KAMUZU COLLEGE OF NURSING

EXPLORING PERSPECTIVES OF ADOLESCENTS LIVING WITH PERINATALLY ACQUIRED HIV REGARDING ANTIRETROVIRAL THERAPY ADHERENCE AT MITUNDU COMMUNITY HOSPITAL, MALAWI.

Master of Science (Child Health Nursing) Thesis

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CERTIFICATE OF APPROVAL

The undersigned certifies that this thesis is the student's own work and has been submitted with my approval.

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DECLARATION

I **CHIFUNDO PHALYCE CHIGWENEMBE**, hereby declare that work presented in this thesis is my original work and that neither part of nor the entire work has been presented to any other academic institution for evaluation, research and examination. Where work of other people has been used, it has been appropriately acknowledged.

Signature……. Date…….

CHIFUNDO PHALYCE CHIGWENEMBE

DEDICATION

I dedicate this work to my mother, Enifa Chigwenembe and my late father, Macdonald Chigwenembe who motivated me to dream big, work hard and be trustworthy in everything.

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ABSTRACT

Despite having the National HIV and AIDS Strategy (2015 - 2020) with the 90-90-90 2020 target, almost 50% of ALWH do not adhere to their treatment in Malawi. It is evident that the ALWH's perception towards treatment influences their adherence. Therefore, there was need to explore the perspectives of the ALWH regarding their treatment adherence. This was an exploratory qualitative study which was conducted at Mitundu Community Hospital, Lilongwe District in Malawi. 26 ALWH aged between 12 and 18 years were purposively sampled. Data were collected over a period of two months using focus group discussions and in-depth interviews. Data were analysed using Thematic Method of Analysis.

The study observed that the ALWH need support from caregivers, peers, entire community and health care workers in order to ensure optimal treatment adherence. The study revealed that ALWH tend to miss ARV doses in the course of fulfilling their household chores and errands. Unbearable ARV side effects, forgetfulness and maintaining secrecy, were perceived as the factors which hinder the ALWH from adhering to treatment. In order to ensure that missing of doses is minimised, the ALWH increase the accessibility and visibility of the ARVs, link the mealtimes to drug administration schedules, set alarms and take the ARVs together with other family members. It is, therefore, recommended that ALWH should take a leading role in ensuring their treatment adherence by abiding to the prescriptions of the ARVs. The caregivers need to ensure that household chores are not interfering with treatment schedules for the ALWH.

Key words: *adolescents, treatment adherence, perinatally acquired HIV, ARVs, perspectives, treatment compliance, ART provider*

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LIST OF ACRONYMS AND ABBREVIATIONS

AIDS	Acquired Immunodeficiency Syndrome
ALWH	Adolescents living with perinatally acquired HIV
ART	Antiretroviral Therapy
ARVs	Antiretroviral drugs
COMREC	College of Medicine Research and Ethics Committee
CPT	Cotrimoxazole Preventive Therapy
DHO	District Health Office
FGDs	Focus Group Discussions
HIV	Human Immunodeficiency Virus
IDI	In-depth Interview
MCH	Mitundu Community Hospital
P	Participant
UNAIDS	Joint United Nations Programmes on HIV/AIDS
WHO	World Health Organization

OPERATIONAL DEFINITIONS

A child: A person aged below 18 years.

Children living with perinatally acquired HIV: Individuals aged below 18 years and acquired HIV during antenatal, delivery or breastfeeding period.

Adolescent living with perinatally acquired HIV: A person aged between 12 and 18 years and acquired HIV from his/her mother during antenatal, delivery or breastfeeding period.

Adolescents' perspectives regarding treatment adherence: This is the view point whereby adolescents living with perinatally acquired HIV perceive their treatment adherence.

HIV status disclosure: This is the process of revealing or giving information about the HIV status to the child living with perinatally acquired HIV.

Primary caregiver: This is an individual aged over 18 years and has been caring for the child living with perinatally acquired HIV for a period of more than one year.

Treatment adherence: This is when an adolescent who is living with perinatally acquired HIV, willingly takes the ARVs according to prescription.

CHAPTER ONE

INTRODUCTION AND BACKGROUND

1.1 Introduction

Globally, it is approximated that around 2.1 million children are living with HIV and almost 81 % of these children are from sub-Saharan Africa (UNAIDS, 2017). Perinatal acquisition of HIV is the commonest mode through which children get infected and this contributes to about 90% of the children who are living with HIV worldwide (Donahue, Dube, Dow, Umar, & Van Rie, 2012; Odiachi & Abegunde, 2016). The increase in accessibility to free Antiretroviral Therapy (ART) to adolescents living with perinatally acquired HIV (ALWH) in sub-Sahara African countries including Malawi, has significantly contributed to a reduction in morbidity and mortality rate of the ALWH and the improvement in the quality of life (Akahara, Nwolisa, Odinaka, & Okolo, 2017: Madiba, 2012). In addition, ART has changed perinatally acquired HIV in children from a fatal disease to a lifelong manageable chronic illness resulting in the eventual growth of children into adolescents and young adults (Murnane et al., 2016). However, the ALWH have the challenge of coping with the stress of growing up with HIV while at the same time trying to adhere to their antiretroviral drugs (ARVs).

ARVs are lifelong treatment and require an optimum adherence to be effective (Merten et al., 2010). According to WHO (2003), adherence is “the extent to which a person’s behaviour corresponds with the agreed recommendation from a healthcare provider”. Therefore, treatment adherence is the extent to which patients are able to follow the prescribed treatment. This entails taking the right dose, following the right route and the right dosing schedule (Dawood, Ibrahim, & Palaian, 2010; Estripeaut et al., 2016; Hugtenburg, Timmers, Elders, Vervloet, & van Dijk, 2013). Therefore, it is worth noting that the success of ARVs is mainly dependent on the patient’s willingness to adhere to the

treatment prescription. Patients who adhere to their treatment are more likely to have an improved healthy life than those who regularly miss their doses (Rafii, Fatemi, Danielson, Johansonn, & Madanloo, 2014). Poor treatment adherence means not taking the ARVs according to the prescription (Kasumu & Balogun, 2014). Therefore, it is important to note that poor adherence leads to treatment failure and the development of resistant HIV strains which can be transmitted to others especially through sexual contacts (Nachega et al., 2011). This can eventually transform HIV into an infection that would be difficult to contain in the near future.

It is believed that the major challenge to successful ART is poor adherence. To show its commitment towards improving treatment adherence in people living with HIV, Malawi developed a National Strategic Plan for HIV and AIDS 2015 – 2020. One of the main objectives of the plan is to retain in care, majority of patients who are on ART. In order to ensure that this objective is achieved, the emphasis is on increasing availability of facility and community based support groups; establishment of norms that facilitate, support and encourage ART adherence; and putting in place the support systems that promote and protect the rights of people living with HIV.

However, in spite of these efforts, it has been observed that ALWH have the worst adherence, with only about half of them adhering to their ARVs in Malawi (Kim et al., 2017). It is not surprising that there are higher incidences of morbidity and mortality in ALWH in Malawi. In fact, there is evidence that the perception of an individual towards HIV infection and ARV treatment greatly influences the treatment adherence (Wasti, Simkhada, Randall, Freeman, & Teijilingen, 2012). Therefore, it is imperative to understand the perspectives of the ALWH regarding treatment adherence with focus on their gender and age.

1.2 Background

It is over 30 years now since the HIV pandemic was discovered in the world and the pandemic is still one of the leading causes of morbidity and mortality especially in adolescents. In 2015, there were about 1.8 million adolescents aged between 10 and 19 years who were living with HIV worldwide and almost 63% of these were in the sub-Saharan Africa region (UNAIDS, 2017). UNAIDS posits that although there is a tremendous decrease in AIDS related deaths in other age groups, no remarkable decrease has been observed in the adolescents especially in developing countries. Malawi is one of the developing countries in the sub Saharan Africa. It has a population of about 17 million people of which over 50 percent are below the age of 18 (NSO & ICF, 2017). This clearly shows that Malawi is a youthful nation. In 2016, UNAIDS estimated that there were 1 million people living with HIV and 24,000 AIDS related deaths in Malawi. UNAIDS also noted that approximately 62, 000 adolescents aged between 10 and 19 years were living with HIV in Malawi.

According to UNAIDS (2017), HIV pandemic remains one of the leading causes of morbidity and mortality among adolescents. This is attributed to suboptimal adherence to treatment. In a systematic review of different literature on treatment adherence in ALWH from various global regions, it was observed that generally treatment adherence was poor. Kim et al. (2014) observed that in European and Northern American countries, ARV adherence rate in the ALWH was low, ranging from 50% to 60%. However, Kim et al. also observed that Asian and African ALWH had a slightly higher adherence rate with an average of 84%. These differences in adherence rates are possibly due to variation in commitment in combating the infection since those countries with higher HIV prevalence put all the efforts to contain the infection; hence having better ART adherence.

Although on average Africa as a whole has better treatment adherence, there are variations especially in the ALWH from the southern part of the sub-Saharan region. The adherence rate in this region ranges between 24% and 97% (Gross et. al., 2015; Haberer, et al., 2011; Maskew, et .al., 2016; Nsheha, Dow, Kapanda, Hamel, & Msuya, 2014; Olds et.al., 2016). Poor treatment adherence in ALWH has also been observed in Malawi. According to a study conducted at Baylor College of Medicine and Zomba ART Clinic, it was proven that almost half of the ALWH who are on ART do not adhere to their treatment (Kim et al., 2017). Poor treatment adherence has been observed in ALWH because of multiple physical changes, psychosocial and clinical stressors which the ALWH undergo at the same time moving from being dependent on their caregivers to being independent in decision making (Mumthas & Muhsina, 2014; Petersen et al., 2010; Phiri & Chilemba, 2015; WHO, 2013).

In order to curb the HIV infection, Malawi has shown commitment through increasing accessibility of ARVs to all people living with HIV including adolescents. This is manifested by the introduction of free ARVs in 2004 (Dasgupta et al., 2016). Furthermore, through its National HIV and AIDS strategy (2015 -2020), Malawi adapted the UNAIDS 90-90-90 2020 goal. The target of this goal is to have 90 percent of people living with HIV diagnosed; 90 percent of those diagnosed HIV positive be initiated and retained on ARVs; and 90 percent of those on ARVs to have a fully suppressed viral load. The success in achieving this goal lies in the adolescents who constitute over half of the national population (NSO & ICF, 2017). Therefore, ALWH are an important group to target in order to ensure that they are adhering to their ARVs, have suppressed viral load and have a healthy life. In order to ensure that the ALWH live quality and healthy lives, it is important that treatment adherence is enhanced and maintained. Evidence has shown that those patients who have suppressed viral load have a healthy life and pose a low risk of transmitting HIV to others and this is attainable when the

patients optimally adhere to ARVs (Cohen, Chen, McCauley & Gamble, 2011;Tanser, Ba¨rnighausen, Grapsa, Zaidi & Newell, 2013).

According to the records from the District Health Office, Lilongwe has a high prevalence and density of people living with HIV in Malawi. During the first quarter of 2017, Lilongwe had a total population of 2,492, 795 people and an HIV prevalence rate of 8 percent. In order to achieve the 90 90 90 goal, the Malawi government established 99 health facilities which were offering ART services in Lilongwe. Mitundu Community Hospital where this study was conducted, is one of such facilities.

1.3 Problem statement

Despite Malawi making strides towards achieving the 90-90-90 2020 target, it has been observed that the ALWH have the lowest adherence rate to ARVs and only almost 50 percent of them adhere to treatment (Kim et al., 2017). In addition, very few ALWH are retained in the care and very few have suppressed viral load. This consequently leads to higher incidences of AIDS related deaths in ALWH as compared to adults living with HIV. According to the Department of HIV and AIDS data base, during the first quarter of 2017, the average adherence rate for Malawi and Lilongwe was 84% and 81% respectively. This includes both adolescents and adults. However during the same period, Mitundu Community Hospital had an adherence rate of 56% which translated to 1285 patients out of the 2276 people who were alive on ART. This is of great of concern because it is far much below the national target of 90 90 90. Therefore, in order to understand ALWH's perspectives regarding their treatment adherence at this health facility, it was imperative to conduct a qualitative study.

1.4 Study objectives

1.4.1 Broad objective

The main purpose of the study was to explore the perspectives of the adolescents living with perinatally acquired HIV on their treatment adherence.

1.4.2 Specific objectives

Specifically, the study wanted to:

(i) Identify factors that facilitate treatment adherence in the adolescents living with perinatally acquired HIV.

(ii) Identify factors which hinder the adolescents living with perinatally acquired HIV from adhering to treatment.

(iii) Analyse the strategies for treatment adherence used by the adolescents living with perinatally acquired HIV.

1.5 Justification of the study

The findings from this study will help to understand from the adolescents' perspectives, their meaning of ARV adherence since they will narrate the facilitators and barriers to treatment adherence. Practical measures which can be put in place to achieve excellent treatment adherence and the resultant optimal health status in ALWH, will be identified.

The findings from this study will help the health care workers to identify the strategies which may help in ensuring that the ALWH adhere to their ARVs and that they do not miss any doses. These strategies can be adapted and used by all ALWH. The findings from this study will help the health care personnel to improve the quality of paediatric HIV care.

The study will also generate new knowledge on the perspectives of ALWH regarding their treatment adherence thereby enabling to find out the ways of promoting treatment adherence in ALWH particularly in Malawi. Therefore, it will contribute to the body of knowledge in practice, nursing education and research.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

This chapter is a review of literature on HIV treatment adherence. It evaluates and synthesizes information on factors that facilitate and hinder treatment adherence and the strategies that have been used by the health care workers to ensure treatment adherence in the ALWH, retrieved from different sources. The literature search was limited to publications from 2008 to 2017.

This was an open search of literature. A computer assisted comprehensive literature search in PubMed, HINARI and Google Scholar data bases was done to find relevant studies related to the research topic. Some of the articles were identified from the bibliography of the retrieved articles. The researcher selected only those articles which were in English. The search terms which were used included, adolescents' perception AND ARV adherence; children OR adolescents AND chronic illness AND treatment adherence; experiences AND children OR adolescents AND living with HIV; challenges AND perinatally acquired HIV AND treatment adherence, mechanism OR strategies AND HIV treatment; influence of gender OR sex AND ARV adherence. The review has been organised around the specific objectives. The review will start with an overview of the importance of treatment adherence in chronic diseases and then focus on HIV/AIDS in particular.

2.2 Understanding adolescence

Adolescence is a crucial period in any individual's life. It is a transition from childhood to adulthood and this is usually between the ages of 10 and 19 (WHO, 2013). Mumthas and Muhsina (2014) describe adolescence as period when an individual manifests increased physical and psychological development. It is within this period that adolescents

manifest emotional and behavioural problems such as mood changes, unruly behaviour, fighting for independency, being uncooperative and disobedient. This behaviour often times affects and strains the relationship with their parents/caregivers; thus making monitoring and assistance of the ALWH's treatment adherence more challenging. During this period, the adolescents also strive to attain independence from their caregivers in decision making. Whilst exploring and experimenting with life at this critical period, adolescents engage in risky sexual activities and have a high risk of secondary HIV infection (Phiri & Chilemba, 2015).

2.3 Importance of treatment adherence in chronic conditions

Adolescents, like adults, also suffer from chronic medical conditions such as diabetes, asthma, cancer and HIV, of which most of them last for lifetime. Compas, Jaser, Dunn and Rodriguez (2012) explain that these chronic conditions require regular medical attention and often result in long and frequent hospital admissions. These chronic infections also tend to have negative impact on the emotional, behavioural, physical and cognitive development of the children. Patients who suffer from chronic conditions are usually initiated on a long term treatment which requires good adherence to be effective. However, there is evidence of poor treatment adherence in adolescents in any chronic condition after a period of longer than six months continuously on treatment (Langat et al., 2012; McGrady & Hommel, 2013).

ARVs require an optimum adherence rate to be effective in preventing the replication of the HIV thereby reducing the risk of transmission to others (Cohen, Chen, McCauley, & Gamble, 2011). Good treatment adherence in ALWH results in quality, improved life and increased protection in the immune system and the eventual reduction in the risk for opportunistic infection (Abongomera, et. al., 2017; Haberer et al., 2012; Mitiku et al., 2013). HIV is a fast replicating and mutating virus, and subjecting it to suboptimal ARVs leads to

the emergence of drug resistant strains (Pennings, 2013). Therefore, it can be concluded that there is a relationship between optimal ARV adherence and viral load suppression.

Poor treatment adherence, as represented by an HIV viral load of more than 1000 copies/ml, is easily detected with blood tests. Likewise, a decrease in the CD4 cell count and progression into an AIDS related infection in a patient who has been on ART for more than six months suggests poor ART adherence (Jobanputra et al., 2015). It is therefore worthwhile to ensure that the ALWH always maintain an optimal treatment adherence and the subsequent viral suppression in order to have quality lives.

2.4 Factors that facilitate treatment adherence in ALWH

Different studies have been conducted to determine the factors which facilitate ARV adherence in patients living with HIV. The factors include: the caregiver-child relationship, knowledge of one's HIV status, age of the individual living with HIV and individual's sex.

2.4.1. The caregiver-child relationship

It has been observed that the nature of caregiver-child relationship can influence how ALWH adhere to the ARVs. In a study conducted by Ugwu and Eneh (2013) in Nigeria, it was noted that the relationship between the ALWH and their primary caregivers plays a great role in treatment adherence. The study observed that those ALWH whose primary caregivers were their biological parents had poor treatment adherence comparing to those who were taken care of by other family members. Those ALWH who were under the custody of other family members had a better treatment adherence. This was especially true in orphans whose both parents had passed away and the whole family teamed up to support the orphaned ALWH to take their drugs regularly. This shows that the involvement of the entire family is essential in ensuring that ALWH adhere to their treatment.

Strong personal relationship between the caregivers and the ALWH often leads to improved treatment adherence. In both quantitative and qualitative studies on children and their caregivers conducted in different parts of Sub-Saharan Africa, it was observed that the caregivers had a role in providing constant social support; physically counting the number of pills and giving the ARVs to the ALWH; and providing a positive reinforcement whenever the child had shown adherence to treatment (Buchanan et al., 2012; Fetzer et al., 2011). Good relationship also leads to effective communication between the caregivers and the ALWH. This is vital especially during the transition phase when the caregivers are surrendering the responsibility of treatment administration to the ALWH themselves (Buchanan et al., 2012). It is therefore evident that good relationship between the caregivers and ALWH is pivotal in ensuring that the ALWH are adhering to their treatment. However, there is no much evidence if the caregiver-child relationship has any impact on how Malawian adolescents adhere to their ARVs.

2.4.2 Knowledge of one's HIV status

The knowledge of one's HIV status also termed as "HIV status disclosure" is one of the factors that determine treatment adherence in ALWH. HIV status disclosure is the process through which an individual learns about one's HIV diagnosis, treatment and prognosis (Negese et al., 2012). According to Kallem, Renner, Ghebremichael and Paintsil (2011), HIV status disclosure is categorized into complete, partial and non-disclosure. In complete disclosure, the child is given all the information including the HIV diagnosis, the details of lifelong medication and how to prevent secondary infection. In partial disclosure, only bits of information about the illness are given out without specifically mentioning HIV, AIDS and ARVs. In non-disclosure, the information is concealed and the ALWH is unaware of the HIV infection and its effects on the health status.

It has been observed that there is significant relationship between complete HIV status disclosure and treatment adherence in ALWH (Ubesie, 2012). In a quantitative cross sectional study carried among caretakers, children and health care workers in a Ugandan paediatric HIV clinic conducted by Namasopo-Oleja, Bagenda and Ekirapa-Kiracho (2015), it was observed that complete disclosure of HIV enhanced strong relationships between parents and children. Such strong relationships were observed to be encouraging free discussion between the ALWH and the caregivers on issues pertaining to treatment adherence. This eventually led to good treatment adherence. Although strong personal relationships between caregivers and the ALWH have proven beneficial in enhancing treatment adherence, it is not clear whether it is applicable in the Malawian setting.

2.4.3. Age of the individual living with HIV

Age of the individual has been highlighted as a factor which either facilitates or hinders treatment adherence. Several studies have noted that young children tend to rely on their caregivers to give them the ARVs hence the treatment adherence in this case is mainly determined by the caregivers' commitment. In a study conducted in Nigeria by Ugwu and Eneh (2013), it was observed that younger children were more vulnerable and more likely to be non-adherent to ARVs. This was because of their dependence on their caregivers who were sometimes preoccupied with personal engagements and failed to administer the ARVs to the children on schedule. Furthermore, it has also been observed that the caregivers tended to forget to give the ARVs to the child especially when the health status had improved and the child was not physically sick (Campbell et al., 2012).

Once the children grow up into adolescents, caregivers surrender the entire responsibility of drug administration to them. The ALWH start taking full control of their ARVs without the influence of the caregivers. Mweemba et al. (2015) emphasize that this independence enables the ALWH to continue accessing ARVs and other health care services

without the assistance of the caregivers. However, it has been observed that when the adolescents were growing older and attaining independence from the caregivers, the likelihood of being non adherent to ARVs and miss ART clinic visits increased more than their younger counterparts (Castro, González, & Pérez, 2015; Maskew et al., 2016). This study therefore seeks to understand how both the younger and the older ALWH perceive treatment adherence during this period of adolescence.

2.4.4 Individual's sex

A number of studies have observed that being male or female has been a factor which influences treatment adherence. In a quantitative study conducted in 545 adults who were on ARVs in Canada by Tapp et al., (2011), it was discovered that females were adhering poorly to ART in comparison with males. This poor treatment adherence was linked to the females spending most of their times in the streets, carrying out income generating activities and eventually were having limited access to healthcare services. Contrary to this finding, Bermudez et al., (2016) observed in their study that although females were reportedly those with a lot of excuses which could lead to missing doses, majority of the females had better adherence to their ARVs than males.

This is the case in Malawi, whereby in adults living with HIV, males were reportedly the ones with poor treatment adherence as compared to women. In a quantitative study conducted in 4670 Malawian working class adults who were on ART, it was observed that men had poor treatment adherence, most likely to be lost to follow up and defaulting to ART and consequently, there was higher mortality rate in men than in women (Taylor-Smith, Tweya, Harries, Schoutene, & Jahn, 2010). This variation in the findings on whether sex influences ARVs adherence in individuals living with HIV prompted this researcher to seek information among Malawian ALWH.

2.5 Factors hindering treatment adherence

Various studies have observed that ALWH face challenges which hinder treatment adherence. The factors include food security, issues of privacy and unbearable side effects.

2.5.1 Food security

Availability of food stuffs for the ALWH and adherence to ARVs are believed to be directly related. In a review of different quantitative and qualitative studies, it was observed that only those patients who had food security and assistance, were observed to have optimum ARV adherence (Singer, Weiser & McCoy, 2015: Young, Wheeler, McCoy & Weiser, 2014). There is a perception that ARVs increase metabolism and body demand for food hence the ALWH had an intractable hunger and had an increased appetite. In addition, Young et al. (2014) reported that taking ARVs without any food stuffs aggravates side effects such as nausea, vomiting and abdominal pains. In order to run away from these side effects, some ALWH opted to take their ARVs only when food availability was guaranteed.

2.5.2 Issues of Privacy

Lack of privacy has been associated with intentional missing of doses especially when ALWH were away from their homes or whenever privacy was not guaranteed. In a review of different studies, privacy was observed to be a key issue in treatment adherence as ALWH tried to keep their HIV status a secret to the community as well as avoiding stigma hence would not want to take the drugs in the places where privacy was not guaranteed (Akahara, Nwolisa, Odinaka, & Okolo, 2017; Ankrah et al., 2016; Denison et al., 2015; Wasti, van Teijlingen, et al., 2012). This suboptimal treatment adherence was observed mostly in children who were living in congested homes and boarding schools because there was no guaranteed privacy for them to hide and take their ARVs.

2.5.3 Unbearable ART side effects

Side effects are undesirable outcomes besides the therapeutic results originating from a drug (Lilley, Snyder, & Collins, 2016). It has been observed that ALWH were either missing doses or stopped taking their ARVs when the side effects were interfering with their daily activities even if the side effects were minor (Ankrah et al., 2016: Monjok, Smesny, Okokon, Mgbere and Essein, 2010). However, ARVs are associated with minor, severe, and even life threatening side effects. Regardless of these side effects, ARVs require an optimal ART adherence (Cohen et al., 2011) hence it is important to mitigate and overcome these side effects.

To the contrary, it has been observed that in spite of the side effects, some ALWH still adhere to their treatment because of the perception that ARVs had improved their health status (Ankrah et al., 2016; Olds, Kiwanuka, Ware, Tsai, & Haberer, 2015; Ross, Aung, Campbell, & Ogunbanjo, 2011). In a cross-sectional qualitative study conducted by Ankrah et al., (2016) among 19 adolescents aged between 12 and 19 years at an HIV clinic in Ghana, it was observed that the perception of improved health status after taking ARVs was motivating the patients to adhere to their ARVs. This perception of improved health status resulting from being adherent to ARVs, increased self-motivation and encouraged the individuals not to miss any dose. Therefore, in a quest to sustain good health status and live longer, the ALWH were motivated to adhering to ARVs.

2.6 Health care providers' strategies used for enhancing treatment adherence

ARVs are lifelong treatment which require optimal adherence to be effective. However, it has been noted that often times ALWH tend to miss their doses due to a number of factors which include forgetfulness (Kim et al., 2017; Estripeaut et al., 2016). Consequently, it has been observed that the ART providers put in place different strategies to ensure that ALWH are not missing any doses. These strategies include educating the

patients and the caregivers, involving caregivers in decision making, doing follow ups and home visiting, and advocating for the use of reminders (Reda & Biadgilign, 2012).

2.6.1 Educating the patients and the caregivers

Various studies have observed that the ART providers ensure that there is always good communication with the ALWH and their caregivers. According to Loeliger, Niccolai, Mtungwa, Moll, and Shenoi (2016), measures to ensure treatment adherence start with providing enough information during initiation of a patient on ARVs. During this time, the patient is given all the information about the diagnosis, treatment and prognosis. The ART providers clearly explain to the caregivers and the ALWH about the regimen and provide written instructions which could be used as reference at home. This information includes the name of the drug, the dosage, the reason for taking the drugs as well as the side effects of drugs and the date of next appointment.

In a review of different literature conducted by Scanlon and Vreeman (2013), it was noted that the health care workers were emphasizing on providing education sessions to the caregivers, patients as well as the patients' peers in order to increase their knowledge and understanding on the diagnosis as well as the methods of addressing barriers to treatment adherence. It was also observed that adherence counselling resulted into increased understanding and positive perception of family members towards ALWH and eventually there was improved support and encouragement to ALWH to be taking their ART.

2.6.2 Involving caregivers in decision making

It has also been observed that involving the caregivers and the children in the decision making in matters which are deemed beneficial and feasible to the ALWH, helps in ensuring treatment adherence. In a qualitative study conducted in 11 HIV care specialised health care workers by Mosack and Wendorf (2011), it was observed that involving caregivers in decision making and direct care of the patients was proven to be effective in

promoting treatment adherence. These caregivers were also helpful in reminding the patients about their drug schedule and some advice which was given at the health facility. It was therefore recommended that seriously involving the caregiver was imperative to ensure optimal adherence. However, the success of involving the caregivers in the decision was dependent on the quality of relationship which was shared between the ALWH and the caregiver (Naar-King et al., 2013).

2.6.3 Doing follow ups and home visiting

Doing follow ups and conducting home visits to the patients on ARVs, enable the health care workers to continuously assess the patients' adherence to treatment and comparing them with the clinical outcomes (Reda & Biadgilign, 2012). This continuous assessment helps in early detection of any signals of poor treatment adherence in the ALWH. In a qualitative study conducted in South Africa by Masquillier et al. (2016) and a review of literature by Bain-Brickley, Butler, Kennedy and Rutherford, (2011), it was observed that home visiting improved ARV adherence because the meetings were held in a relaxed and familiar environment. It was also observed that follow up and home visits increased interaction between the health care workers, the patients and their family members compared to the limited time which the ALWH were given during a clinic visit.

Furthermore, Bain-Brickley et al. (2011), observed that the family members were becoming more supportive to their relatives who were on ART and ensured treatment adherence. However, Masquillier et al. (2016), also observed that follow ups and home visits by the health care workers were proven uncomfortable to other patients. This was mostly noted in those patients who were keeping their HIV status a secret and those who were facing stigma and discrimination in their communities.

2.6.4 Encouraging the use of reminders

Literature has shown that the health workers advocate and emphasize on the use of reminders. Recent findings from various studies have shown that those patients who were using reminders such as cell phone alarms as well those whose family members were actively involved in reminding the patients to take their ARVs, had an optimal adherence (Fu, Hu, & Lu, 2015; Holtzman, Brady, & Yehia, 2015; Tran, Nguyen, Nguyen, & Hoang, 2013). In a cross-sectional study conducted in 1,016 patients living with HIV in Vietnam by Tran, Nguyen, Nguyen and Hoang (2013), it was observed that the use of reminders was directly linked to improved treatment adherence. It is, therefore, important for the patients to have at least a strategy for remembering to take their ARVs. However, it is not known whether ALWH in Malawi have any strategies which they put in place to ensure that they are adhering their treatment.

2.7 Conclusion

This chapter has reviewed literature on the factors influencing treatment adherence in ALWH. It has been observed that the longer the duration an individual has been on treatment, the more likely the drop in adherence level. It has also been observed that whether an individual is young and dependent on caregiver for treatment administration or an individual is attaining adolescence and independence, treatment adherence is not perfect as both groups tend to miss their doses. Lastly, the literature has highlighted the strategies which the health workers use to detect the likelihood of poor treatment adherence. However, there is paucity of information on the strategies which the ALWH themselves put in place to be reminded on taking their ARVs hence the need for this study to explore on those strategies.

CHAPTER THREE

METHODOLOGY

3.1 Introduction

This chapter describes the study design, study setting, population and sampling technique. It also describes the data collection tools, data collection and analysing methods as well as ethical considerations.

3.2 Study Design

This was an exploratory qualitative study. Qualitative research design centres on the social world and studies the phenomenon from the perspectives of those individuals who are experiencing them (Khanken et al., 2015). This design is also helpful in understanding and exploring human experiences and situations which are difficult to quantify (Fitzpatrick, 2011; Kalu & Bwalya, 2017). The researcher, using this design, was able to gain a better understanding of treatment adherence from the ALWH's perspectives.

Furthermore, in depth information was obtained as the ALWH were articulating and revealing issues surrounding their experiences with ARVs. The researcher believes in the assumption that the reality is constructed by those who are participating in it and that knowledge comes from an individual's experience (Wright, O'Brien, Nimmon, Law & Mylopoulos, 2016). An inductive logic was applied in data collection and analysis, whereby the researcher collected and analysed the data and then got a meaning from the findings (Ritchie, Lewis, Nicholls, & Ormston, 2013). It is, therefore, against this background that exploratory qualitative approach was preferred.

3.3 Study Setting

This study was conducted at the ART Clinic for Mitundu Community Hospital (MCH). This is a rural referral facility for eight health centres in Lilongwe district which provides health care services for both inpatients and outpatients. According to the records available at the health facility, Mitundu Community Hospital caters for over 709,420 people from Lilongwe and neighbouring Dedza district. During the first quarter of 2017, there was a total of 2276 active registered clients on ART, of which, 324 of them were adolescents aged between 12 and 18 years. Apart from offering ART services, the clinic also offers ALWH Teen Club, HIV Testing and Counselling services as well as Early Infant Diagnosis. This site was chosen because it offers ART services to ALWH from both the semi urban and rural settings such that the information was collected from the perspectives of the ALWH from both the semi urban and rural areas.

3.4 Study Population

The study population comprised adolescents living with perinatally acquired HIV aged between 12 and 18 years who had been on ARVs for more than 2 years. The adolescents in this age range were old enough to articulate their experiences of taking ARVs and challenges encountered. These adolescents could decide to take their ARVs willingly without being forced or coerced by their caregivers.

3.5 Sample Size

Initially, the researcher intended to conduct 5 FGDs and 7 in depth interviews. This number of FGDs was decided basing on the fact that 90 percent of the most prevalent themes are discovered within 3 to 6 FGDs (Guest, Namey & McKenna, 2017). Furthermore, in qualitative studies, the focus is on getting in depth and rich data, though with least number of participants (Polit & Beck, 2017). Therefore, the number of participants in this study was

determined by data saturation (Fusch & Ness, 2015). This is when the researcher no longer obtained new information, new data and new codes from the participants. A total of 26 participants were recruited in the study.

There were 4 FGDs of which two of them had 7 participants each and the other two had 6 participants each. These participants were categorized into FGDs according to their sex and age range. The younger ALWH were aged between 12 and 15 years whilst the older ALWH were aged between 16 and 18 years. This ensured that each sex freely expressed its views without the interference of the opposite sex. It also helped the researcher to explore different views from different age groups since some of the issues affecting younger ALWH were different from those affecting the older ALWH. This also ensured that the older ALWH did not dominate the FGDs or intimidate the younger ALWH.

The FGDs were preferred in collection of data because they usually generate a conversation amongst the participants and this revealed issues surrounding ARVs adherence in the ALWH (Polit & Beck, 2014). The researcher also interviewed six participants who were drawn from the FGDs to complement the findings from the FGDs. These in depth interviews ensured that the ALWH were able to articulate their experiences and express their perceptions without being influenced by their peers' responses (Alshenqeeti, 2014).

3.6 Inclusion criteria

The ALWH who were included in the study were those aged between 12 and 18 years because they were old enough to articulate their perspectives on treatment adherence. These ALWH were only those who had been on ARVs for more than 2 years since being exposed to the treatment for more than two years ensured that they had experience with their ARVs. Recruitment for the study was also restricted to only those ALWH with a completely

disclosed HIV sero-status to avoid accidental disclosure. No participant was compelled to participate hence this study only included those ALWH who were willing to participate.

3.7 Exclusion criteria

The ALWH who were aged below 12 years and those aged above 18 years were excluded from the study. Furthermore, those ALWH with undisclosed HIV sero-status, those ALWH who had been on ARVs for less than two years and those ALWH who were unwilling to participate, were not included in the study.

3.8 Sampling Method

Purposive sampling was used to recruit the ALWH who met the inclusion criteria. Polit and Beck (2017) describe purposive sampling as a method where the researcher intentionally chooses the participants who are well conversant with the subject matter thereby enabling optimal contribution towards the study. In this regard, the participants who were chosen to participate in this study were those ALWH who had been on ARVs for more than two years and had experience with taking ARVs as well as the challenges faced. This helped in maximizing the richness of the data which were collected.

3.9 Pre-testing the Data Collection Instruments

Pre-testing of the FGD guide and interview guide was done at Kang'oma Health Centre which is also located within Lilongwe District. Kang'oma Health Centre is a rural health facility located about 13 kilometres away from Lilongwe City and offers paediatric ART services similar to Mitundu Community Hospital, which was the study site. The only difference is that Mitundu Community Hospital has a Teen club with a larger number of ALWH and also offers inpatient services. This pre-testing setting was therefore much similar to the actual study site. Five ALWH who had come for ART refill and teen club were identified for the pre-test. The pre-testing enabled the researcher to rectify the problems on

the data collection tool (Hurst et al., 2015). After the pre-testing some of the questions on the FGD guide and interview guide were rephrased to ensure that more detailed information was obtained.

3.10 Data Collection

An FGD guide **(Appendices G and H)** and a semi structured interview guide **(Appendices I and J)** were used in the collection of data from the participants. All FGDs and in-depth interviews were audio recorded. Field notes were also written down. Enough time was allocated to each item to ensure that all the ideas from the participants had been exhausted. The researcher facilitated the FGDs and in-depth interviews. The data were collected for a period of two months, from 2nd September to 4th November, 2017.

3.11 Data Collection Procedure

The Paediatric ART Clinic at Mitundu Community Hospital was held once a month, on the first Saturday of every month. Two days before the clinic day, the researcher went to the clinic and discussed with the ART provider in charge about the research, its objectives and the eligibility criteria of the ALWH. Thereafter, the researcher was given the list of those ALWH who were eligible to participate in the study. On the actual ART clinic day, the researcher went to Mitundu Community Hospital to recruit the participants who were eligible to participate in the study. The ART providers at the health facility approached the eligible participants and their caregivers. The ART provider explained to them about the study and thereafter referred them to the researcher. The researcher thoroughly explained the objectives and procedures of the study to the ALWH and their caregivers.

After understanding, the ALWH aged 18 years gave a verbal and written informed consent. The minors, aged below 18 years, gave an assent to participate in the study and their caregivers were approached to provide informed consent. The researcher followed up on

those ALWH aged below 18 years, who came alone to the facility to obtain informed consent from their caregivers. Before collecting the data, the ALWH were individually encouraged to ask question and verbalise their fears. All those who were free to participate gave an assent and their caregivers gave a consent. Thereafter, the ALWH were grouped into their categories according to age range and gender. Two FGDs were held on first visit and the remaining two FGDs were held on the subsequent visit. All the participants who were identified for in-depth interviews were interviewed on the third visit.

Permission to use an audio recorder was sought from all the participants before starting the FGDs and the in-depth interviews. The data collection was done in Chichewa because all the ALWH were conversant with Chichewa. The FGDs took between 60 and 90 minutes whilst the in-depth interviews took between 40 and 48 minutes. During data collection, the researcher had predetermined questions which had probes. The FGDs and in-depth interviews were conducted in a familiar but closed room to ensure privacy and minimize disturbances. After each FGD and in-depth interview, the researcher thanked the ALWH and reassured that everything that was discussed would be kept confidentially and privately.

3.12 Data management

Data management is a process of ensuring that the data resources are properly handled, safely kept and well identified for easy retrieval (Grove, Gray, & Burns, 2015). Consent and assent forms which were signed by the participants were filed together with the demographic data and were locked in a cabinet only accessible to the researcher. All the audio recorded data were transcribed verbatim and were labelled with codes. These documents were saved in a laptop with a password to prevent unauthorised access to the information.

3.13 Data Analysis

Data analysis was done concurrently with data collection. An inductive approach, where the researcher got the meaning from the data, was applied. The data which were collected from the participants were analysed using thematic analysis. Using this method of data analysis, themes were identified, analysed and reported within the data collected (Polit & Beck, 2017; Vaismoradi, Turunen, & Bondas, 2013). Firstly, the audio recordings were listened to several times to ensure that the researcher was acquainted with the whole text. Then, transcription was done word by word.

Thereafter, the researcher translated the transcripts which were in Chichewa language into English. Words and sentences which contained significant information to the research objectives were noted and underlined. Codes were assigned to phrases, according to similar units. These codes were then compared to sentences or paragraphs to the whole data set to identify variations, similarities, patterns and relationships. Thereafter, categories were defined from these codes. Lastly, themes and sub themes which were created in reference to the study objectives, were used by the researcher in the organization of the data and have been reported as results of the study.

3.14 Trustworthiness of the Data

Lincoln and Guba (1985), explains that trustworthiness of a qualitative research has four criteria namely: credibility, dependability, confirmability and transferability. To ensure trustworthiness of the data in this study, the researcher applied these criteria and are discussed herein.

3.14.1 Credibility

According to Polit and Beck (2014), credibility is the confidence in the truth and how accurate the data interpretation is. In order to ensure this, the researcher visited Mitundu Community Hospital and talked to the Hospital in Charge before the commencement of the study. This enabled the researcher to be familiar with the activities of the health facility. Before recruiting the ALWH in the study, it was clearly explained that they were free to withdraw from the study at any time without giving reasons. Furthermore, in this study, no participant was forced or coerced to participate. This ensured that all the participants willingly and honestly answered the research questions thereby ensuring credible data.

During data collection, two different techniques, FGDs and in depth interviews, were used. Probes were used to get more information from the participants whenever the point was not clearly explained. This helped the researcher to collect adequate and rich data. During the analysis of the data, the researcher read and re-read all the transcripts to get an understanding of the ALWH's perspectives regarding their ART adherence. Throughout the data collection process and analysis, the researcher had frequent meetings with her research supervisor to ask for guidance. The researcher also showed the supervisor the emerging themes so that she could offer her insight into the higher level of analysis.

3.14.2 Dependability

This is how consistent the study findings are, such that they can be repeated by other researchers on the same sample and context and still produce similar results (Nowell, Norris, White, & Moules, 2017). All the activities which were carried out throughout the study, have been clearly documented in detail so that other researchers who might wish to conduct the similar study, can obtain the similar findings.

3.14.3 Confirmability

Confirmability refers to objectivity and truthfulness in the data findings (Nowell, Norris, White, & Moules, 2017). It is the extent to which the findings of a study can be verified by others. It is a way of ensuring that the findings are emerging from the collected data and that there is no bias from the researcher. To ensure confirmability in this study, the researcher has narrated in detail, a step by step account of the actual procedures used in the recruitment process, data collection and analysis of the data.

Furthermore, during data collection, the researcher audio-recorded whatever was discussed during the FGDs and the in depth interviews. This ensured that there was no bias from the researcher because it was easy to distinguish the views of the researcher from the participants' responses. The researcher also allowed the participants to give a detailed account in relation to the research questions, to their best of ability. During analysis of the data, the researcher quoted verbatim the words spoken by the participants.

3.14.4 Transferability

This is the extent to which the findings from this study can be applied to a wider population (Polit & Beck, 2014). In order to ensure transferability, the researcher has provided appropriate detail of all the processes carried out in the research thereby enabling others to decide whether it is justifiable to apply the findings to other settings.

3.15 Ethical Consideration

An ethical approval to conduct the study was obtained from College of Medicine Research and Ethics Committee (COMREC). Permission to conduct the study at Mitundu Community Hospital was sought from Lilongwe District Health Office. Adequate information about the study (the purpose of the study, benefits and risks of the study) was given to all the participants. An informed consent was obtained from the ALWH aged 18

years and from the caregivers, on behalf of the minors below 18 years who had provided an assent to participate in the study. The participants were informed that their acceptance, withdrawal and refusal to participate in the study would not in any way affect their access to the health care services offered at the ART clinic.

It was clearly explained to the participants that in case of minimal psychological trauma resulting from the ALWH being reminded of the circumstances surrounding their treatment adherence, an arrangement for the services for a counsellor was made. Fortunately, there was no participant who needed the services of a counsellor throughout the data collection period. The researcher used codes to maintain the anonymity of all participants. The FGDs and the in depth interviews were held in a familiar but closed room to ensure privacy. The information gathered from the participants was handled confidentially and was only accessed by those who were directly involved in the study.

3.16 Conclusion

This chapter has narrated in detail, the methodology which was used in the study. The chapter has given an overview of the study design, study setting, study population, sample size and sampling technique, the inclusion and exclusion criteria, data collection methods, data management, data analysis and ethical considerations.

CHAPTER FOUR

PRESENTATION OF FINDINGS

4.1 Introduction

This chapter presents the findings from the exploratory qualitative study whose broad objective was to explore the perspectives of the adolescents living with perinatally acquired HIV regarding their treatment adherence.

4.2 Demographic characteristics

The total number of participants in this study was 26. There was an equal number of adolescent boys and girls living with perinatally acquired HIV who participated in the study. Neither of the participants was married nor was in a boarding school. All the ALWH were staying with their direct blood relations. Furthermore, it was noted that some of the participants who had both parents alive, were living with single parent because their parents were either divorced or had remarried. The demographic characteristics of the participants are highlighted in Table 1.

Table 1: Demographic characteristics of the participants

Demographic characteristics	Number (N = 26)
Age ranges (years)	
12 to 15 years	**14**
16 to 18 years	**12**
Sex	
Boys	**13**
Girls	**13**
Condition of parents	
Both parents alive and on ARVs	**10**
Both parents alive but only one on ARVs	**4**
Both parents died whilst on ARVs	**4**
Only one parent alive and on ARVs	**8**
Duration on ARVs	
Less than 5 years	**6**
Between 5 an d 10 years	**6**
More than 10 years	**10**
The relationship with primary caregiver	
Both biological parents	**8**
Single parent	**14**
Others (Sister, Brother, Uncle, Aunt or Grandparent)	**4**

4.3 Themes and subthemes

Data from the FGDs and in-depth interviews were analysed using thematic analysis and four themes emerged from the data. The identified themes were: support and encouragement from family members and peers, linking ART services to improved health status, reminders for taking ARVs and facing challenges. These themes mainly focused on how different age ranges and sex of the participants perceived their treatment adherence. The themes and the subthemes are highlighted in the table 2 below:

Table 2: Themes and subthemes

Themes	Subthemes
Support and encouragement from family members and peers	Being encouraged and supported by family members
	Being encouraged and supported by peers
Linking ART services to improved health status	Personal beliefs of improved health status
	Knowing individual's HIV status
	Accessing a wide range of services
Reminders for taking ARVs	Increasing the visibility of the drugs
	Setting alarms
	Linking mealtimes to ARV administration
Facing challenges	Being mocked and called names
	Being challenged with unbearable side effects of the ARVs
	Trying to fulfil household chores and errands
	Maintaining secrecy
	Being forgetful
	Lacking food

4.3.1 Theme one: Support and encouragement from family member and peers

This theme emerged from the ALWH's responses where they narrated the support which they were receiving from their family members and their peers. The ALWH narrated that the support which they were getting from their family members and peers played a great role in improving their treatment adherence. This theme had two subthemes namely: being encouraged and supported by family members; and being encouraged and supported by peers.

4.3.1.1 Subtheme one: Being encouraged and supported by family members

Most of the ALWH reported that they were living with either one or both of their biological parents. However, those who had lost both parents, mainly the older ALWH, were living with their close blood relations such as aunts, uncles and grandparents. The ALWH narrated that these family members were supportive in ensuring that they were adhering to their treatment. They explained that their caregivers were directly helping and reminding them to take their ARVs at the recommended time, on daily basis. Most of the caregivers were also reported to be reminding ALWH about the date to go to the ART clinic for refill of their ARVs. This support ensured that the ALWH were not missing doses and had a readily supply of their ARVs as expressed in the following sentiments:

"My mother is the one who encourages me to take the ARVs daily. She always tells me that if I take my ARVs daily, at the same time and without missing doses, I will be very healthy. I will live long and I will not be falling sick frequently. Whenever, she is around, she ensures that I have taken the ARVs, she sometimes gives me water and the ARVs to take." (P13, a 15 year old girl).

However, most of the older adolescents aged between 16 and 18 years showed that they were independent and were taking full control of their drugs without any monitoring or assistance from their caregivers. Some of them reported that this independence sometimes made them to be missing their doses as reflected in this response:

"I take full control of my drugs and take the ARVs on my own without anyone's help. However, sometimes I tend to miss doses because I forget to take the drugs". (P3, 17 year old boy).

All the ALWH emphasized that the family members, especially the primary caregivers ensured that food stuffs were readily available in the home at all times. They explained that it is their caregivers' responsibility to ensure that food is readily available in the home although some of the ALWH reported that were starving sometimes. One of the ALWH narrates:

"I stay with my grandmother, although she is old, she tries her best to ensure that there is food for me in the house". (IDI 1, an 18 year old boy).

The caregivers were also a source of emotional support for most of the younger adolescents. These ALWH reported that their caregivers were comforting them whenever the ALWH were going through emotional distress. This was especially when they were being mocked and insulted by their friends and some community members as highlighted in the following response:

"*One day, my stepbrothers and sisters were mocking me that I am a dead person and useless. I reported them to my parents who told me not to mind them and emphasized that I am not the only one living with HIV"* (P19, a 14 year old boy).

The ALWH who were coming from a home where majority of the family members were on ARVs, explained that they were encouraging each other to take their drugs. Some of them were taking their ARVs at the same time together with the other family members. The ALWH explained that this ensured that none of them was missing their ARV doses. This was reflected in a statement below:

"In my, family, there are six of us who are on ARVs (both my parents, my three siblings and myself). My mother is very supportive, she collects and keeps all our drugs at one place in her

bedroom. When it is time for us to take the drugs, she calls all of us, we gather and then we take our drugs at the same time. This makes all of us to adhere to our treatment because no one can miss doses". (P11, a 15 year old girl).

4.3.1.2 Subtheme Two: Being encouraged and supported by peers

Most of the younger ALWH explained that those members of the Teen club who had been on ARVs for a long period and were seen to have an improved health status acted as role models and usually encouraged others on treatment adherence. These members were encouraging the other ALWH to adhere to their ARVs. This encouragement was usually voiced out during their meeting at the Teen Club. One of the ALWH explains as follows:

"*At this health facility, we are in a group and we meet once every month. In this group, some members who have been on treatment for a long time, are still alive and healthy, even you (referring to the researcher) can't notice that they have HIV. Some of us are new on treatment. We encourage each other to be taking our drugs as per health care workers' advice*". (P17, a 12 year old boy).

All ALWH explained that their meetings in the teen club brought oneness, togetherness and a sense of belonging. This feeling made them to be motivated and adhere to their ARVs. These sentiments are highlighted in the following response:

"We are in a teen club where all of us feel that we are one family and we understand each other because we are all living with HIV. Whenever we have met in the teen club, we encourage each other to take the drugs." (P23, an 18 year old girl).

4.3.2 Theme Two: Linking ART services to improved health status

The ALWH explained that they linked their improved health status to the ART services which they were receiving. Three subthemes which made up this theme were:

personal beliefs of improved health status; knowing individual's HIV status; and accessing a wide range of services.

4.3.2.1 Subtheme One: Personal beliefs of improved health status

Most of the ALWH explained that they were motivated to take their drugs because they believed that the ARVs had improved their health status. They reported that they were no longer falling sick frequently as before being initiated on ARVs. Those ALWH who were initiated on ARVs at an age older than 5 years were able to recall their health status before ARVs. Almost all the ALWH reported that they had at least a hospital admission due to HIV related conditions. Some of them narrated that without taking their ARVs, they would have been dead by then. This is illustrated by the following responses from two of the ALWH:

"I no longer get sick often as I used to do in the past before I started taking the ARVs. I know that taking the ARVs faithfully has helped me to have a disease free life". (P11, 15 year old girl).

Another ALWH narrating her experience:

"*I can attest to the fact that taking ARVs has really improved my wellbeing. I believe that ARVs have prolonged my life because had it been that I was not initiated on treatment, I would have been dead by now".* (IDI 6, 18 year old girl).

Some ALWH, especially the younger boys, explained that they were ensuring that they were taking their ARVs according to the prescription in order to maintain their good physical appearance. They believed that the ARVs were helping them to have a smooth body without rash, sores, scars and spots. The ALWH referred to this good physical outlook as "smooth body" as reflected in the statement below from one of the respondents:

"I am happy that ARVs have improved the smoothness of my skin. In the past, before being initiated on ARVs, I used to have rash and dark spots all over my skin but now my skin is smooth". (P17, a 12 year old boy).

4.3.2.2 Subtheme Two: Knowing individual's HIV status

Although all the ALWH were aware of their HIV status, they reported that they were told at different ages, by different people and with different disclosure duration. Most of the ALWH narrated that they had their HIV status disclosed after already being initiated on ARVs. This disclosure ranged from a onetime event to a gradual process lasting for months and even years. Most of the ALWH explained their main source of disclosure were the primary caregivers, with few of them having a joint session of disclosure with the health care workers.

After having HIV status disclosure, the ALWH reported that they had mixed reactions such as anxiety, grief, depression and acceptance. All the ALWH reported that ever since their HIV status was disclosed, their knowledge on their HIV diagnosis, the treatment regimen and the importance of adhering to their treatment, had greatly improved. The younger adolescents revealed that HIV status disclosure helped them to understand the reason why they were taking their ARVs on daily basis as well as the implications of missing their ARVs. This eventually improved their adherence to treatment as they no longer refused to take their ARVs or deliberately missed their doses. One of the ALWH explains:

"I started taking ARVs when I was 7 years old. When I was 15 years old, I started refusing to take the ARVs and my father decided to tell me the details of my HIV diagnosis. I had a lot of unanswered questions, why me and how come I have HIV? After sometime, I then came into reality and accepted my fate. I am now well knowledgeable of the dangers of not adhering to treatment and I try my best to take my drugs on daily basis". (P20, a 16 year old girl).

Although most of the ALWH were able to describe properly the number of pills and the dosing schedule of their ARVs, they showed lack of knowledge on their treatment regimen. Regardless of their duration on ARVs, some ALWH could not specify the name of the ARVs and how they function in their bodies. This was especially observed in the younger ALWH who could not properly explain their treatment regimen. Here is one of the ALWH narrating his experience:

"I do not know the exact names of the ARVs which I am taking but I take one pill at 6 o'clock every morning and 6 o'clock every evening. In the evening, I also take a half tablet of Bactrim. I cannot explain exactly how they work in my body but I was told that they help to make me healthy such that I should not fall sick frequently". (IDI 2, a 12 year old boy).

4.3.2.3 Subtheme Three: Accessing a wide range of services

The ALWH narrated that there was a wide range of ART services at the health care facility which were accessible, readily available and cost effective. All the ALWH explained that they were getting free access to all ART services including a refill of their ARVs at the government facility. None of them reported of ever buying or getting the ARVs from other sources. All the ALWH explained that the health facility never runs out of stock of the ARVs. One of the younger ALWH explains as follows:

"I usually get a refill of my ARVs from this health facility. Ever since I started taking ARVs, I have never run out stock of my ARVs. I do not buy the drugs, I always get them for free and are readily available at this health facility (P17, a 12 year old girl).

The ALWH added that the ART providers were also facilitating adherence because they were harmonizing the Teen club visit with the ALWH's ART clinic appointment date. This was reducing travelling costs as well as the number of clinic visits. On every visit to the ART clinic, the ALWH were having their body weights and heights checked, had monitoring

of side effects of the ARVs, were given ARV adherence lessons, had refills for ARVs and Cotrimoxazole and attended to the Teen club. This enabled the ALWH to access all the services during one visit. One ALWH explains:

"The health care workers ensure that our clinic days whereby we refill our drugs, have a check on how we are growing up as well as checking if we are having problems with our drugs, are held concurrently with the Teen club. This makes us save some money and time as we come here only once every month". (P10, a 13 year old girl).

4.3.3 Theme Three: Reminders for taking drugs

This theme emerged from the ALWH's response to a question on the strategies which they had put in place to ensure that they were not missing their ARVs doses. The following were the three subthemes; increasing the visibility of the drugs; setting alarms; and linking mealtimes to ARV administration.

4.3.3.1 Subtheme One: Increasing the visibility of the drugs

The ALWH explained that they ensured that their ARVs were accessible by placing them at a place where they could easily see and find them. Almost all the younger ALWH reported that they were having morning and evening doses. They explained that they were placing their pill bottles near their schoolbags so that they could easily remember taking the drugs before going to school, in the morning. Those ALWH with the evening pills were putting their drugs on the table in their bedroom. Some ALWH were placing their pill bottles on the bed or under the pillow in their bedroom such that when they get into the bed and they could hear the noise of the pills spilling in the bottle and could be alerted to take the drugs.

"I put my ARV pill bottle on my school bag and before I leave for school every morning, I see the drugs and remember to take them, I then put the bottle on the table in my bedroom. In the evening before I go to bed, I see the ARVs bottle and remember to take the drugs." (P15, a 12 year old boy).

Some of the older boys explained that they always kept their drugs handy by carrying some of the ARVs everywhere they were going. This was especially when they had anticipated that they would come home late or spend a night away from their homes. They explained that when it was time for them to take their drugs, they were just sneaking out without the notice of their friends and take their drugs, thereafter, continue with whatever they were doing.

"I take my ARVs twice a day, at 6 o'clock in the morning and at 6 o'clock in the evening. Wherever I go, I take with me some of the ARVs. When it is time for my drugs, even before I get home, I just sneak out get some water and take them. This makes me not to miss my doses". (P4, an 18 year old boy).

4.3.3.2 Subtheme Two: Setting alarms

Most of the ALWH narrated that they were using different sets of alarms for them to remember to take their drugs such as church bells, the call for Islamic prayers, radio programs as well as alarms from phones and wall clocks. One of the ALWH explained her reminder as follows:

"I take my drugs together with other family members who are also on ARVs. We wait for the Islamic call for prayers (known as "Mwazini" in local language) for us to take our drugs. Sometimes, my mother uses a wall clock to determine the right time for us to take the drugs. Since last month, I have never missed any dose." (P11, 15 year old girl)

The ALWH who were staying in a family with other people living with HIV, stated that they preferred to take their drugs together and they were reminding each other. This strategy ensured that no one forgot to take their ARVs. However, this method was only used by a few individuals whose family members were free with each other and were comfortable with exposing their HIV status.

"In my, family, there are six of us who are on ARVs (my parents, my three siblings and myself). When it is time for us to take the drugs, she calls all of us, we gather and then we take our drugs at the same time. This makes all of us to adhere to our treatment because no one can miss doses". (P11, a 15 year old girl).

4.3.3.4. Subtheme Three: Using mealtimes as times for drug administration

Some of the ALWH indicated that they used breakfast and supper times as an opportunity for them to take their ARVs and used this as a strategy for remembering to take their drugs. They explained that they were either taking their ARVs soon before or after their breakfast and supper. This was also reflected in their daily work plans. This became a routine for most of the ALWH. They explained that each and every time they had their meals, they would remember to take their ARVs.

"When I wake up every morning, I start with sweeping around the compound. Thereafter, I prepare and eat my breakfast and then take my ARVs. In the evening, I prepare supper and then take the ARVs. I always ensure that I have eaten before taking the drugs." (IDI 6, an 18 year old girl).

4.3.4 Theme Four: Facing challenges

This theme emerged from the responses whereby the ALWH reported the challenges which they were encountering in the course of taking their treatment. This theme emerged from six subthemes namely: being mocked and called names; trying to fulfil household chores and errands; maintaining secrecy; being forgetful; being challenged with unbearable side effects of the ARVs; and lacking food.

4.3.4.1 Subtheme One: Being mocked and called names

Majority of the ALWH reported that they were depressed, frustrated and humiliated because their friends in the community and at school were mocking them. The ALWH also reported that in their community, they were perceived as being useless and as good as already

dead. Emotional stress and a sense of being worthless was commonly reported by majority of the ALWH and this made some of the ALWH to be deliberately missing their doses. Majority of the ALWH had at least been mocked or ridiculed by their schoolmates or friends regarding their HIV status. The older ALWH narrated that they were uncomfortable to take their drugs in the presence of their friends who were HIV non-reactive. This was because these friends were insulting the ALWH and calling them names such as "wophwanya" (the one grinding/crushing ARVs) because they were taking ARVs as reflected in the following statement:

"I am compelled to miss my doses depending on where I am currently staying and who is surrounding me. In other homes they insult me, calling me "wophwanya" (a person who is grinding ARVs), a person suffering from AIDS and this frustrates me so much such that I end up missing my doses." (P4, an 18 year old boy).

4.3.4.2 Subtheme 2: Trying to fulfil household chores and errands

Most of the ALWH reported that one of their major responsibilities in their respective homes was to carry out household chores such as cleaning kitchen utensils, fetching water and being sent on different errands by their caregivers. However, they reported that sometimes the household chores, especially those that required travelling away from home, were interfering with their ARV schedules. Some of the ALWH reported that they were sent on errands which coincided with the time for them to take their ARVs and they ended up missing their doses.

When they were narrating their daily work plan, it was noted that all girls regardless of age range, had more daily house chores than the boys. However, most of the younger boys revealed to have missed at least a dose of ARVs in the previous 72 hours because they were away from their homes, in the course of accomplishing their household chores. One of the boys explains:

"I missed my drugs three days ago because my mother sent me to the market early in the morning before I had taken my ARVs. When I came back from this first trip, she sent me on another trip where I spent the whole morning and I ended up missing my morning dose." (P16, a 14 year old boy).

4.3.3.3 Subtheme Three: Maintaining secrecy

All the ALWH explained that taking ARVs is accorded a secret status and would like no one, apart from their family members, to know their HIV status. They explained that they were shy and uncomfortable to take their drugs in the presence of strangers who had come to their homes. The ALWH explained that this was common when the strangers were almost their age mates and when they were sharing the same bedroom.

They also explained that they were sometimes missing doses when they had gone to a new place. The ALWH reported that in order to keep their HIV status a secret whilst at the same time hiding their ARVs, they opted to miss their doses until when they were at a place where they could comfortably take the ARVs. The ALWH explained that ARVs are not supposed to be seen by everyone hence the need to hide them from strangers. One of the ALWH explains:

"Whenever I have gone away from home, I feel embarrassed to take my drugs in the presence of strangers and I sometimes end up missing doses. I do not want strangers to know that I am living with HIV". (P3, 17 year old boy).

4.3.4.4 Subtheme Four: Being forgetful

The ALWH who had missed their doses within the previous 72 hours reported that they had forgotten to taken their ARVs. Some of them confessed to have missed some doses because their reminders which were set, did not function properly. Others reported that due to tiredness especially in the evening, they were retiring to bed before taking their ARVs.

"I missed my evening ARV dose three days ago because my mother who usually reminds me to take my drugs, was tired and she forgot to remind me to take my drugs. After I had finished eating my supper, I couldn't remember to take my drugs; I just went straight to sleep". (IDI 4, a 13 year old girl).

4.3.4.5 Subtheme Five: Being challenged with unbearable side effects of the ARVs.

All the ALWH explained that at every visit to the ART Clinic and Teen Club, the health care workers were advising them to adhere to their ARVs, in order to be healthy and have a long life. However, some ALWH reported that they missed their ARV doses because they were facing unbearable side effects from the drugs such as severe headache, nausea, heart palpitations and general body weaknesses. These side effects were compromising their level of concentration in class as well as affecting their day to day life. Therefore, some of the ALWH were compelled to miss their doses in order to avoid the side effects and be able to carry out their daily activities.

"I have twice been switched from one regimen of ARVs to another regimen. When I was just initiated on ARVs, I was taking one pill in the morning and one pill in the evening and I was having no side effects. I was then switched on to another regimen whereby I was taking one pill only when going to bed. With this second regimen I developed a lot of side effects, I was feeling dizzy, weak and sick. I could sometimes fail to go to school because these side effects were unbearable. Since I did not know the importance of reporting the side effect to the health workers, I decided to stop taking the ARVs. After some months, I came to this health facility and I was switched on to another regimen." (IDI 1, 18 year old boy).

Some ALWH reported that the complexity of the ARV regimen and the increased pill burden attributed to the multiple prescribed treatment was hindering majority of the ALWH from adhering to their treatment. Majority of the ALWH narrated that were taking their ARVs twice every day, in the morning and in the evening. Furthermore, the evening ARVs

were taken concurrently with Cotrimoxazole Preventive Therapy (CPT) also known as "Bactrim". These multiple doses were a burden to most of the ALWH and made some of them to get tired of their ARVs and eventually miss their doses.

"I take my ARVs twice a day. In the morning I take two ARV tablets and in the evening, I take two ARV tablets plus one tablet of Bactrim. These are too much drugs for me to take in a day. I sometimes feel tired with them and decide not to take them at all". (P24, 18 year old girl).

4.3.4.6 Subtheme Six: Lacking food.

Most of the ALWH reported that availability of food in the home was one of the major determinants on whether to take their ARVs or not. The ALWH narrated that before taking their drugs, they made sure that food was readily available in the home and others preferred to eat before taking the ARVs. Some of the ALWH who had ever tried to take their ARVs on an empty stomach reported to have experienced severe hunger, weakness and severe abdominal pains. As a result, they decided to miss their doses whenever there was no food available.

"The main challenge which I face with my ARVs is severe hunger. These drugs require that I take a lot of food all the times such that when I have taken them without food I feel sick and weak. Therefore, I always make sure that before taking drugs there is food readily available." (P3, 17 year old boy).

4.4 Conclusion

This study has identified that support from family members and peers was the motivation factor in the treatment adherence among the ALWH. This support from the family members include constant reminding the ALWH to take their scheduled drugs, to go for ART refill, provision of food stuffs and offering emotional support. The ALWH were also linking

their improved health status to the readily availability of ART services, personal beliefs that ARVs had improved their health status and the knowledge and acceptance of HIV status.

It has also been observed that younger boys were the ones who frequently missed their doses. This was attributed to the fact that they were sent on long errands which coincided with their drug schedule. Furthermore, forgetting to take the drugs, being called names and ARVs side effects were the common challenges which made the ALWH to miss their doses.

Lastly, it has also been observed that all the ALWH were determined to adhere to their treatment and this was manifested through everyone's report of having at least a strategy which was used to remember to take their ARVs. The common strategies which were pointed out by the ALWH included placing the ARVs at easily accessible places, using mealtimes as right times for drug administration as well as using reminders like alarms and church bells.

CHAPTER FIVE

DISCUSSION OF THE FINDINGS

5.1 Introduction

This chapter discusses the key findings of the study titled "Exploring perspectives of adolescents living with perinatally acquired HIV regarding antiretroviral therapy adherence at Mitundu Community Hospital, Malawi". The broad objective of the study was to explore the perspectives of the adolescents living with perinatally acquired HIV on their treatment adherence. 26 ALWH aged between 12 and 18 years were included in the study. Four themes emerged from the findings of the current study and these are: support and encouragement from family members and peers, linking ART services to improved health status, facing challenges and reminders for taking ARVs. The discussion will specifically focus on the factors that facilitate treatment adherence in ALWH, factors which hinder treatment adherence in the ALWH and the strategies for treatment adherence used by this distinctive group at risk of non-adherence.

Demographically, notable in this study was that all the ALWH were staying with either their biological parents or a direct relation like aunt, uncle and grandparent. In Malawian culture, the upbringing of children, including those living with HIV, is the responsibility of the family as well as the entire community (Tembo & Oltedal, 2015). It is, therefore, obvious that soon after the passing on of the parents, close relations automatically assumed the responsibility of the orphans including monitoring and enhancing their ART adherence. After the loss of the parents, the family members ensured that the ALWH were adhering to their ART in order to improve their health status.

This is similar to the findings of Ugwu and Eneh, (2013) in a Nigerian study whereby the close relatives were taking a leading role in caring for children who had lost their parents

to HIV infection. These family members were also ensuring that these orphans were adhering to treatment with the aim of saving them. Taking care of the bereaved children is also perceived as a way of maintaining closeness to their departed family members.

The ALWH in this study acknowledged that they were aware of the benefits of adhering to their ARVs. However, they pointed out that there were factors which either facilitated or hindered treatment adherence hence the need for strategies for them to remember to take the ARVs. These key findings are discussed herein.

5.2 Factors that facilitate treatment adherence in ALWH

Findings from the study indicate that the ALWH perceived support from caregivers and other family members as one of the facilitators to treatment adherence. This support was in the form of material, financial and emotional. Living with HIV has been reported to be associated with stigma and discrimination from the community as well as school mates. Therefore, it was noted that the emotional support and encouragement from the caregivers helped the ALWH to live positively and be motivated to take their drugs. ALWH also had frequent medical visits and appointments which usually incurred costs. The caregivers' financial support therefore, helped the ALWH to be adherent to the clinic appointments, hence being assured of having enough stock of their ARVs. This concurs with the findings from Zambia where patients who were getting total support from the family and community members were proved to have an improved treatment adherence compared to those who lacked the support (Haberer et al., 2011).

All the ALWH in this study belonged to a teen club where they reportedly got peer mentorship, counselling and encouragement which gave them self-efficacy regardless of their gender and age, hence improving their treatment adherence. In this teen club, every member was well aware of their HIV status and this made them to be easily mixed with each other

since they were facing same challenges. Apart from getting a refill of the ARVs during the teen clubs, the ALWH also shared their personal experiences on living with HIV, their challenges with the ARVs as well as discussed on how to cope with those ARV challenges. The ALWH also participated in various sporting activities to show their oneness. This peer support also brought a sense of belonging in the ALWH hence easily retaining them on the ARVs and also improving their adherence to ARVs.

Being in a teen club has been argued to be beneficial to the ALWH since there is greater likelihood to be retained in care than those who were not in the teen club (MacKenzie et al., 2017). Furthermore, the importance of getting encouragement and support from peers has been highlighted in other studies whereby the ALWH tend to realise that there are also many people who are living with HIV and are taking ARVs thus this boosts their confidence (Mupambireyi, Bernays, Bwakura-Dangarembizi, & Cowan, 2014). In teen clubs, there is ample time for the ALWH to discuss issues affecting their treatment and this informal way of discussion allows interaction and sharing of ideas.

This study has also observed that the ALWH were directly linking their improved health status to taking ARVs as per prescription. These ALWH were mainly focusing on having symptom free life thereby living a normal life as any other adolescent. It is evident that the ALWH perceived taking ARVs as the reason behind their improved health status. Unique to this study was the observation that the young males were those who mainly focused on the physical outlook of their bodies especially the skin. Therefore, the perception that ARVs were improving their physical outlook motivated the ALWH to be adherent to the treatment.

Younger adolescence is basically when the ALWH are introduced into puberty whereby there are multiple physical, physiological and psychological changes. This is the period when the adolescents are establishing their personal identity, striving to be accepted in

the society as well as having a sexual debut (Mumthas & Muhsina, 2014). It is therefore, notable that in this study, the main concern in younger male adolescents, was on their body image especially the appearance of their skin. Body image concern in boys has also been found in other studies where younger boys were observed to be more interested in their physical outlook compared to the older boys (Fortes, Conti, Almeida, & Ferreira, 2013). However, in this current study, the younger boys focused more on their skin appearance especially a smooth skin without rash, scars and spots.

Contrary findings were observed in a study conducted by Silva, Pedro and Kirsten, (2011), where the main concern of the adolescent boys was on the body weight especially the leanness of the body as the adolescent boys were growing older. It is obvious that during early and middle adolescence, between the ages of 10 and 16 years, the individual faces rapid changes in the body, at the same time, they tend to focus more on the values of their peer groups and have an increased scope of feelings. This is possibly the reason why the younger adolescent boys in this current study were more focused on their physical outlook in order to be asymptomatic and easily be accepted in the peer groups, sexual partners and avoid stigma and discrimination.

Findings of the study observed that ALWH perceived the availability and accessibility of all services at the health facility like teen club, ARV refill clinic, growth and development monitoring as being linked to improved ARV adherence. This ensured that all the services were accessed within one visit to the health facility. The study also observed that the health care providers were giving the ALWH an appointment date which fell on a weekend, once every month, to enable them attend to their academic matters during the weekdays. Similar findings were observed in other studies whereby integrating the ART services as well as offering the services outside the traditional operating hours were helpful as the patients did not waste time, it was convenient and cost effective since almost all the services were

available during one visit (Govindasamy et al., 2014; MacKenzie et al., 2017). This helped the ALWH to adhere to their clinic appointments because all their health needs were met within one clinic visit.

5.3 Factors that hinder treatment adherence in ALWH

Although the ALWH acknowledged that taking their ARVs as per prescription was important, they thought it was difficult to adhere because of unbearable side effects, forgetfulness, being sent on long errands which coincided with times for drug administration as well as trying to keep their HIV status a secret. This study has observed that regardless of age, the ALWH tend to miss the ARVs at one point in time. This is contrary to findings from other studies conducted in the sub-Saharan Africa where it was observed that those adolescents who were aged between 11 and 15 years were more non adherent to their ART doses compared to other age ranges of children (Kabogo, Muniu, Wamunyokoli, Musoke, & Songok, 2018).

Forgetfulness was perceived by the ALWH, in this current study, to be the leading cause for unintentional missing of ARV doses. It was observed during the data collection that majority of the ALWH reported that they had missed at least a dose within the previous 72 hours prior to the study due to forgetfulness. It is inevitable to miss dosages especially when the patient is asymptomatic. It can therefore, be confirmed that forgetting to take ARVs is a common setback for Malawian adolescents as similar findings were also found by Kim et al., (2017) where ALWH reported that they were missing their doses.

The findings of this study have shown that the ALWH's perception that the side effects were unbearable and also were compromising with their daily activities, was making them to intentionally miss doses. All the ALWH were in school and it is an expectation that they remain active in class. It was therefore noted that the effects of ARVs were making the

ALWH drowsy and developed generalised body weaknesses hence compromising their activity level. In order to be active and participate fully in their daily activities, they were opting to miss their ARV doses.

Similar findings have been observed by Ankrah et al., (2016) where the patients would opt to miss their ARV doses whenever they perceived that the side effects were unbearable. ARVs are usually a combination of multiple drugs with each drug having its own different side effects, thereby exposing the patients to multiple side effects. However, regardless of the several side effects of the ARVs, it is essential that an optimum adherence rate has to be maintained.

This study has found that complexity of the ARVs was hindering the ALWH from adhering to treatment. The ALWH perceived that it was a burden for them to be taking more than one dose per day, containing multiple pills and more challenging in ensuring that the doses were taken at almost exact times every day. ARVs are a complex regimen with multiple doses and are supposed to be taken daily for the ALWH's entire life. According to the Ministry of Health (2016), every patient weighing less than 35 kilograms is initiated on ARVs belonging to regimen 2. This regimen comprises of Zidovudine, Lamivudine and Nevirapine (AZT/3TC /NVP) and is taken every 12 hours. Majority of the ALWH in this study were on this regimen.

Besides taking the ARVs, the ALWH were also concurrently taking their evening doses with CPT consequently taking multiple pills at once. This was increasing the pill burden to the ALWH. A key to perfect adherence is the ability to take the ARVs as per prescription and at the scheduled time despite these challenges. Contrary to these findings, Ankrah et al., (2016) observed that regardless of having side effects, patients were still determined to taking their ARVs.

Gender roles have been highlighted in this study as one of the factors which influences on how the ALWH adhere to their ARVs. It has been noted that the younger male adolescents reported that they were missing more doses than females of the same age, especially in the course of fulfilling the household chores and errands. Although, the girls had more house hold chores comparing to boys, they were accomplishing majority of them within the homes whilst boys were sent on long distant journeys. These errands mostly took hours and collided with the schedule for ALWH's ART administration hence missing their drugs. Caregivers opted to send younger boys on errands possibly because they were more obedient comparing to the older boys who were a sort of gaining their independence.

However, these findings are contrary to what Nsheha et al., (2014), discovered that majority of girls were missing their drugs because of their cultural norms whereby they were assigned to majority of tasks which left them exhausted at the end of the day and eventually missed their doses. However, other studies discovered that there were no variations in the pattern of HIV treatment adherence between the genders as similar patterns of ART intake were observed in both males and females (Gultie, Amlak, & Sebsibie, 2015; Ioannides et al., 2017; Kim et al., 2017).

5.4 Strategies used by the ALWH to remember to take the ARVs

The ALWH reported that there were different ways whereby they could be helped to remember to take their ARVs. The use of different strategies in ensuring that the ALWH are reminded to take their ARVs has been highlighted and linked to improved treatment adherence in this study. It was noted that every ALWH in this study had at least a strategy for remembering to take the ARVs. This shows the commitment of the ALWH in ensuring that they were not forgetting to take their doses as a way of ensuring treatment adherence. Although the use of strategies is common in this study, it contradicts the findings of Souza et

al., (2016) where the patients hardly used reminders because they perceived that taking their ARVs was already part of their daily routine activities.

This current study has observed that the commonly mentioned strategy in ensuring that the ALWH were adhering to drug intake schedule was by increasing the accessibility and visibility of the drugs by placing the pill bottles where they could be easily seen. This strategy was also identified in another study where Souza et al., (2016) observed the same. It has been observed that this strategy worked better when the ALWH were within the vicinity of their drugs which implied that they were unable to take their drugs whilst away from home. Increasing the accessibility and visibility of the drugs ensures that the drugs can be taken anywhere without missing doses.

Apart from placing the pill bottles at a visible place, other ALWH opted to keep their ARVs handy. However, taking the drugs everywhere can lead to unnecessary or unintentional disclosure of the ALWH's status to the community as they can be seen taking the drugs or the pill bottles can be seen. Furthermore, taking the ARVs everywhere can lead to loss of the drugs, increase the risk of contamination and can reduce the potency of the drugs as they are exposed to unfavourable conditions and extreme temperatures. It is recommended that ARVs which are under a cold chain should be stored at temperatures between 2 and 8 degrees Celsius whilst the rest of the ARVs are supposed to be stored between 8 and 30 degrees Celsius (Gabriel & Tefesse, 2017).

This study has observed that having more than one person on ARVs in the family with the same drug schedule has been seen as an opportunity to enhance treatment adherence and was also used as a strategy for remembering to take the ARVs. This is possibly because of the support they offer to each other. This study has observed that in family settings with more than one person living with HIV, the family members would gather and take their ARVs

together. This strategy ensured that no one in the home was missing their doses. This strategy even helped them to remind each other whenever it was time for them to go for a refill of their ARVs.

However, this strategy was only applicable in settings where the family members were free to disclose their HIV status to each other and had really accepted their status. Various studies have emphasized on the importance of having emotional support and constant reminders from family members in order to adhere to ARV (Afolabi, Afolabi, Afolabi, Odewale, & Olowookere, 2013; Iacob, Iacob, & Jugulete, 2017; Scott et al., 2014). Distinctive to this current study, is that, it was observed that treatment partners within the family were more supportive in encouraging each other to take their ARVs hence ensuring that no one was missing doses.

Harmonising mealtimes with the times for ARV administration was pointed out by ALWH as an effective way to remember to take their drugs in this study. As explained earlier, majority of the ALWH in this study were taking their ARVs twice a day, morning and evening hence coinciding with their breakfast and supper times. Taking ARVs on an empty stomach has been observed in other studies to be associated with intractable hunger and severe abdominal pains which eventually made the ALWH miss their doses when there was no food in the household (Singer et al., 2015; Young, Wheeler, McCoy, & Weiser, 2014).

This can be possibly the reason why the ALWH in this current study were opting to take their ARVs only when they were assured of availability of food hence eventually making it a strategy for remembering to take their drugs. However, in Malawian rural settings, food security is a challenge as sometimes the ALWH have their meals once a day or even starve the whole day. This makes this strategy for remembering to take ARVs to be ineffective since it is food security dependent.

Use of reminders such as alarms, radio programs as well church bells were also pointed out as one of the strategies used for remembering to take the ARVs in this current study. This contradicts the findings from Saberi and Johnson, (2011) whereby although the reminders like phone alarms were available, the individuals still opted to ignore and still missed their dose. This current study also observed that these strategies which were used for remembering to take ARVs were working better when the ALWH had more than one strategy, for example having an alarm and keeping the drugs visible and accessible. The concurrent use of strategies has also been found in other studies whereby the use of more than one technique has been proven to be helpful in ensuring that the ALWH do not miss their doses since these techniques complement each other (Estripeaut et al., 2016; Fu, Hu, & Lu, 2015b; Holtzman, Brady, & Yehia, 2015; Shaw & Amico, 2016; Tran et al., 2013).

5.5 Conclusion and recommendations

5.5.1 Conclusion

This exploratory qualitative study on perspectives of ALWH regarding treatment adherence at Mitundu Community Hospital, Lilongwe District, Malawi, demonstrates that there are multiple factors which either facilitates or hinder ART adherence. Emotional and financial support from the caregivers as well as encouragement from peers has been associated with adhering to clinic appointment dates, sticking to drug schedule as well as having a boosted sense of belonging hence improved treatment adherence.

The integration of the health care services and conducting clinics on a weekend in order to cater for academic, physical and physiological needs of the ALWH has been instrumental in ensuring that all the services are accessed within one visit to the clinic. A concern to live a healthy asymptomatic life and good physical outlook motivated the ALWH to adhere to their treatment. Unique to this study was the observation that the young males were those who mainly focused on the physical outlook of their bodies especially the skin.

Therefore, the perception that ARVs were improving their physical outlook motivated the ALWH to be adherent to the treatment.

Notable in this study is that being a young male ALWH has been linked to missing ARV doses because the caregivers opt to send them on long errands coinciding with the drug administration time. Furthermore, side effects of the drugs and forgetfulness are some of the factors which hinder treatment adherence. However, the ALWH in this study have shown commitment to improving their ART adherence as they had at least a strategy to enable them to remember to take their drugs. The strategies include having treatment partners and taking the ARVs in a group, synchronising mealtimes with treatment administration schedules and setting reminders like wall clock alarms.

5.5.2 Recommendations

Based on the findings of the study, the following recommendation are specifically made to the:

ALWH

There is need for the ALWH to be empowered in taking a leading role in ensuring their own treatment adherence by abiding to the prescriptions of their ART. As peers, the older adolescents could be considered as mentors and role models to the younger adolescents or those adolescents who are new on ART or those facing challenges with their treatment adherence through offering consistent and sustainable support and motivation. There is also need for the peers to be given an opportunity in the teen club to share their experiences on treatment adherence with younger ALWH and newly diagnosed peers.

Caregivers

These caregivers need to be empowered on monitoring treatment adherence of the ALWH. The caregivers need to specifically consider the ARV administration schedule of

their wards before sending them on errands or assigning them household chores to ensure that no doses are missed.

Health care providers

The health care service providers should ensure that although the ALWH share their experiences in the teen club, there is need to enhance individualized care thereby addressing certain issues which cannot be addressed in a group. There is also need to note that some issues specifically affect treatment adherence in one gender or age range. Furthermore, the ART providers need to conduct ongoing regular individualized treatment adherence counselling to the ALWH besides the group counselling sessions which are held in the teen club. This will help to identify and address personal issues which the ALWH face in treatment adherence.

Community members

There is need for community sensitization on the importance of supporting and being non-discriminatory to all the ALWH as these behaviours and attitudes affect ALWH's adherence to their treatment. The ALWH are also part of the community as such the community leaders need to be in the forefront in supporting them.

Areas for further studies

There is need to replicate the study on a larger scale. There is need to explore the impact of HIV status disclosure on treatment adherence in children living with HIV. There is also need to compare ARV adherence between the adolescents living in the rural and urban settings. Lastly, there is need to explore if the duration on antiretroviral therapy has any effect on treatment adherence.

5.6 Limitations

The study only focused on the perspectives of the ALWH from one health facility in Lilongwe and the data collection did not include the caregivers and health workers who also play a greater role in monitoring treatment adherence of the ALWH. There was also a potential for recall bias in the ALWH on the number of missed doses and exact information which they got during HIV status disclosure. Some participants might have forgotten, exaggerated or deliberately decided to conceal the truth. In addition, the findings of this study are more likely to be transferable to adolescents who acquired the HIV perinatally and unclear on those adolescents with behaviourally acquired HIV.

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APPENDICES

Appendix A: Information Letter to the Caregivers

Study Title: EXPLORING PERSPECTIVES OF ADOLESCENTS LIVING WITH PERINATALLY ACQUIRED HIV ON ANTIRETROVIRAL THERAPY ADHERENCE AT MITUNDU COMMUNITY HOSPITAL, MALAWI.

Investigators: Chifundo Chigwenembe (Kamuzu College of Nursing) and Dr. G. Mwalabu (Kamuzu College of Nursing).

Contact details of the Study Principal Investigator: Chifundo Chigwenembe, Kamuzu College of Nursing, P.O. Box 415, Blantyre. Cell: 0999 342 301. Email: fundogwen@gmail.com or chigwenembe2016chifundo@kcn.unima.mw.

I am Chifundo Chigwenembe, a student pursuing Master of Science in Child Health Nursing at Kamuzu College of Nursing. In partial fulfilment of my Masters Programme, I am conducting a study titled "Exploring perspectives of adolescents living with perinatally acquired HIV regarding antiretroviral therapy adherence at Mitundu Community Hospital, Malawi."

I would like to invite your child to participate in this study.

Purpose of the study

The purpose of the study is to explore the patients' perceptions of antiretroviral therapy adherence in adolescents living with perinatally acquired HIV, aged between 12 and 18 years.

Reason for choosing your child to take part in the study

Your child has been chosen to participate in the study because he/she is aged between 12 and 18 years old, living with perinatally acquired HIV, aware of his/her HIV serostatus and has been on antiretroviral therapy for more than two years.

Willingness to participate in the study

The child's participation in the study is voluntary. I also wish to inform you that there are no direct benefits from the study for your child's participation. The child can withdraw from being a participant at any time and there is no punishment. The withdrawal from the study will not affect the child's health care in any way.

Risks in participating in the study

The procedures followed in the study might have minimal psychological effects on your child and arrangement has been made for the services of a psychological counsellor. The study and its procedures have been approved by The Research and Ethics Committee at College of Medicine, Kamuzu College of Nursing and Lilongwe District Health Office.

Study procedure

The study procedure involves participating in an FGD which will take approximately one hour. The discussions will be conducted in a closed and quiet environment to ensure privacy and avoid disturbances. Anonymity will be ensured by using codes. The FGDs will be recorded. The collected information will be kept by the researcher and will only be accessed by people directly involved in the research. The collected information will be destroyed by burning after data analysis.

If you have any comments, questions or complaints concerning the study, please contact:

The Chairperson
COMREC Secretariat
Private Bag 360
Chichiri
BLANTYRE 3

Dr. G. Mwalabu

Kamuzu College of Nursing

Private Bag 1

LILONGWE

Cell: 0996 960 677

Appendix B: Information Letter to the ALWH

Study Title: EXPLORING PERSPECTIVES OF ADOLESCENTS LIVING WITH PERINATALLY ACQUIRED HIV REGARDING ANTIRETROVIRAL THERAPY ADHERENCE AT MITUNDU COMMUNITY HOSPITAL, MALAWI.

Investigators: Chifundo Chigwenembe (Kamuzu College of Nursing) and Dr. G. Mwalabu (Kamuzu College of Nursing).

Contact details of Study Principal Investigator: Chifundo Chigwenembe, Kamuzu College of Nursing, P.O. Box 415, Blantyre. Cell: 0999 342 301. Email: fundogwen@gmail.com or chigwenembe2016chifundo@kcn.unima.mw.

I am Chifundo Chigwenembe, a student pursuing Master of Science in Child Health Nursing at Kamuzu College of Nursing. In partial fulfilment of my Masters Programme, I am conducting a study titled "Exploring perspectives of adolescents living with perinatally acquired HIV on antiretroviral therapy adherence at Mitundu Community Hospital, Malawi".

I would like to invite you to participate in this study.

Purpose of the study

The purpose of the study is to explore antiretroviral therapy adherence for adolescents living with perinatally acquired HIV infection aged between 12 and 18 years at Mitundu Community Hospital.

Reason for choosing you to take part in the study

You have been chosen to participate in the study because you are aged between 12 and 18 years old, living with perinatally acquired HIV, aware of serostatus and have been on antiretroviral therapy for more than two years.

Willingness to participate in the study

Your participation in the study is voluntary. I also wish to inform you that you will not have any direct benefits from the study for your participation. You are free to withdraw from being a participant at any time and there is no punishment. Your withdrawal from the study will not affect your health care in any way.

Risks in participating in the study

The procedures followed in the study might have a minimal psychological effect on you and an arrangement for a psychological counsellor has been made. The study and its procedures have been approved by The Research and Ethics Committee at College of Medicine, Kamuzu College of Nursing and Lilongwe District Health Office.

Study procedure

The study procedure involves participating in a focus group discussion which will take approximately one hour. The discussions will be conducted in a closed and quiet environment to ensure privacy and avoid disturbances. Anonymity will be ensured by using codes. The discussions will be recorded. The collected information will be kept by the researcher and will only be accessed by people directly involved in the research. The collected information will be destroyed by burning after data analysis.

If you have any comments, questions or complaints concerning the study, contact:

The Chairperson

COMREC Secretariat

Private Bag 360

Chichiri

BLANTYRE 3

Dr. G. Mwalabu

Kamuzu College of Nursing

Private Bag 1

LILONGWE

Cell: 0996 960 677

Appendix C: Kalata Yofotokoza Za Kafukufuku Kwa Makolo

KALATA YOFOTOKOZA ZA KAFUKUFUKU PA KUUNIKA KAMWEDWE KA NDONDOMEKO KA MA ARV KWA ANA OMWE ANABADWA NDI HIV KU MITUNDU, MBOMA LA LILONGWE, MALAWI.

Wokondedwa ……

Ine ndine Chifundo Chigwenembe, mmodzi mwa ophunzira za unamwino pa sukulu ya ukachenjede ya Kamuzu Koleji komwe ndikupanga maphunziro a zosamalira ana. Padakali pano, ndikupanga kafukufuku wofuna kufufuza kamwedwe ka mankhwala a ma ARV mwandondomeko kwa ana omwe anabadwa ndi kachirombo ka HIV.

Cholinga cha kafukufuku

Cholinga cha kafukufukuyu ndi kuunika kamwedwe ka ndondomeko ka ma ARV kwa ana omwe anabadwa ndi HIV Tikufuna tifufuze zomwe zimalimbikitsa kapena kupinga anawa kumwa mankhwala a ARV mwandondomeko. Tikufuna tifufuzenso njira zomwe anawa anayika kuti adzikumbukira kumwa mankhwala. Kafukufukuyu athandiza kupeza zifukwa zomwe anawa samamwera mankhwala a ARV mwandondomeko. Ndi cholinga choti papezeke njira yomwe a chipatala angathandizire ana omwe ali ndi HIV kuti adzilandira chisamaliro chokwanira ndinso choyenera.

Kutenga nawo mbali mu kafukufuku

Mwana wanu wasankhidwa kutenga nawo mbali mu kafukufukuyu chifukwa anabadwa ndi HIV ndipo wakhala akumwa mankhwala a ma ARV kwanthawi yoposa zaka ziwiri. Mwanayu sakukakamizidwa kutenga nawo mbali mu kafukufukuyu ndipo sadzalandira mphoto iliyonse. Mwana wanuyu ndi ovomerezedwa kusiya kutengapo mbali mu kafukufukuyu nthawi iliyonse popanda kupereka zifukwa ndipo palibe chilango chilichonse

chomwe adzalandire komanso izi sizidzasokoneza chithandizo chomwe mwana wanu akulandira. Padzakhala uphungu ngati pangapezeke kuti mwana wanu wakhumudwa ndi mafunso omwe adzafunsidwe mu kafukufukuyu.

Kafukufukuyu anavomerezedwa ndi akadaulo owunika za kafukufuku a College of Medicine, Kamuzu College of Nursing ndinso Lilongwe District Health Office. Mukavomereza kuti mwana wanu atengepo mbali mu kafukufukuyu, mwanayo adzakhala nawo mu zokambirana kwa ola limodzi. Mwana wanu adzajambulidwa mawu pamene akuyankha mafunso komanso opangitsa kafukufukuyu adzizalemba zina mwa zomwe anawa azidzakambirana. Kenako, khadi lomwe mwana wanuyu amalandilira ma ARV lidzaunikidwa pofuna kuona mmene ankamwera mankhwala kale asanaudzidwe zoti ali ndi HIV ndi pano pamene akudziwa zoti ali ndi HIV.

Ngati mungakhale ndi mafunso, nkhawa kapena madandaulo ena ali onse okhuza kafukufukuyu muli omasuka kutero popereka dandaulo lanu kwa:

The Chairperson

COMREC Secretariat

Private Bag 360

Chichiri

BLANTYRE 3

Dr. G. Mwalabu

Kamuzu College of Nursing

Private Bag 1

LILONGWE

Cell: 0996 960 677

Appendix D: Kalata Yofotokoza Za Kafukufuku Kwa Ana

KALATA YOFOTOKOZA ZA KAFUKUFUKU PA KUUNIKA KAMWEDWE KA NDONDOMEKO KA MA ARV KWA ANA OMWE ANABADWA NDI HIV KU MITUNDU, MBOMA LA LILONGWE, MALAWI.

Wokondedwa ……

Ine ndine Chifundo Chigwenembe, mmodzi mwa ophunzira za unamwino pa sukulu ya ukachenjede ya Kamuzu Koleji komwe ndikupanga maphunziro a zosamalira ana. Padakali pano, ndikupanga kafukufuku pakuunika kamwedwe ka ndondomeko ka ma ARV kwa ana omwe anabadwa ndi HIV ku Mitundu, mboma la Lilongwe, Malawi.

Ndikukupemphani kuti mutenge nawo mbali mu kafukufukuyu.

Cholinga cha kafukufuku

Cholinga cha kafukufukuyu ndi kuunika kamwedwe ka ndondomeko ka ma ARV kwa ana omwe anabadwa ndi HIV. Tikufuna tifufuze zomwe zimalimbikitsa kapena kupinga anawa kumwa mankhwala a ARV mwandondomeko. Tikufuna tifufuzenso njira zomwe anawa anayika kuti adzikumbukira kumwa mankhwala. Kafukufukuyu athandiza kupeza zofukwa zomwe anawa samamwera mankhwala a ARV mwandondomeko. Ndi cholinga choti papezeke njira yomwe a chipatala angathandizire ana omwe ali ndi HIV kuti adzilandira cmaliro chokwanira ndinso choyenera.

Kutenga nawo mbali mu kafukufuku

Mwasankhidwa kutenga nawo mbali mu kafukufuku chifukwa munabadwa ndi kachirombo ka HIV ndipo mwakhala mukumwa mankhwala a ma ARV kwanthawi yoposa zaka ziwiri. Simuli okakamizidwa kutenga nawo mbali mu kafukufukuyu ndipo simudzalandira mphoto iliyonse. Ndinu ovomerezedwa kusiya kutengapo mbali nthawi iliyonse popanda kupereka

zifukwa ndipo palibe chilango chili chonse komanso sizingasokoneze chithandizo chomwe mukulandira. Padzakhala uphungu ngati pangapezeke kuti inu mwakhumudwa ndi mafunso omwe mudzafunsidwe mukafukufukuyu.

Kafukufukuyu anavomerezedwa ndi akadaulo owunika za kafukufuku a College of Medicine ndi Lilongwe District Health Office. Mukavomereza kutenga nawo mbali mukafukufukuyu, mudzakhala nawo pa zokambirana zomwe zidzatenge pafupifupi ola limodzi. Mudzajambulidwa mawu pamene muli mkati mwazokambirana komanso opangitsa kafukufukuyu adzizalemba zina mwa zomwe mudzidzakambirana. Ngati mungakhale ndi nkhawa kapena mafunso ena ali onse okhuza kafukufukuyu muli omasuka kutero popereka dandaulo lanu kwa:

The Chairperson

COMREC Secretariat

Private Bag 360

Chichiri

BLANTYRE 3

Dr. G. Mwalabu

Kamuzu College of Nursing

Private Bag 1

LILONGWE

Cell: 0996 960 677

Appendix E: Participants' Consent and Assent for Minors

PLEASE READ AND SIGN ON THE FORM IF YOU ARE INTERESTED IN TAKING PART IN THE STUDY

The study has been described to me in a language that I understand and I freely and voluntarily agree to participate. I have been given an opportunity to ask questions about the study and its process and my questions on the study have been answered. I understand that my identity and information will not be disclosed at any point and that I am free to withdraw from the study without giving reasons. I have been informed that an arrangement for a psychological counsellor will be made, in case the study has caused psychological trauma.

Declaration of Consent:

Under the terms which are stated above, I voluntarily give consent to take part in this research.

…… ……..

Participant's signature or thumbprint Date

…… …….

Researcher's signature Date

I voluntarily give consent on behalf of my child to participate in this research.

…….. ..…….

Caregiver's signature or thumbprint Date

…….. ……..

Researcher's signature Date

Appendix F: Consent for caregivers and assent for minors translated in Chichewa

MUTU WA KAFUKUFUKU: KUUNIKA KAMWEDWE KA NDONDOMEKO KA MA ARV KWA ANA OMWE ANABADWA NDI HIV KU MITUNDU, MBOMA LA LILONGWE, MALAWI.

Opangitsa kafukufuku: Chifundo Phalyce Chigwenembe (Kamuzu College of Nursing) ndi Dr. G. Mwalabu (Kamuzu College of Nursing).

Mwini kafukufuku: Chifundo Phalyce Chigwenembe, Kamuzu College of Nursing, P. O. Box 415, Blantyre. Cell phone: 0999 342 301. Email: chigwenembe2016chifundo@kcn.unima.mw kapena fundogwen@gmail.com

Ine ndalongosoleredwa bwino tsatanetsatane wa kafukufukuyu ndipo ndavomereza kuti nditenga nawo mbali mopanda kuopsezedwa, kukakamizidwa komanso kunyengeleredwa. Ndapatsidwa mpata ofunsa mafunso ndipo mafunso anga onse ayankhidwa bwino lomwe. Ndamvetsetsa kuti kafukufukuyu ndi wa chinsinsi ndipo zonse zomwe ziyankhulidwe mukafukufukuyi sidzidzaululidwa. Ndamvetsetsa kuti palibe phindu limene mwana wanga atapeze potenga nawo mbali mukafukufukuyu koma kuti zotsatira za kafukufukuyu zidzathandiza kuunikiranso zaka zimene mwana aziudzidwira kuti ali ndi HIV komanso kulimbikitsa kumwa mankhwala a ma ARV mwandondomeko yake.

Ngati pangakhale vuto lina lililonse lomwe lingadze kwa mwana wangayu kamba ka kafukufukuyu, ndaudzidwa kuti adzalandira thandizo nthawi yomweyo kuchokera kwa phungu. Ndadziwitsidwanso kumene ndingathe kukadandaula ngati ufulu wa mwana wanga waphwanyidwa potenga nawo mbali mukafukufukuyu. Ndamvetsetsanso kuti mayankho amene mwana wanga angapereke mukafukufukuyu sadzagwiritsidwa ntchito motsutsana ndi mwanayu kapena kumuyimba mulandu.

Ndikudziwa kuti mwana wanga sakukakamizidwa kutenga nawo mbali mukafukufukuyu komanso ali ndi ufulu otuluka mukafukufukuyu nthawi iliyonse popanda kupereka chifukwa china chilichonse.

Kuvomereza kutenga nawo mbali mukafukufukuyu

Ine……ndikuvomereza kuti nditenga nawo mbali mukafukufukuyu mopanda kukakamizidwa.

…… ……

Sayini kapena chidindo cha chala cha yemwe atenge nawo mbali Tsiku

…… ……

Sayini ya yemwe akupangitsa kafukufuku Tsiku

Ndikuvomereza kuti mwana wanga atenge nawo mbali mukafukufukuyu mopanda kukakamizidwa.

……..

Sayini kapena chidindo cha chala cha kholo la mwana yemwe atenge nawo mbali mukafukufuku

……

Tsiku

..... ……..

Sayini ya opangitsa kafukufuku Tsiku

Appendix G: Focus Group Discussion Guide

Title of the Study: EXPLORING PERSPECTIVES OF ADOLESCENTS LIVING WITH PERINATALLY ACQUIRED HIV REGARDING ANTIRETROVIRAL THERAPY ADHERENCE AT MITUNDU COMMUNITY HOSPITAL, MALAWI.

Focus Group Number…… Date……

Time started…… Time finished…….

Demographic characteristics

Serial number	**Age**	**Sex**	**Level of Education**	**Duration on ART**	**Condition of parents (Both alive, both dead, one parent alive)**	**Whom do you live with?**

1. People learn about their positive HIV serostatus in different ways. Can you share with me how you got the information about your status? Probe more on the disclosure process. How old were you? Who told you? What were you told or how did you discover this?

2. For how long have you been taking ARVs? ***Probe.*** Do you manage your own ARVs? If not, can you explain who manages them for you and why?

3. Explain to me the medications which you are taking in relation to the HIV infection. ***Probe:*** Can you explain the dose and the frequency. Where do go to refill your ARV supply? Where and how do you store the ARVs in your home?

4. Can you explain what motivates you to take your ARVs? What are the factors which discourage you from taking your ARVs as advised at the hospital? ***Probe why?*** What is the most difficult thing about taking your ARVs? What is your experience about ARVs?

5. We all sometimes tend to forget certain important things in our day to day life. How often do you forget to take your ARVs? ***Probe why***? How many doses have you missed in the past 72 hours? Last week? Last month? ***Probe why?*** Can you explain to me what mechanism did you put in place to ensure that you do not forget to take your ARVs?

6. Explain to me your daily activity schedule. ***Probe:*** How do you manage to fit in your ARVs in this schedule?

7. Do you have any questions, any additions and any comments pertaining to our discussion?

Thank you for your participation.

Appendix H: Focus Group Discussion Guide Translated in Chichewa

Nambala yachinsinsi	Zaka zanu ndi zingati?	Mnyamata/ mtsikana?	Kodi sukulu muli mkalasi yanji?	Makolo anu alipo?	Kodi mwakhala mukumwa ma ARV kwa zaka zingati?	Kodi mumakhala ndi ndani?

1. Pali njira zingapo zomwe anthu amadziwira kuti ali ndi HIV. Mungandifotokozere mmene inu munadziwira kuti muli ndi kachirombo ka HIV? ***Funsani:*** munadziwa muli ndi zaka zingati? Anakuuzani ndani? Longosolani ndondomeko ya mmene munadziwira? Ngati munadziwa nokha, chinachitika ndi chani kuti mudziwe?

2. Tsopano mutaudzidwa kuti muli ndi HIV ndi chiyani chomwe chinasintha pa moyo wanu, kunyumba kwanu, kusukulu komanso pakati pa anzanu?

3. Kodi mwakhala mukumwa ma ARV kwanthawi yayitali bwanji ndipo ndi ndani amakuthandizirani kumwa mankhwala anu?

4. Mungandilongosolereko mankhwala amene mukumwa panopa, mulingo wake ndiponso kodi mumawatenga kuti?

5. Longosolani mwatsatanetsatane chomwe chimakulimbikitsani kapena kukulepheretsani kumwa ma ARV anu mwandondomeko? Funsani: Kodi ndi mavuto anji omwe mwakhala mukukumana nawo mukamamwa ma ARV?

6. Aliyense amatha kuiwala zinthu zina zofunikira nthawi zina monga kumwa mankhwala. Ndiuzeni kodi inu mumaiwala kangati kumwa ma ARV anu pa sabata? nanga pamwezi? Kodi ndi chani chomwe chimakukumbutsani kumwa ma ARV anu?

7. Ndiuzeni ndondomeko ya ntchito zanu za tsiku ndi tsiku. Kodi mumakwanitsa bwanji kumwa mankhwala ndi ndondomeko imeneyi?

8. Kodi palinso zina zilizonse zomwe mukufuna kundifunsa kapena kuonjezerapo pa zomwe takambiranazi?

Zikomo kwambiri chifukwa chondilongosolera zimenezi

Appendix I: In depth Interview Guide

Title of the Study: EXPLORING PERSPECTIVES OF ADOLESCENTS LIVING WITH PERINATALLY ACQUIRED HIV REGARDING ANTIRETROVIRAL THERAPY ADHERENCE AT MITUNDU COMMUNITY HOSPITAL, MALAWI.

Participant Number: ……... **Date: ……**

Time started……. **Time finished: …….**

Demographic characteristics

Age	Sex	Level of Education	Condition of parents	For how long have you been on ARVs?	Whom do u live with?

1. People learn about their positive HIV serostatus in different ways. Can you share with me how you got the information about your status? ***Probe more on the disclosure process***. How old were you? Who told you? What did they say HIV and AIDS are? Tell me in detail what you were exactly told or what information did you gather which made you realise that you have HIV?

2. After being told or realizing that you have HIV, how did your life change, at home, school or with friends? ***Probe why?***

3. Can you explain to me how you manage your ARVs? Who has been taking a leading role in managing your ARVs? ***Probe why?***

4. Explain to me the medications which you are taking in relation to the HIV infection. How often do you take your drugs and how many tablets per dose? Where do you go to refill your ARV supply? Where and how do you store the ARVs? Have you ever been switched from one ART regimen to another? ***If yes, why?***

5. Can you explain what motivates or demotivates you to take your ARVs? What challenges do you face with your ARVs? What is your experience about ARVs?

6. We all sometimes tend to forget certain important things in our day to day life. Explain to me the mechanism which you put in place as a reminder for you to take your ARVs? How many doses have you missed last month, last week and the past 72 hours? ***Probe*** What happened for you to miss your drugs?

7. How can you relate your knowledge of your HIV status to the way you take your ARVs?

8. Do you have any questions, any additions and any comments pertaining to our discussion?

Thank you for your participation

Appendix J: In Depth Interview Guide Translated in Chichewa

Nambala yachinsinsi	Zaka zanu ndi zingati?	Mnyamata/ mtsikana?	Kodi sukulu muli mkalasi yanji?	Makolo anu alipo?	Kodi mwakhala mukumwa ma ARV kwa zaka zingati?	Kodi mumakhala ndi ndani?

1. Pali njira zingapo zomwe anthu amadziwira kuti ali ndi HIV. Mungandifotokozere kuti chinachitika ndi chiyani kuti mudziwe kuti muli ndi HIV? ***Funsani:*** Longosolani ndondomeko uthenga womwe munalandira wokudziwitsani kuti muli ndi HIV? Kodi anakuuzani kuti HIV komanso AIDS ndi chiyani? Ngati munadziwa nokha, chinachitika ndi chani kuti mudziwe?

2. Tsopano mutaudzidwa kapena mutazindikira kuti muli ndi HIV, moyo wanu unasintha motani, kunyumba kwanu, kusukulu komanso pakati pa anzanu?

3. Kodi mwakhala mukumwa ma ARV kwanthawi yayitali bwanji ndipo ndi ndani amene amatenga gawo lalikulu pokuthandizirani kumwa mankhwala anu mwandondomeko?

4. Mungandilongosolereko kuti ndi mankhwala anji omwe mukumwa chifukwa choti muli ndi HIV? ***Funsani,*** kodi mumamwa kangati patsiku, nthawi zanji ndiponso mulingo wake ndi wotani? Kodi mumakatenga kuti mankhwalawa? Mungandifotokozerepo ngati munayamba mwasinthidwirapo mankhwala kuchoka ku ma ARV amtundu wina kupita ku ma ARV amtundu wina? Ngati eya, kodi chinachitika ndi chiyani kuti musinthidwe?

5. Longosolani mwatsatanetsatane chomwe chimakulimbikitsani kumwa ma ARV anu mwandondomeko? Kodi ndi chiyani chomwe chimakulepheretsani kapena

kukugwetsani mphwayi kumwa ma ARV anu mwandondomeko? ***Funsani:*** Kodi ndi mavuto anji omwe mwakhala mukukumana nawo mukamamwa ma ARV?

6. Aliyense amatha kuiwala zinthu zina zofunikira nthawi zina monga kumwa mankhwala. Ndiuzeni kodi inu mumaiwala kangati kumwa ma ARV anu pa sabata? nanga pamwezi? ***Funsani:*** Kodi ndi chani chomwe chimakukumbutsani kumwa ma ARV anu? Ndiuzeni ndondomeko ya ntchito zanu za tsiku ndi tsiku. Kodi mumakwanitsa bwanji kumwa mankhwala ndi ndondomeko imeneyi.

7. Fotokozani kuti kudziwa kuti muli ndi HIV kwasintha bwanji kamwedwe ka ma ARV anu. Longosolani mwatsatanetsatane.

8. Kodi palinso zina zilizonse zomwe mukufuna kundifunsa kapena kuonjezerapo pa zomwe takambiranazi?

Zikomo kwambiri chifukwa chondilongosolera zimenezi.

Appendix K: Permission from the Lilongwe District Health Officer

In reply please quote NO DZH/MALAWI,
Lilongwe District Health Office
P.O. Box 1274
Lilongwe
Malawi

Ref. No.:
Telephone No.: 265 726 466/464
Telefax No.: 265 727817
Telex No.:
E-Mail. lilongwedho@malawi.

COMMUNICATIONS TO BE ADDRESSED TO:

19th April, 2017

The In-charge, Kang'oma Health Centre
The In-charge, Mitundu Community Hospital

Sir/Madam

PERMISSION TO CONDUCT A RESEARH STUDY IN LILONGWE

Approval has been granted to Chifundo Chigwenembe, from Kamuzu College of Nursing to conduct a pre-test and research study at your facility,

" The impact of HIV status disclosure on treatment adherence in children living with perinatally acquired HIV infection, at Mitundu Community Hospital "

Any assistance rendered would be appreciated.

Dr. E. Rambiki Kajawo
MEDICAL OFFICER

Appendix L: COMREC Certificate of Approval

UNIVERSITY OF MALAWI

CERTIFICATE OF ETHICS APPROVAL

This is to certify that the College of Medicine Research and Ethics Committee (COMREC) has reviewed and approved a study entitled:

P.05/17/2190 – The impact of HIV status disclosure on treatment adherence in children living with perinatally acquired HIV infection at Mitundu community hospital, Lilongwe by Chifundo Phatyce Chigwenembe

On 10th July 2017

As you proceed with the implementation of your study, we would like you to adhere to international ethical guidelines, national guidelines and all requirements by COMREC as indicated on the next page

Approved by College of Medicine
10 JUL 2017
(COMREC) Research and Ethics Committee

Dr. L. Alfazema-Chiuzeni – Vice-Chairperson (COMREC)

10/7/2017
Date