatally acquired HIV. There is need for the service providers to integrate sexual and reproductive health into HIV services specialising in the provision of HIV care to adolescents living with HIV. Service providers need to be proactive in ensuring that all young people living with HIV are offered an integrated services according to their needs HIV treatment, psychosocial , cervical cancer screening, family planning and antenatal care, STI diagnosis

and management and life-skills development. The following three subthemes from structured interviews emerged; disinterest with family planning methods, youth tailored services and sexual and reproductive preferences of adolescents.

### **Youth tailored services.**

Both service providers and adolescents agreed that adolescents like interacting with fellow youth service providers and that they like youth friendly health services. The adolescents would love to be assisted by fellow youths. Findings revealed that most of the service providers were old and did not have any knowledge on youth friendly services and the service providers believed that this was a gap that needs redressing as most of them were grownups and some were even on the verge of retiring.

*“They need youth friendly health services and also they need their HIV status to be known at an early stage so that as they are growing they understand better”.*

### **Informational needs.**

Both the adolescents and the service providers agreed that there was lack of information that was being provided to the adolescents at the clinic. When asked what information about SRH do they (adolescents growing with HIV) get from the clinic, it was noted from a group of six participants that they were not sure about the information on SRH they get from the clinic which was also corroborated by the service providers. Here are some snippets from the respondents.

(.....silence for about a minute and participants looking at one another.....)

*“They tell us on how we can do daily to protect ourselves so that we can have a bright future”.*

When asked what information do they as adolescents growing with HIV need from the clinic, equally the participants had no response to the answer. One participant felt that the

clinic should be providing them with family planning methods. They did not have knowledge about the information they needed from the clinic.

*(.....silence for about a minute and participants looking at one another..... and the researcher probing more...)*

*“Maybe if they can offer us with family planning methods like injectables, wait, there are also family planning methods such as Norplant, pills and diaphragm”.*

However despite providing the required information on how to access the family planning methods, sexual education and abuse against drugs and alcohol, teen club meetings, continuous counseling and being provided with ARVs, it was observed that there are also some challenges with service provision as noted by the service providers. They noted that the place they provide the service in lacks privacy as the space where services are provided is very small despite having a lot of the teenagers. This makes interaction with adolescents problematic. Secondly, service providers are not adequate and that the service providers lack teaching aids. The adolescents are normally shy with the service providers and are in denial that they are suffering as well. Another challenge that emerged from the service providers was that adolescents are told later in life that they are HIV positive. This poses a challenge to the parents as the adolescents blame them (parents) for their sickness.

*“Majority of them have denial that they are sick due to poor disclosure by the health workers and their parents. I think they just need more and adequate information from us as health workers”.*

### **Disinterest with family planning methods.**

Health services providers believe that the adolescents growing with HIV are provided with enough information and education on how to access and to use family planning methods. Despite that they are given family planning methods, the adolescents are not

interested to use them hence many more getting pregnant. All the service providers interviewed felt that the adolescents do not like family planning methods and as a result most of them get pregnant as they also need children of their own. Service providers also believe that offering the sexual and reproductive health services is not that effective as most of the adolescents are not free to express themselves to the health workers. It was also noted that the adolescents are freer getting services from same sex providers rather than those from the opposite sex. They felt that the adolescents are not open to the service providers. This though has its own repercussions as summed up by one service provider;

*“They don’t want family planning methods as a result they get pregnant. Last year alone six adolescents got pregnant as a result of not using family planning methods. They are not very open to using family planning methods but we know they are indulging in sexual activities but we cannot force them to use the methods as it is their own choice”.*

## **Conclusion**

This study explored sexual and reproductive health (SRH) needs for adolescents growing with perinatally acquired HIV at Mzuzu Central Hospital. This chapter presented the study findings according to major themes that emerged from the analysis. The findings have shown that adolescents living with HIV know about their HIV status but some are still engaging in sex. They face a lot of problems in accessing health services and they need services that are tailor made for them. Accessing the services is problematic as there is no privacy at the clinic and they are afraid that their HIV status will be disclosed to their relatives.

## **CHAPTER 5**

### **Discussion**

#### **Introduction**

This chapter presents a discussion on the findings of the study that was qualitative in nature. An exploratory design was used to understand the SRH needs for adolescents growing with perinatally acquired HIV. The aim of the study which was to explore the SRH needs for adolescents growing with perinatally acquired HIV at Mzuzu Central Hospital. The key findings from the study to be discussed will focus on the themes that emerged in relation to literature review based on the objectives of the study. The first theme was preferred SRH needs of the adolescents which had the following subthemes; need for youth friendly services, access to a variety of family planning methods, informational needs and access to SRH services. The second theme was the perceived challenges to service provision. Subthemes that emerged included; poor infrastructure, SRH service provision and drug stock outs. The third theme that emerged was the sexual behaviour of the adolescents and the subthemes namely early sexual debut, HIV status disclosure to sexual partners and feeling of stigmatisation and abandonment. The results will be interpreted in the context of the research literature and the extent to which each research question has been addressed will be discussed. Study limitations and recommendations for practical strategies to improve SRH service delivery for adolescents with perinatally acquired HIV will follow. Lastly suggestions for further research and the conclusion will follow.

#### **Demographic Data**

The study revealed that the age range of the service providers was 36 to 50 years. The majority of the service providers were Nurse Midwife Technicians and Clinical Officers. According to Ministry of Health Malawi (2014), Nurse Midwife Technicians form the bulk of the health professionals. From the clinical side, Clinical Officers cadre also form the bulk of

the staff unlike doctors within the Central Hospitals. All the service providers had Diploma in either Nurse Midwife Technician or Clinical Medicine. As more Nurse Midwife Technicians are female, sex was also predominantly female. The number of experience at the clinic ranged from 6 months to 16 years.

All the service providers were not trained in youth friendly health services. In contrast to these findings, the Ministry of Health Malawi, (2015) proposes that service providers should be trained in provision of such services in order to provide quality youth friendly services high-quality services that are relevant, accessible, attractive, affordable, appropriate and acceptable to the young people in line with the minimum health package and aims to increase acceptability and use of health. The study also revealed that all the adolescents knew that they were HIV positive and that disclosure of HIV results was mostly done at the hospital by nurses and very few by the clinicians rather than parents or guardians. In consistency to a qualitative study that was conducted in Uganda, in which Mutumba et al., (2015) observed that majority of disclosure events took place within the health care setting, and counselors and physicians generally facilitated them, while parents/caregivers assumed a comforting or supportive role. On the contrary, in Zimbabwe Kidia et al., (2014) uncovered approaches for disclosure to HIV-positive adolescents that were highly varied and that did not follow any standard protocol and that healthcare workers encouraged parents to initiate disclosure to their children in the home environment, while adolescents themselves preferred a clinical setting. Older adolescents found it difficult to understand why they are HIV positive unlike their other adolescents and the young adolescents. This is consistent to a study by Mutumba et al. (2015) in which it observed that, increasing with age at disclosure was associated with more negative reactions. Those who had been younger at disclosure described their reactions as not bad, felt nothing, felt bad a little, felt good to know the truth, and felt bad. The study findings also revealed that two adolescents knew that they were HIV positive

between ages of 6 to 10. Five of them knew about their status when they were between 11 and 15 years old while ten knew about their status when they were between sixteen and eighteen years. Kidia et al., (2014) concludes by observing that HIV-status disclosure to adolescents is distinct from disclosure to younger children and requires tailored, age appropriate guidelines. Disclosure to younger children in a healthcare setting may help overcome some of the barriers associated with caregivers disclosing in the home environment and make the HIV status seem more credible to an adolescent. Younger children should be informed incrementally to accommodate their cognitive skills and emotional maturity, in preparation for full disclosure (Mburu, et al., 2014, Sariah et al., 2016). Other service providers were not at ease to disclose HIV status to the adolescents for various reasons. These service providers need to know that there are individual differences in maturity with adolescents growing with HIV and ability to understand and cope as some adolescents will require more physiological and psychosocial support.

### **SRH needs from the perspectives of the adolescents growing with perinatally acquired HIV**

The study findings revealed that most adolescents growing with HIV have indeed reached puberty and are engaging in sex with some adolescents having risky sexual encounters. As a result, some adolescents are getting pregnant and having sexually transmitted infections. Thus, it could be deduced that as adolescents are surviving into adolescence, their sexual and reproductive health needs should be defined as they grow. Coupled with consequences of prolonged HIV infection and stigma, defining adolescents sexual needs in context of growing with HIV need not to be overlooked. By the definition of this study, SRH needs of adolescents with perinatally acquired HIV includes access to promotion of sexual health, provision of high-quality services for family planning, information and negotiating skills on safer sex, combating sexually transmitted infections

among those receiving antiretroviral therapy and issues relating to self esteem, worries as well as experiences of sexual and physical violence. Therefore, this study agrees with some authors Birungi., Obare., Mugisha., Evelia., & Nyombi., (2009), Hodgson., Rossa., Gitau-Mburu., & Choolwe., (2012), Dorrell & Katz, (2014) and Lowenthal., et al., (2014) who have argued that adolescents with perinatally acquired HIV need access to promotion of sexual health, provision of high-quality services for family planning, antiretroviral treatment during pregnancy and childbirth and postpartum, information and negotiating skills on safer sex, elimination of unsafe abortions in adolescents receiving antiretroviral therapy and combating sexually transmitted infections among adolescents with perinatally acquired HIV receiving antiretroviral therapy and issues relating to self esteem, worries as well as experiences of sexual and physical violence. If these services are not provided then there will be a lot of SRH unmet needs to adolescents growing with HIV. The transitional change to adulthood is not usually met as service providers lose track of the adolescents when they are over 18 or 19 years old. There is also need to highlight that literature supports that there are complex yet interrelated gaps in understanding the sexual and reproductive health needs of the adolescents growing up with HIV both globally, in Africa and in Malawi in particular (Beksinska et al., (2014), Hodgson, Ross, Haamujompa, & Gitau-Mburu, (2012), Mwalabu et al., (2017).

In order to explore the SRH needs for adolescents growing with perinatally acquired HIV adolescents growing with HIV and the service providers believed that adolescent sexual and reproductive needs that are being met include the provision of information on family planning, psychological support and counseling, medical and nutritional support, meeting as peers in teen club meetings, how to cope with stress and behavior change lessons are being met. On the other side, adolescent sexual and reproductive needs are also not being met as there are missed opportunities to meet the adolescents in the clinic. Adolescents are not very

open to using family planning methods despite that they are indulging in sexual activities. Offering the sexual and reproductive health services is not that effective as most of the adolescents are not free to express themselves to the health workers and most of the adolescents have denial that they are sick due to poor disclosure by the health workers and their parents. The majority reported unmet need by adolescents was their interaction with the service providers and the adolescents themselves. Other unmet needs were that were they lacked effective communication with service providers which negatively impacted on the care received by the adolescents. Most of the adolescents henceforth reported that most of their SRH needs are not being met at the clinic. However there was limited literature that had focused on sexual and reproductive needs of these adolescents in Malawi despite that some similar studies have been done within the Sub-Saharan region.

#### **Preferred SRH needs of the adolescents.**

For service providers to provide age appropriate and holistic care, there is need to reduce the disparity between services that are being provided and those that adolescent growing with HIV need. The study findings revealed more complex SRH needs of adolescent growing with HIV which included getting more information and education on SRH issues. Furthermore, some adolescents wanted to know how to avoid pregnancy and other related complications such as sexually transmitted infections or getting re-infections. It may not be surprising, therefore, that majority of adolescents wanted to be closer to the service providers so that their immediate problems such as provision of adolescent counselling services and health education and separate services to ensure privacy for them were tackled. This is similar to what was found in literature on the needs for the adolescents growing with HIV which had themes such as availability of HIV information, SRH needs of adolescents and health services' capacity (Idele. et al., 2014, Pettitt, et al., 2014, Birungi & Obare, 2011). What then needs to be improved is to capacity build and train health workers to better

understand the needs of adolescents and address the needs and challenges that adolescents living with HIV face. This may indicate the need for service providers to be trained in order to provide age appropriate health services to adolescents growing with HIV.

### **Youth friendly health services.**

Consistent with the findings in the present study, UNFPA (2015) suggest that for the provision of efficient delivery of a holistic youth-friendly health-care package of services, the following should be included; universal access to accurate sexual and reproductive health information, a range of safe and affordable contraceptive methods, sensitive counseling, quality obstetric and antenatal care for all pregnant women and girls and prevention and management of sexually transmitted infections, including HIV. However, Denno, Hoopes, & Chandra-Mouli, (2014) argue that effective strategies to provide adolescent sexual and reproductive should include sexual and reproductive health commodities and sexual and reproductive health biologic outcomes as there is limited evidence to the effectiveness of initiatives that simply provide adolescent friendliness training for health workers. It may not be surprising, therefore, that both the adolescents growing with HIV and the service providers were of the view that service providers lacked experience in provision of youth friendly health services. Despite a well stipulated package for the services this study found that not all services were available despite adolescents need to have the health services that can improve their health and well-being, including sexual and reproductive health services.

The majority of adolescents in this study wanted adolescent specific clinics that are spacious, provides youth friendly health services and integrated sexual and reproductive services such as post-abortal care. Consistent with results from this study, Atuyambe et al., (2015) in a study titled understanding sexual and reproductive health needs of adolescents in Uganda found that adolescents reported a need for a dedicated teenage health centre equipped with youth friendly health workers and stocked medicines. The current study revealed that

service providers were aware of the youth friendly service concept but none of them was trained in the concept. Ministry of Health Malawi, (2015) realises that youth continue to have limited access to targeted youth sexual and reproductive health services, which is contributing to and exacerbating many of the SRH problems adolescents face. Service providers found it hard to deliver a service that was needed but were not trained in it. Godia et al.,(2013) suggests that service provider related improvements should include increase in staffing levels, appropriate staff deployment, training of more staff which should include staff in youth friendly approach.

It is not surprising for the current study to reveal the obvious disconnect between the adolescents and service providers in the way they perceived and provided the youth friendly health services. It was noted that what was lacking mostly was the communication aspect between the adolescents and the service providers. This indicates that service providers should ensure that they have a nonjudgmental approach to adolescents when giving information or communication especially when discussing sexual behaviour as adolescents tend to disengage from care if they feel that they have been treated in a bad manner. There could be a possibility that the age gap between the service providers and the adolescents provided this disconnect as the study findings revealed.

Policy from Ministry of Health, (2015) on the youth friendly health services standard number three, states that all young people should be able to obtain health information (including on SRH and HIV) relevant to their needs, circumstances, and stage of development. However, the Rainbow clinic had no youth-specific and appropriate IEC materials on display for young people to take away but had established linkages with other organizations/institutions in the area that are providing information, counselling, and education on health for young people (including sexual and reproductive health). In the same policy document, (Ministry of Health 2015) standard number four, provides that service

providers should have the required knowledge, skills, and positive attitudes to effectively provide youth friendly health services. The study findings revealed that the facility had no service provider who was trained in youth friendly health services. Coupled with that finding, the facility did not provide training for service providers in youth friendly health services. It is not surprising therefore adolescents wanted to have services that fellow adolescents could offer at the clinic. These services could be tailored in such a way that they do not discriminate but meets the needs of the adolescents growing with HIV in a user-friendly and adolescent specific manner. Consistent to this finding, other studies Denno, Hoopes, & Chandra-Mouli, (2014) and Ndwiga et al., (2014) recommends that peer to peer services is also effective and feasible approach for capacity building in the context of integrated SRH and HIV services as the benefits of mentoring are particularly relevant for settings with moderate or high HIV prevalence, limited funding for provider capacity building and staff shortages.

#### **Contraceptive knowledge and use.**

The current study revealed that while few adolescents had ever used contraceptives, all of them were not on contraceptives as they stopped using any contraceptives at the time of interviews. This is similar to what was found by the Malawi Demographic and Health Survey (2016) which agrees that in terms of contraceptive use, which is low, less than half (40%) of sexually active 15-19 year old boys are using condoms and less than 30% of unmarried, and one quarter (25%) of married girls 15 -19 years old girls use modern contraception. Studies (Beksinska et al., 2014, Nandini et al., 2015, Godia et al., 2013) from other countries have shown that contraceptive use among adolescents is low despite that knowledge of contraceptives is high. The most widely available contraceptive at the clinic was a male condom. This could have a negative impact especially on the female adolescent growing with HIV. There could be a possibility that female adolescent would need negotiating skills in order to convince her partner to practice safe sex and lack of this skill would render the

female adolescent powerless increasing the risk of re-infection with HIV, getting pregnant or getting a sexually transmitted infection. Notably most adolescents growing with HIV confirmed that sex among them is common but that contraceptives are discouraged for girls under age 18 by the service providers which is a barrier to access of the service. It may not be surprising, therefore, that the majority of service providers were of the view that the adolescents did not need contraceptives while the adolescents felt otherwise. Thus, it could be deduced that denial to access the services can increase the propagation of unwanted pregnancies. Thus, it would be necessary to decipher that correct and comprehensive information, use of contraceptives in SRH is therefore urgently needed to improve access to SRH services. Majority of the adolescents interviewed knew a contraceptive method which is vital information for bringing up interventions. Chandra-Mouli, McCarraher, Phillips, Williamson, & Hainsworth,(2014) in a qualitative study in contraception for adolescents in low and middle income countries on needs, barriers, and access found that research evidence and programmatic experiences suggests that adolescents sexually need contraception. This confirms that all adolescents face a number of barriers in obtaining contraception and in using them correctly and consistently.

It may be of great importance to understand that effective interventions to improve access and use of contraception should include enacting and implementing laws and policies requiring the provision of contraceptive services for adolescents, increasing the access to and use of contraception by making health services adolescent-friendly, integrating contraceptive services with other health services, and providing contraception through a variety of outlets (Fair et al., 2013). Cognizant that information on contraceptives and other related information, provided to adolescents growing with HIV is important and critical as providing conflicting messages can be detrimental therefore provision of coherent information is important. Due to adolescents' rapid social and physical development, transition services

provided should meet these needs of an adolescent. Therefore service providers need to be encouraged to provide age appropriate information and services to adolescents growing with perinatally acquired HIV.

### **Perceptions of Adolescents on the SRH Services**

The study also looked at the perceptions of adolescents on the services that are being provided if they meet their sexual and reproductive health needs. Oluwatoyin Folayan et al., (2014) argues that adolescents growing up with HIV face challenges in their everyday lives as they require support to cope with sex and sexual needs, through full integration of individualized SRH services into the HIV services received. Majority of adolescents in this study were of the view that most of the services being provided at the clinic do meet their sexual and reproductive health needs.

### **Challenges with service provision.**

The study also looked at the challenges that adolescents growing with HIV and the service providers face during service provision. Both adolescents and service providers were in agreement that there were some challenges which included information giving. Adolescents felt that the service providers do not provide them with adequate information about contraceptive use while the service providers were of the view that the information given to adolescents was quite adequate. Not only were the service providers not good at provision of the youth friendly health services but were also harsh to adolescents. What adolescents really required was that they be welcomed with open hands when so that they reduce their anxiety levels. The adolescents also felt that the service providers were stigmatising them by the way they were being treated. So it is hard for adolescents to express themselves in front of older patients especially women. This leads to adolescents getting pregnant and terminating their pregnancies which can cause sudden deaths to the adolescents.

Service provision therefore should be geared towards having HIV and SRH interventions that can be fully integrated together whilst utilizing the existing resources. Service provision that appreciates and ensures integration between support provided by service providers and the needs of the adolescents growing with HIV rather than having a one size fits all program. Integrating SRH and HIV services at the Rainbow clinic can improve the way information, access and counseling on contraceptive methods is provided for adolescents living with HIV. There is need to espouse a comprehensive approach to put together an approach that covers a wide range of SRH needs for adolescents growing with HIV at the Rainbow clinic. Peer programmes such as Teen Clubs should be maintained to promote interaction amongst adolescents growing with HIV as evidenced by the findings. This is in line with a study titled exploring experiences in peer mentoring as a strategy for capacity building in sexual reproductive health and HIV service integration in Kenya, Ndwiga et al., (2014) argues that mentorship was perceived as a feasible and acceptable method of training among mentors and mentees. Both mentors and mentees agreed that the success of peer mentoring largely depended on cordial relationship and consensus to work together to achieve a specific set of skills. Mentees reported improved knowledge, skills, self-confidence, and team work in delivering integrated SRH and HIV services as benefits associated with mentoring. They also associated mentoring with an increase in the range of services available and the number of clients seeking those services. It is imperative therefore to set departments under one roof within the clinic to address and meet the SRH needs of adolescents growing with HIV should include the rights adolescents to exercise informed health and sexual choices including ART adherence and information on sexual health, contraception and family planning.

### **Early sexual debut.**

The current study revealed also revealed that adolescents are engaging in early sexual encounters which have a direct bearing on the SRH needs of the adolescents. UNFPA, (2015) argues that millions of girls are coerced into unwanted sex or marriage putting them at risk of unwanted pregnancies, unsafe abortions, sexually transmitted infections (STIs) including HIV, and dangerous childbirth. The findings also revealed that by age ten some had already started engaging in sexual activities. Most of the HIV-positive adolescents desired to have sex or many have had sex or intended to have sex in future due to psychological, physical, and social changes associated with adolescence. Some of them had multiple sexual relationships. It is not surprising that adolescents claimed that they had started having sex due to the problems they were experiencing at home as some had nobody to assist them as they were living as orphans. They were also responsible for taking care of other siblings. Others were having sex just like any other adolescent as they were undergoing normal rapid physical and psychological development which was a natural response. The Malawi Demographic and Health Survey (2010), reveals that there is unequal access to the already limited opportunities in social realms which has further increased the vulnerability among adolescent girls and put them at greater risk of HIV, STI and other sexual and reproductive health risks including physical, psychological, and sexual violence. The same survey continues to show that adolescents' pregnancies comprise 26% of all births, 20% of the adolescents have had a live birth, 6% are pregnant with their first child and they contributed to 20% of the maternal deaths which is very risky considering their tender age. Most of the sexual activities were consensual due to various reasons such as having sex just like any adolescent or due to financial problems. Stephenson, Simon, & Finneran, (2014) in a study titled community factors shaping early age at first sex among adolescents concluded that given the high costs of early sexual debut, including HIV and unintended pregnancy, there is an urgent need for

place-specific programmes to promote sexual health of adolescents. Most of these adolescents were not using condoms as a source of protection in subsequent sexual encounters with their partners though they did so in the first encounter. One female adolescent was engaging in risky sexual relationships and she had multiple partners. Except for two adolescents, the rest of them had started menstruating and ejaculating and within the age range of 13 to 15. All the adolescents in this study were not married. Despite not being married, four of the adolescent girls had already given birth as compared to their male counterparts. In a study titled factors influencing the experience of sexual and reproductive healthcare for female adolescents with perinatally-acquired HIV, a qualitative case study in Malawi, which is consistent to this study results, Mwalabu et al.,( 2017) found that young women reported becoming sexually active at an early age for different reasons. Some sought a sense of intimacy, love, acceptance and belonging in these relationships, noting that they lacked this at home and/or within their peer groups. For others, their sexual activity was more functional – related to meeting survival needs. Young women reported having little control over negotiating safer sex or contraception. Their priority was preventing unwanted pregnancies yet several of the sample already had babies. Transfer to antenatal services created major disruptions in their HIV care. As such adolescent reproductive and sexual issues needs to be looked into, just like any other normal adolescent, those growing with HIV have the same needs such as having relationships, sexual desires, getting married to start families and other needs. However, Oluwatoyin et al., (2014) in a review titled tackling sexual and reproductive health and rights of adolescents with HIV/AIDS a priority need in Nigeria, when finding if there are SRH differences between adolescents who are free from HIV against those adolescents growing with HIV infection found that there are a few research that have been conducted on how adolescents growing with HIV deal with sexual and reproductive health challenges faced in their everyday lives to help make any meaningful

inferences on these differing needs. The review suggests that the SRH needs and practices of HIV free adolescents may differ from that of adolescents growing with HIV who would require support to cope with sex and sexual needs, through full integration of individualized HIV and SRH services.

### **HIV status disclosure to sexual partners.**

The study findings also revealed that about half of the adolescents who ever engaged in sex did disclose to their partners and the rest were not disclosing to their partners citing fear to be beaten as reasons for nondisclosure. Among those who have had sex some had consensual protected first sex then subsequent ones were unprotected sexual encounters. This is consistent to a study by UNFPA, (2015) that shows that disclosure of sero status remains a major concern for adolescents growing with HIV. Once they know they are growing with HIV, adolescents face important dilemmas in relation to their sexuality and sexual relationships. While many want to protect themselves and their partners, they often fear that disclosure may lead to a relationship ending. This is also consistent to findings by Mburu et al.,(2014) who noted that adolescents' disclosure of their HIV status to their sexual partners, was marked by fear of rejection as a common barrier.

Despite increased public awareness of HIV, stigma has been shown to greatly impact adherence and disclosure amongst a spectrum of people growing with HIV including adolescents from this study. In a study by Jobson, (2014) it was noted that disclosure had various outcomes which were both positive and negative in nature, some adolescents described being anxious, depressed and blaming themselves after being told they had HIV but at the same time disclosure created opportunities for adolescents to access, adherence, and other forms of psychosocial from family members and peers reducing levels of rejection. Mostly adolescents growing with HIV in this study found it difficult to disclose their status due to perceived stigmatisation.

### **Infrastructure.**

For services to run effectively, infrastructure plays a crucial role in delivery of health services. The findings of this study showed that infrastructure at the Rainbow clinic was not favourable enough for the provision of SRH and HIV services at Mzuzu Central Hospital. The area where services are provided is too small compared to the number of adolescents accessing services at the clinic. These factors are likely to compromise confidentiality and privacy to adolescents seeking SRH services. The environment should be free and there are a lot of disturbances as adolescents literally fight to get services earlier. Due to poor infrastructure the services that are provided do not provide enough privacy to the adolescents growing with perinatally acquired HIV. In a qualitative study Godia et al., (2013) found that if privacy in the consultation rooms has to be improved, there is need for facility improvement initiatives such as having youth-specific rooms where adolescents can be served without needing to queue. Lack of privacy makes adolescents shy away and opts out of the services provided at the clinic rendering adolescents vulnerable to pregnancies and/or sexually transmitted diseases. The adolescents felt that the clinic itself was small to accommodate the numbers that attend the clinic making the environment not conducive to service provision. As such they felt that they need a place where they would interact with the service providers that could not offer any disturbances and where they would get other services such as for the SRH. It should be encouraged to provide HIV services for adolescents at the Rainbow clinic separately from adult services and in a setting that assures privacy and confidentiality as adolescents are very sensitive to issues surrounding their health.

### **Stigmatisation and abandonment.**

Findings also revealed that adolescents were feeling stigmatised by both the community and service providers. In a mixed method approach of the study involving

caregivers of HIV infected children and adolescents aged 4–19 years attending the three hospitals in Ghana, Gyamfi, Okyere, Appiah-Brempong, Adjei, & Mensah, (2015) confirms that in a world of changing societies, increasing poverty problems, governmental conflicts, inequality as main parts of the main social problems, the HIV/AIDS stigma remains rooted. Although the main reason for this stigma remains unclear, it is commonly accepted that they originate from within the core of society. The social stigma is a pervasive problem regarding the attempts of HIV prevention, diagnosis, and treatment. Sirikum et al., (2014) found that the major barrier to disclosure of HIV status was the stigma associated with the illness as HIV is seen as sickness caused by the supernatural powers as a result of either punishment or breaking communal taboos. Once people get to know of your HIV status, you are labelled and people will not be willing to interact with you is consistent to this study. It is imperative to understand that adolescents growing with HIV face multifaceted problems. They are more likely to be in advanced stages of HIV infection, having opportunistic infections, being put on complicated ART regimens which can bring heavy antiretroviral exposure. They can also be having problem with their growth and development due to the advanced HIV infection. Especially with a girl child, when pregnant she can also have a higher risk of complications due to immune response or the advanced infection. Therefore service providers need to understand these needs while underpinning the developmental process of adolescence.

The study findings also revealed that most of the adolescents growing with HIV have either lost one or both parents. Adolescents therefore undergo emotional loss and they need support from caregivers and service providers. In this study, there was no adolescent who had all parents alive while three had one parent alive. Ten of them were living with relatives while four got pregnant and were living as single parents and/or with their siblings. This is consistent to a study by Bernays, Jarrett, Kranzer, & Ferrand, (2014) titled children growing with HIV infection, the responsibility of success that notes that HIV is a household disease.

Having inherited the virus from a parent they are more likely to be orphaned and have changing or absent guardianship, which could lead to being isolated through neglect or separation from other family members. They may also have psychosocial and economic problems due to loss of their parents. Without support they reflect on their earlier losses and bereavement experiences as such they feel abandoned and in some cases stigmatised. This then makes an adolescent growing with HIV more vulnerable than his/her counterparts. They had a sense of abandonment as they were living as single parents due to the fact they were abandoned by their boyfriends. Kontomanolis, Michalopoulos, Gkardaris, & Fasoulakis, (2017) concludes by noting that stigma devalues and diminishes the dignity of people who are subjected to it and it needs to be addressed and corrected, since the inevitable social consequences of being stigmatized lead to severely reduced opportunities, discrimination, and even rejection. One of the tragic consequences of discrimination is that it has a deep impact on vulnerable and sensitive groups.

### **Perceptions Service Providers' of SRH needs of the Adolescents**

Service providers felt that due to staff shortages more staff were needed at the clinic that would provide age appropriate and youth friendly health services and would understand adolescents' needs whilst spending more time with the service providers. It was discovered that adolescents growing with HIV needed to have their own space where they would get ARVs and contraceptives but the clinic was also being used by older patients. Contraceptives, including condoms need to be provided through integrated services in a place whereby the settings provides a conducive environment that is supportive and confidential to all adolescents growing with perinatally acquired HIV and are sexually active. According to the UNFPA report,(2015) majority of the young people have limited access to sexual and reproductive health services and yet their knowledge and practices related to sexual and reproductive health still needs to be improved. This is also in line with a study conducted by

the Southern Africa AIDS Trust,( 2014) on adolescents growing with HIV identified key interventions adolescents perceive could improve the effectiveness of HIV services that must be encouraged and motivated to access local groups and providers of psychosocial support in their community. Offering relevant preventive information, skills and services to adolescents growing with HIV who are already vulnerable should be conducted in an enabling and protective environment. Adolescents also need several family planning methods that they could choose from. Without this it was observed that the youth tend to shun away from the health services being provided at the clinic. Relationship between service providers and adolescents growing with HIV is very important as it can enhance positive health outcomes to the adolescents and reduce any barriers that can undermine access to health services. Another theme that emerged was relationship of the adolescents with the service providers. This was important so as to determine the perceptions of adolescents growing with perinatally acquired HIV on the SRH services offered at the clinic. Adolescents growing with HIV experiences in health are shaped by those that provide the care and their parents due to lack of autonomy and social experience. Their exposure to social stigma is also underappreciated and has a profound effect on growing with HIV. That is where health service providers should come in to bridge this gap. Bernays, Jarrett, Kranzer, & Ferrand, (2014) have noted that the lived experiences of adolescents have been constructed through the symbiotic relationships between adolescents and service providers and how this relational complexity shapes how children consider and articulate what it is like to grow with HIV. Sustainable interventions and multidisciplinary services need to be developed for adolescents growing with HIV. Adolescents revealed that they would love to have friendly health care workers. Participants from this study felt that they needed providers who were kind to them and were treating them with due respect as not doing so was demotivating the adolescents from getting the required.

The study findings also revealed the perceptions of the service providers that they needed staff who are trained in adolescent social, physical and psychological development to effectively care for adolescents growing with HIV. Service providers also believe that they need ongoing information and education on SRH issues. For their physical growth service providers believe that adolescents growing with perinatally acquired HIV need to be given nutritional supplements and that they need to be involved in exercises and s activities and to empower them economically especially the girl child with life skills. When disclosing adolescents HIV status, the service providers were of the view that they needed to engage parents earlier and partner with them to smoothen the process. The service providers believe that they need to provide the adolescents with adequate information and education on SRH. These concerns were similar to results that were conducted in Kenya by Godia et al., (2013) found out that service providers report not being competent in adolescent counselling, facing a dilemma and not being comfortable with providing SRH services to adolescents. Service providers also report being torn between their personal feelings, cultural norms and values and respecting adolescent right to accessing SRH services. The integrated model however was limited in provision of a wide the range of services due to deficiencies in staffing, supplies and equipments. The service providers were in total agreement with the adolescents that adolescents needed youth friendly health services despite that there were no personnel that were trained in youth friendly health service provision and in adolescents' specific clinics. The service providers felt that adolescents growing with perinatally acquired HIV need youth friendly services to be provided by peers with the same sex as they are free and trust them rather than attending clinics with adults. Nonetheless the service providers felt that some needs such as psychological support, counseling, adherence, teen club meetings, nutritional and medical are met.

Other findings from the study also revealed that service providers' perceptions of SRH needs of the adolescents growing with perinatally acquired HIV were slightly different from the perceptions of the adolescents. Service providers were of the opinion that the adolescents did not want family planning methods as a result they get pregnant due to poor disclosure. Service providers also felt that the adolescent growing with perinatally acquired HIV were not open to use family planning methods as such they could not force the adolescents to use family planning methods. Despite that most have denial that they are sick, they were also engaging in sexual activities and that there was need to empower girl child with life skills through giving them information on family planning methods, sexual education, and abuse against drugs and alcohol.

It is a common belief that the services that are being provided do not meet the needs of the adolescents due to various reasons. UNICEF, (2015) confirms this by explaining that existing sexual and reproductive health (SRH) services rarely meet young people's needs in an effective way. Often, they fail to take into account factors that compound their vulnerability to HIV and other sexually transmitted infections (STI) such as imbalanced power dynamics, gender inequality, an increased propensity to risk, attitudes and norms relating to adolescents and sex, and a lack of confidentiality. The findings from this study clearly affirms that the environment was not conducive and service providers were starting to work very late making the adolescents to wait for long to get the drugs and family planning commodities. The other reason was that the service providers, who were supposed to mentor the adolescents in the support groups, were found out to be going out within the communities and reveal adolescent statuses. This made the adolescents to shun away from attending the clinic making some adolescents get pregnant along the way. In terms of contraceptive use, the study showed that there is a high level of knowledge of contraceptive methods available and where to get them but the level of contraceptive use is relatively lower for the sexually active

adolescents growing with HIV which could be attributed to barriers to contraceptive use as highlighted by themselves such disapproval by partner and lack of proper knowledge of contraceptive. This means that majority of sexually active adolescents are highly exposed to consequences of unprotected sex and sexually transmitted diseases. The other challenge was that adolescents who are in secondary schools do not get enough ARVs when going to school and are forced to come back to get more supplies. When somebody comes to the Rainbow clinic everybody knows that they are on ARVs which actually stigmatises the adolescents growing with HIV. Growing up as orphans and being single parents exacerbate stigmatisation and adolescents start to indulge in sex as they do not have support from their real parents. This then forms a vicious circle as adolescents who dropped from accessing the services can do anything in their community which is contrary to the goals of the Ministry of Health to reduce or eradicate HIV.

### **Suggestions for Further Research**

Findings from this study have showed that there are implications that can be used to improve delivery of sexual and reproductive health services and HIV services to adolescents growing with HIV. Adolescents growing with HIV and service providers in the study suggested that the following areas need to be improved. Recommendations have been drawn to improve paediatric services in practice, education, management and research.

### **Practice**

The study recommends that adolescents need more time to be with the service providers so that they can interact with them and address their problems as soon as possible. Adolescents also need a variety of family planning methods that are available at the clinic rather than provision of condoms alone. These family planning methods should be provided under one roof. Adolescents also need adolescent specific services based on their

developmental phase as adolescents do not like to be with either young children or older service seekers to be accessing services together.

### **Education**

The study also recommends that adolescents receive adequate information on SRH services that are offered to adolescents at a referral clinic. Having noted the discrepancy in understanding youth friendly health services by the service providers, the study also recommends that all service providers at the clinic be trained in youth friendly health service provision.

### **Management**

The study also revealed that there are multiple problems that adolescents encounter when accessing services at the clinic. Adolescents recommended that there is need to improve staff attitudes, make availability of commodities, enhance staff interaction with the adolescents, mitigation against stigmatization by service providers and integrate SRH and HIV services. Adolescents also need a special space as more people are not comfortable coming to this clinic as it is small and too open. The space should be the one that can only provide services to adolescents rather than mixing them with older service seekers. There is also need for the hospital to lobby for more staff to run the clinic. The staff should be the ones that are available at the clinic, who are trained in provision of youth friendly health services but they should also be youthful service providers.

### **Research**

Exploring sexual and reproductive health needs for adolescents' growing with HIV can greatly improve service care and delivery. These adolescents should not be viewed as any other adolescents as their service needs are different from the normal adolescent. As such this study recommends that this research be replicated on a large scale to inform policy.

## **Strength and Limitations of the Study**

The study gave an in-depth understanding of the sexual and reproductive health needs of adolescents growing with HIV at Mzuzu Central Hospital and it was the first of its kind. It was qualitative in nature and used an exploratory design so as to understand the SRH needs for adolescents growing with perinatally acquired HIV designed for discovery rather than verification (Brink, Rensburg & Walt, 2014). It also gave in the insights of health service providers opinion on how they perceive the services they provide. Service providers and adolescents were able to communicate their challenges and put in place practical strategies to improve SRH services that can be incorporated in policies and programmes.

As a qualitative study which took place at one facility the results presented may not be generalised to the whole of adolescents growing with HIV and service providers in the Malawian population. Adolescents growing with HIV and service providers that were interviewed were only from urban area and there is need to also understand SRH needs for those adolescents who are in rural areas who could be more vulnerable and marginalised. More research is needed to explore the sexual and reproductive health needs in Malawi. Health service providers' technical competencies need also to be evaluated in order to strengthen the provision of such services.

## **Recommendations**

Practical strategies to improve SRH service delivery for adolescents with perinatally acquired HIV at Mzuzu Central Hospital that were both identified by the adolescents and the service providers were that;

- Management to increase staffing levels at the clinic that can provide youth friendly services.
- Management should ensure that there are peers who can educate fellow peers can also improve service delivery.

- Service providers to spend more time for interaction with the adolescents growing with HIV at the clinic.
- Funding of youth friendly HIV and SRH services should be done to meet the needs of adolescents at each point in their development.
- Management to provide a wide range of long acting contraceptives and having a method mix in contraceptives to meet long term plans for adolescents.
- Service providers delivering HIV, SRH and psychosocial interventions should facilitate earlier testing of children at risk of HIV to mitigate the negative psychological trauma that adolescents face.
- Service providers delivering HIV and SRH services should lobby for the availability of resources for adolescents growing with HIV.
- Health information giving and sensitization of the communities on SRH services for adolescents with HIV needs to be strengthened so that interventions within the communities are adolescent specific which are cohesive in nature to ensure an end-user is not presented with conflicting messages.
- The Ministry of Health should come up with policies that are age specific for adolescents growing with HIV.

### **Conclusion**

The study utilized the qualitative approach to research to explore the sexual and reproductive health needs for adolescents growing with HIV who access services at Mzuzu Central hospital. It also unveiled the preferences of adolescents in sexual and reproductive health and the challenges they face when accessing these services. Adolescents growing with HIV need age appropriate services which should be comprehensive so as to assist adolescents growing with HIV with the challenges so as to improve their quality of life. The need for adolescents to access services under one roof ensures that adolescents living with HIV can

have an easy access to both HIV and SRH services at the same facility as is with the Rainbow clinic thereby reducing problems that adolescents face in accessing services without being referred to other clinics within the hospital thereby increasing services provided rather than HIV treatment and care alone. Adolescents growing with HIV should not be treated like any other adolescent as their social, economic, psychological and physiological aspects need to be understood in order to provide holistic care as they mature and transition in adulthood. Service providers also play a crucial in the healthier outcomes on the sexual and reproductive health needs of adolescents as such their involvement and understanding about adolescence is very crucial.

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## Appendices

### Appendix 1: Participants Information Sheet

**Research title:** Exploring sexual and reproductive health (SRH) needs for adolescents growing with perinatally acquired HIV at Mzuzu Central Hospital.

**Principal Investigator;** Thom George Ngwira

My name is Thom Ngwira, a student of Kamuzu College of Nursing, University of Malawi. I am doing a study on exploring sexual and reproductive health (SRH) needs for adolescents growing with perinatally acquired HIV at Rainbow clinic, Mzuzu Central Hospital. For any clarifications and concerns about the study, you can contact; The Acting Principal, Kamuzu College of Nursing, Blantyre Campus Professor E. Chirwa on 0888940513 or my supervisor, Dr. G. Mwalabu on 0996960677. You can also contact The Chairperson, College of Medicine Research and Ethics Committee, Private Bag 360, Chichiri, Blantyre 3 on 01989766.

The broad objective is to explore the SRH needs for adolescents growing with perinatally acquired HIV at Mzuzu Central Hospital. The Specific objectives are: to identify SRH needs for adolescents growing with perinatally acquired HIV at Mzuzu Central Hospital; to determine perceptions of adolescents growing with perinatally acquired HIV as to which SRH needs are being met or unmet at Mzuzu Central Hospital; to establish how the SRH needs for adolescents who acquired HIV perinatally feel their SRH needs may better be addressed at Mzuzu Central Hospital; to determine service providers perceptions of SRH needs of the adolescents with perinatally acquired HIV.

You will be interviewed by the researcher for 30 minutes. The information that you will provide shall be confidential and will not be shown to other people except those concerned with the study. The information that you will provide will be documented on the questionnaire. You will not be asked your name but will be required to give some background

information such as your age and marital status. Your participation in the study is voluntary and any refusal to do so shall not affect the type of services you receive at this health facility. There are no risks attached to the study other than that you will spend some time with the researcher apart from the usual health services. There are no direct benefits for participating in the study but the information you will provide will help to identify practical strategies to improve SRH needs for adolescents growing with perinatally acquired HIV.

## **Appendix 2: Chichewa Translated Information Sheet**

**Mutu wa kafukufuku:** Kufufuza momwe achinyamata omwe anatengera kachilombo ka HIV kwa makolo angathandizikire pa umoyo wa za uchembele pa chipatala cha Mzuzu Central.

**Mwini Kafukufuku;** Thom George Ngwira

Dzina langa ndine Thom Ngwira. Ndachokera ku sukulu ya azamba ndi anamwino ya Kamuzu College of Nursing nthambi ya University of Malawi. Ndikanga kafukufuku wa momwe achinyamata omwe anatengera kachilombo ka HIV kwa makolo awo angathandizikire pa umoyo wa za uchembele pa Mzuzu Central Hospital. Ngati mungakhale ndi mafunso kapena kufuna kudziwa zambiri za kafukufuku ameneyi mutha kuyimba lamya kwa wamkulu wo yanganira ku Kamuzu College of Nursing, Blantyre Campus, a Professor E. Chirwa pa nambala iyi 0888940513, Supervisor Dr. G. Mwalabu pa nambala iyi 0996960677 kapena kwa Wamkulu wa College of Medicine Research and Ethics Committee, Private Bag 360, Chichiri, Blantyre 3 pa nambala iyi 01989766.

Mukafukufukuyi tikufuna tipeze kuti ndi zofunikira ziti zomwe achinyamata omwe anatengera kachilombo ka HIV kwa makolo awo amfuna kuchokera kuchipatala cha Mzuzu Central Hospital. Kodi ndi zinthu zANJI zomwe achinyamata amafuna kuthandiziridwa ndi achipatala potukula umoyo wawo wa uchembere. Kodi ndi zinthu zANJI zomwe achipatala angachite potukula uchembele wabwino kwa achinyamatawa. Kodi pangakhale angiri wanji woti achinyamata omwe anatengera kachilombo ka HIV kwa makolo awo ndi achipatala angapange pofuna kutukula moyo wa achinyamatawa.

Ndikufunsani mafunso womwe atitengera nthawi pafufi mphindi makumi atatu. Zomwe mutandiwuze pakafukufuku ameneyi zikhala za chinsinsi ndipo sizikaonetsedwa kwa wina aliyense. Simufunsidwa dzina lanu koma zina zokhudza inu zoti zikathandize pakafukufuku

ameneyi. Kutenga nawo mbali mu kafukufuku ameneyi sikokakamiza ndipo palibe chilango china chilichonse chomwe chidzaperekedwe mutakana kulowa nawo kafukufuku ameneyi. Palibe chovuta chomwe mukumane nacho pakafukufukuyi katulapo nthawi yowonjezera yomwe muzakhale mukuyankha mafunso. Palibe chomwe mutapindule mu kafukufuku ameneyi koma zomwe muyankhe zidzathandizira keza njira zothandizira achinyamata omwe anatengera kachilombo ka HIV kwa makolo awo kuti alandire chithandizo chabwino cha zauchembele pa chipatala chino.

**Appendix 3: Consent Form**

**Study title:** Exploring Sexual and Reproductive Health (SRH) needs for adolescents growing with perinatally acquired HIV at Rainbow clinic, Mzuzu Central Hospital.

**Principal Investigator;** Thom Ngwira, Kamuzu College of Nursing, P.O. Box415, Blantyre. Cell: 099414 5060.

For any clarifications and concerns about the study, you can contact; The Acting Principal, Kamuzu College of Nursing, Professor E. Chirwa on 0888940513 or my supervisor, Dr. G. Mwalabu on 0996960677. You can also contact The Chairperson, College of Medicine Research and Ethics Committee, Private Bag 360, Chichiri, Blantyre 3 on 01989766.

Please read and sign this form if you are participating in this study.

I have read the attached information sheet about the study and have understood the purpose of the study. My questions have been answered to my satisfaction. I give permission to the researcher to ask me questions. I understand that the information that will be obtained will be kept confidential and that there are no financial benefits for participating in the study. I have the right to withdraw from the study at any point. I have been assured that any publication and research dissemination will not have any name. I voluntarily agree to take part in the study.

Participant name.....Signature/Thumbprint.....Date.....

Name of researcher.....Signature.....Date.....

Thank you for participating in the study.

## **Appendix 4: Chichewa Translated Consent Form**

### **Kalata ya chilolezo**

**Mutu wa kafukufuku:** Kufufuza momwe achinyamata omwe anatengera kachilombo ka HIV kwa makolo angathandizikire pa umoyo wa za uchembele pa Mzuzu Central Hospital.

**Mwini Kafukufuku;** Thom Ngwira, Ndachokera ku sukulu ya azamba ndi anamwino ya Kamuzu College of Nursing nthambi ya University of Malawi, P.O. Box415, Blantyre. Cell: 099414 5060.

Ngati mungakhale ndi mafunso kapena kufuna kudziwa zambiri za kafukufuku ameneyi mutha kuyimba lamyamba kwa wamkulu wo yanganira ku Kamuzu College of Nursing, Blantyre Campus, a Professor E. Chirwa pa nambala iyi 0888940513, Supervisor Dr. G. Mwalabu pa nambala iyi 0996960677 kapena kwa Wamkulu wa College of Medicine Research and Ethics Committee, Private Bag 360, Chichiri, Blantyre 3 pa nambala iyi 01989766.

Chonde werengani ndi kuika chizindikiro cha dzina lanu ngati mukutenga nawo mbali pa kafukufukuyu. Ndawelenga ndipo ndamvetsa zonse zokhudza kafukufuku ameneyi. Mafunso anga onse ayankhidwa. Ndikuvomerza kuti wochita kafukufukuyi andifunse mafunso wokhudzana ndi kafukufukuyi. Ndatsimikiziridwa kuti zonse zomwe tikambirane zikhala za chinsinsi komanso kuti palibe phindu la ndalama potenga nawo mbali pakafukufukuyi. Ndili ndi ufulu wosiya kutenga mbali pa kafukufukuyi nthawi ili yonse. Ndatsimikiziridwanso kuti zotsatira zakafukufukiya sizidzasonyeza dzina la munthu wina aliyense. Ndavomera kulowa nawo mu kafukufuku ameneyi mwakufuna kwanga.

Sayini ya wotenga mbali mukafukufuku .....

Tsiku.....

Chidindo cha chala cha otenga mbali mukafukufuku (ngati sakutha kulemba).....

Tsiku.....

Sayini ya mboni (ngati wotenga mbali sakutha kulemba).....

Tsiku.....

Sayini ya opangitsa kafukufuku.....

Tsiku.....

**Appendix 5: Assent Form for Adolescents less than 18 years old from Parents**

**Study title:** Exploring Sexual and Reproductive Health (SRH) needs for adolescents growing with perinatally acquired HIV at Rainbow clinic, Mzuzu Central Hospital. Please read and sign this form if you agree that your child participates in this study.

**Principal Investigator;** Thom Ngwira, Kamuzu College of Nursing, P.O. Box415, Blantyre. Cell: 099414 5060.

For any clarifications and concerns about the study, you can contact; The Acting Principal, Kamuzu College of Nursing, Blantyre Campus Professor E. Chirwa on 0888940513 or my supervisor, Dr. G. Mwalabu on 0996960677. You can also contact The Chairperson, College of Medicine Research and Ethics Committee, Private Bag 360, Chichiri, Blantyre 3 on 01989766.

I have read the attached information sheet about the study and have understood the purpose of the study. My questions have been answered to my satisfaction. I give permission to the researcher to ask my child questions. I understand that the information that will be obtained will be kept confidential and that there are no financial benefits for participating in the study.

I have the right to withdraw from the study at any point. I have been assured that any publication and research dissemination will not have any name. I voluntarily agree that my child take part in the study.

Parent’s name.....Signature/Thumbprint.....Date.....

Name of researcher.....Signature.....Date.....

Thank you for participating in the study.

## **Appendix 6: Chichewa Translated Assent Form**

Kalata ya chilolezo kwa ana osachepera zaka khumi, chisanu ndi ziwiri kuchokera kwa makolo.

**Mutu wa kafukufuku:** Kufufuza momwe achinyamata omwe anatengera kachilombo ka HIV kwa makolo angathandizikire pa umoyo wa za uchembele pa Chipatala cha Mzuzu Central.

**Mwini Kafukufuku;** Thom Ngwira, Ndachokera ku sukulu ya azamba ndi anamwino ya Kamuzu College of Nursing nthambi ya University of Malawi, P.O. Box415, Blantyre. Cell: 099414 5060.

Ngati mungakhale ndi mafunso kapena kufuna kudziwa zambiri za kafukufuku ameneyi mutha kuyimba lanya kwa wamkulu wo yanganira ku Kamuzu College of Nursing, a Professor E. Chirwa pa nambala iyi 0888940513, Supervisor Dr. G. Mwalabu pa nambala iyi 0996960677 kapena kwa Wamkulu wa College of Medicine Research and Ethics Committee, Private Bag 360, Chichiri, Blantyre 3 pa nambala iyi 01989766.

Chonde werengani ndi kuika chizindikiro cha dzina lanu ngati mukufuna mwana wanu atengepo nawo mbali pa kafukufukuyu. Ndawelenga ndipo ndamvetsa zonse zokhudza kafukufuku ameneyi. Mafunso anga onse ayankhidwa. Ndikuvomerza kuti wochita kafukufukuyi andifunse mafunso wokhudzana ndi kafukufukuyi. Ndatsimikiziridwa kuti zonse zomwe tikambirane zikhala za chinsinsi komanso kuti palibe phindu la ndalama potenga nawo mbali pakafukufukuyi. Ndili ndi ufulu wosiya kutenga mbali pa kafukufukuyi nthawi ili yonse. Ndatsimikiziridwanso kuti zotsatira zakafukufukiyi sizidzasonyeza dzina la munthu wina aliyense. Ndavomera kuti mwana wanga akhonza kanga nawo kafukufuku ameneyi mwakufuna kwanga.

Sayini ya kholo lovomeleza kuti mwana atenge nawo mbali mukafukufuku

.....Tsiku.....

Chidindo cha chala cha otenga mbali mukafukufuku (ngati sakutha kulemba).....

Tsiku.....

Sayini ya mboni (ngati wotenga mbali sakutha kulemba).....

Tsiku.....

Sayini ya opangitsa kafukufuku..... Tsiku.....

## Appendix 7: Semi Structured Interview Guide English for Adolescents

Code Number.....

Date of interview.....

Name of interviewer.....

### A Demographic Data

1 How old are you (a) 13-15 { }

(b) 16-18 { }

2 What is your marital status (a) Married { }

(b) Single { }

(c) Others specify { }

3 If married, probe on the age of the Partner?.....

4 What is your tribe? (a) Chewa { }

(b) Tumbuka { }

(c) Mtonga { }

(d) Others specify.....

5 Where do you come from? Village/Town.....

T/A .....

6 What do you do in life? (a) Farming { }

(b) Business { }

(c) Student { }

(d) Others specify { }

7 Level of education (a) None { }

(b) Primary level { }

(c) Secondary level { }

(d) Tertiary level { }

8. At what age did you know that you are HIV positive? .....

9. Age at menarche? .....

10. Have you ever got engaged in sexual activity? If yes probe on age and type of sexual activity .....

11. Have you ever had STI/Pregnancy/Abortion? If yes probe on outcome.....

12. Are you on any contraceptives? If yes probe on methods and reasons for being on contraceptives .....

13. What information about SRH do you get from the clinic?

14. What information about SRH do you need from the clinic?

15. What SRH services do you get from the clinic?

16. What challenges have you encountered at the clinic?

17. What SRH services do you need from the clinic?

## Appendix 8: Mafunso Mchichewa

Code Number-----

Tsiku la mafunso-----

Dzina la ofunsa mafunso -----

- Gawo Loyamba

*Ndikufunsani mafunso okhudzana ndi inuyo.*

### A Mbiri yanu

1. Muli ndi zaka zingati zakubadwa? 13-15 { }

16-18 { }

2. Nanga muli pabanja?      Wosakwatiwa { }

Wokwatiwa { }

Zina onjezerani { }

3. Ngati ali pa banja, amunanu ali ndi zaka zingati?.....

4. Ndinu a mtundu wanji?      Chewa { }

Tumbuka { }

Mtonga { }

Wina fotokozani.....

5. Mumakhala kuti      Mudzi .....

T/A .....

6. Tanduzani mumachita chiyani moyo wanu wa tsiku ndi tsiku

Ulimi { }

Mwana wa sukulu{ }

Bizimisi { }

Zina onjezerani.....

7. Sukulu yanu munafika nayo pati sindinayimbeko? Sindinapiteko{ }

Pulayimale { }

Sekondale { }

8. Munadziwa kuti muli ndi kachilombo ka HIV muli ndi zaka zingati? .....

9. Munayamba kusamba/kuthira umuna muli zaka zingati? .....

10. Munayamba mwagonanapo za dama? Ngati inde munapanga chain?.....

11. Munayamba mwatengapo matenda opatsirana pogonana/mimba/kapena kutaya mimba?  
Ngati inde zinathat bwanji?..... .

12. Muli pa njira ina ili yonse yakulera? Ngati inde njira yanji ndi pa chifukwa chanji?..... .

13. Kodi mumalandira uthenga wanji wa zauchembele pa chipatala chino?

14. Ndiye ndi uthenga wanji wa zauchembele umene mumafuna kulandira kuchipatala kuno?

15. Kodi mumalandira thandizo lanji la zauchembele pa chipatala chino?

16. Kodi ndi mavuto anji anji omwe mumakumana nawo mukamalandira chithandizo cha  
zauchembele pa chipatala chino?

17. Kodi mumafuna kuti muzilandira thandizo lanji la zauchembele pa chipatala chino?

## **Appendix 9: Focus Group Interview Guide for Adolescents**

Date.....

Number of participants..... Male..... Female.....

1. What information about SRH do you get from the clinic?
2. What information about SRH do you need from the clinic?
3. What SRH services do you get from the clinic?
4. What challenges do you encounter at the clinic?
5. What SRH services do you need from the clinic?

## **Appendix 10: Focus Group Interview Guide for Adolescents in Chichewa**

Tsiku.....

Nambala yaopanga nawo kafukufuku..... Anyamata..... Atsikana.....

1. Kodi mumalandira uthenga wanji wa zauchembele pa chipatala chino?
2. Ndiye ndi uthenga wanji wa zauchembele umene mumafuna kulandira kuchipatala kuno?
3. Kodi mumalandira thandizo lanji la zauchembele pa chipatala chino?
4. Kodi ndi mavuto anji anji omwe mumakumana nawo mukamalandira chithandizo cha zauchembele pa chipatala chino?
5. Kodi mumafuna kuti muzilandira thandizo lanji la zauchembele pa chipatala chino?

## **Appendix 11: Semi Structured Interview Guide English for Service Providers**

Code Number.....

Date of interview.....

Name of interviewer.....

### **A Demographic Data**

1. How old are you?.....
2. For how long have you been working at this Clinic?.....
3. Can you tell me your experience of offering SRH services to adolescents growing with perinatally acquired HIV?
4. What challenges do you often meet when providing SRH services to adolescents growing with perinatally acquired HIV?
5. What do you think are the SRH needs of adolescents growing with perinatally acquired HIV?
6. Which needs are met or not met for adolescents growing with perinatally acquired HIV?
7. In your opinion, what are the gaps as regards to SRH services to adolescents growing with HIV?
8. In your opinion how can these gaps in SRH service provision be filled?

## **Appendix 12: Semi Structured Interview Guide English for Service Providers in**

### **Chichewa**

Code Number.....

Tsiku la Kafukufuku.....

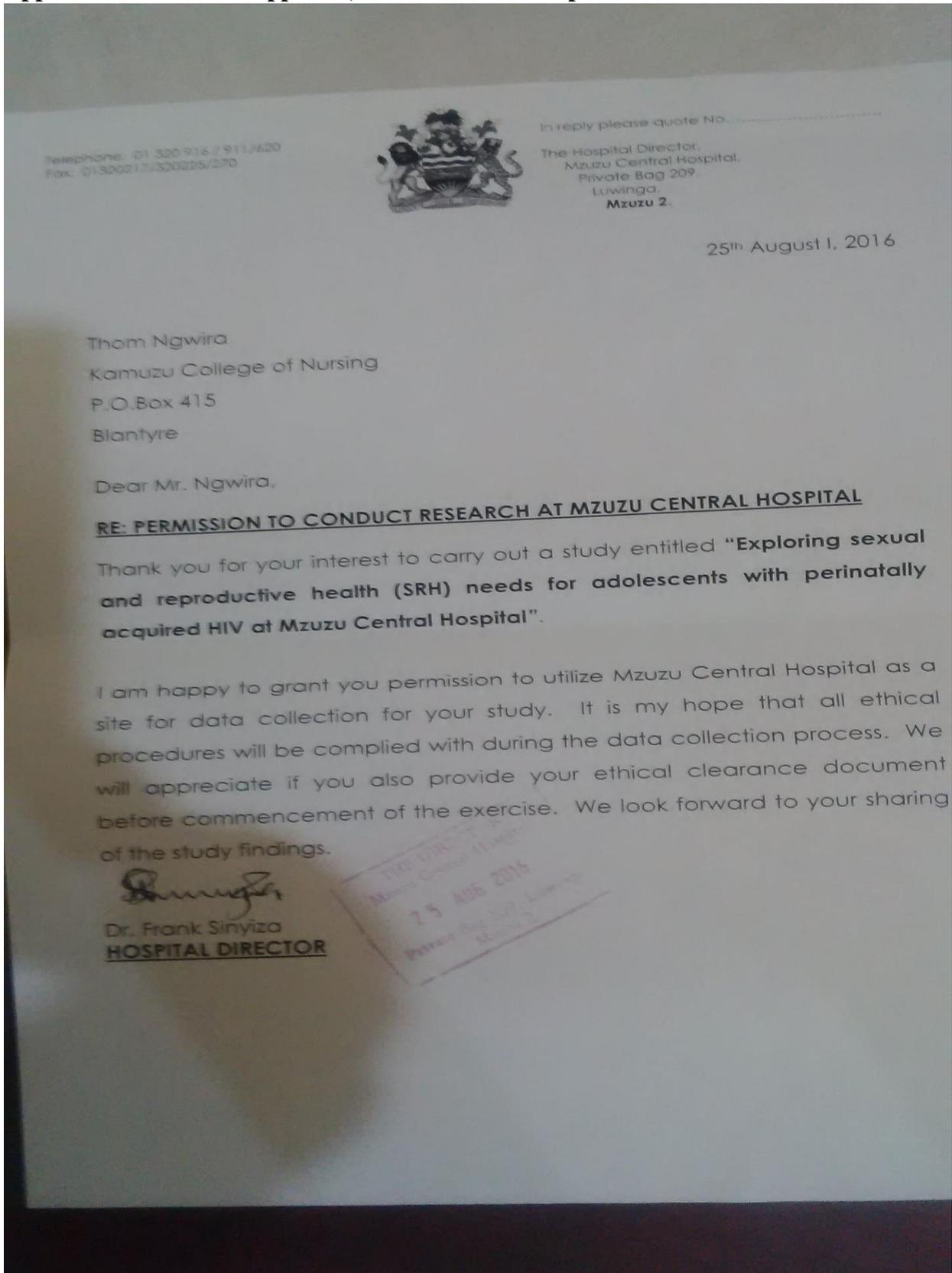
Dzina la Ofufuza.....

#### **A Mbiri Yanu**

1. Muli ndi zaka zingati?.....
2. Mwakhala mukugwira ntchito pa chipatala chino kwa nthawi yayitali bwanji?.....
3. Tanduzani ndemanga kapena angiri wanu wokhudzana ndi chithandizo chomwe chimaperekedwa kwa achinyamata omwe anatengera kachilombo ka HIV kuchokera kwa makolo awo?
4. Kodi ndi mavuto anji anji omwe mumakumana nawo mukamapereka thandizo kwa achinyamata omwe antengera kachilombo ka HIV kuchokera ku makolo pa chipatala chino?
5. Kodi mukuganiza kuti nzosowekera zanja mukamapereka thandizo pa zauchembere kwa achinyamata omwe antengera kachilombo ka HIV kuchokera ku makolo pa chipatala chino?
6. Kodi nzosowekera ziti zomwe zilipo kapena palibe mukamapereka thandizo kwa achinyamata omwe antengera kachilombo ka HIV kuchokera ku makolo pa chipatala chino?
7. Mumaganizo anu, kodi nzosowekera ziti zomwe zilipo mukamapereka thandizo kwa achinyamata omwe antengera kachilombo ka HIV kuchokera ku makolo zokhudza uchemebre?

8. Mumaganizo anu, kodi zosowekerazi tingapange bwanji kuti tizithetse zauchembele pa chipatala chino?

**Appendix 13: Letter of Approval, Mzuzu Central Hospital**



**Appendix 14: Letter of Approval, Rumphi DHO**

Telephone: (265) 0137222/287/212  
Fax: (265) 01372538  
All communications should be addressed  
To: The District Health Officer



In reply, please quote RDH/25  
Rumphi District Health Office  
P.O. Box 225  
Rumphi  
Malawi.

Thom Ngwira  
Kamuzu College of Nursing  
P.O. Box 415  
Blantyre  
25 August 2016

Dear Mr. Ngwira,

**RE: PERMISSION TO CONDUCT PRETEST FOR RESEARCH AT RUMPHI DISTRICT HOSPITAL**

Thank you for your interest to carry out a study entitled **“Exploring sexual and reproductive health (SRH) needs for adolescents with perinatally acquired HIV at Mzuzu Central Hospital”**.

I am happy to grant you permission to utilize Rumphi District Hospital as a site for pretesting <sup>data</sup> collection for your study. It is my hope that all ethical procedures will be complied with during the data collection process. We will appreciate if you also provide your ethical clearance document before commencement of the exercise. We look forward to your sharing of the study findings.

  
Mrs. M. Mkandawire  
**DISTRICT HEALTH OFFICER**

25 AUG 2016

**Appendix 15: COMREC Approval Certificate**

