AN EXPLORATORY STUDY OF PERCEIVED BARRIERS TO ANTIRETROVIRAL THERAPY ADHERENCE AMONGST ADOLESCENTS IN OMUTHIYA DISTRICT, NAMIBIA

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ABSTRACT

One of the most counterproductive behaviour in disease control both in clinical trials and clinical practice is non-adherence to medication especially among patients with chronic illnesses. This study sought to explore the perceived barriers to Anti-Retroviral Therapy (ART) adherence amongst adolescents in Omuthiya District, Namibia. Omuthiya was selected because it was where the researcher resides so they identified the problem among the Omuthiya vicinity and therefore this study is a way to solve challenges faced by Omuthiya district inhabitants. To help research this study, the researcher used a qualitative and exploratory implementation design conducted within the theoretical perspective of ecological system. Participants were Ten (10) Adolescents Living with Human Immuno-Deficient Virus (ALHIV) aged 15-19 as well as Six (6) Health Care Workers as key informants. Both were purposively sampled. Data for the study were gathered through in-depth interviews using interview guides as research instrument. The study employed the thematic data analysis method. The study found that perceived barriers to non-adherence were mostly family related with the main reason being poor parental care at home. Other factors also contribute which include side effects, stigma associated with having Human Immuno-Deficient Virus (HIV) drugs and socio-economic challenges such as dietary restrictions. It was further found that health care facilities provide adequate support to all patients including ALHIV in addressing barriers to treatment adherence, however some ALHIV had a negative attitude towards ART adherence. It was also found that Health Care Workers perceive that the barriers to ART adherence amongst ALHIV are due to lack of knowledge and poor parental care at home. It is therefore recommended that the treatment regimen be thoroughly explained to ALHIV upon full disclosure and at every resupply visit to ensure they understand the importance of not defaulting. Multi-sectored interventions' including parental involvement in the adherence promotion initiatives is recommended. It is further recommended that the ALHIV receive support through adherence advocacy programs at local, district and national level.

Keywords: Adherence, antiretroviral therapy, adolescents.

LIST OF ACRONYMS AND ABBREVIATIONS

HIV: Human immunodeficiency virus

ALHIV: Adolescents living with HIV

ART: Antiretroviral therapy

MoHSS: Ministry of Health and Social Services

WHO: World Health Organization

UNICEF: United Nations Children's Emergency Fund

UNAM: University of Namibia

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DECLARATIONS

I, Ester Nefungo, hereby declare that this study is my own work and is a true reflection of my research, and that this work, or any part thereof has not been submitted for a degree at any other institution.

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Ester Nefungo		April 2024
Name of Student	**Signature**	**Date**

CHAPTER ONE: INTRODUCTION AND BACKGROUND

1. Introduction and Background of Study

1.1. Introduction

Human Immuno-Deficiency Virus/Acquired Immuno-Deficiency Syndrome (HIV/AIDS) is a pandemic which gained prominence in the early 80s believed to have originated from animals as Simian Immuno-Deficiency Virus (SIV). More than 45 million people (WHO, 2022) have so far lost their lives to the deadly disease since HIV/AIDS was discovered. With no permanent cure, many resigned their fate to time as their CD4 count dwindled to dangerous levels which may result in opportunistic infections and death (WHO, 2014). To help avert the inevitable death of patients, scientists came up with a therapy which delays the reproduction of the virus inside the host cell. This therapy can prevent the multiplication of the virus and therefore prolonging the life of the patient. HIV/AIDS requires the patient to take the anti-retroviral drugs for their entire life. This lifelong use of medication has brought adherence challenges especially among adolescents as adhering to ART comes with its own challenges. These challenges include stigmatization, experimenting with defaulting, deliberate defaulting due to hopelessness, peer pressure, and sometimes false sense of healing emanating from religious practitioners who tell them to stop medication as they are spiritually healed. In Omuthiya, this researcher has observed a prevalence of the adherence problem which has become cause for concern for health authorities and communities alike. The adherence problem is what prompted this researcher to seek to explore this study with a view that its findings will greatly assist in identifying the perceived barriers to antiretroviral therapy adherence amongst adolescents in Omuthiya District.

1.2. Background to the study

Since Namibian independence in 1990, the custodian Ministry of Health and Social Services (MoHSS) has been involved in interventions to fight the HIV pandemic (MoHSS, 2019). It is further indicated that efforts were intensified as from 2002 with the provision of free antiretroviral therapy to the public when the prevalence rate was at 22%. The global AIDS update (2018) pointed out that HIV remains a leading top ten cause of death among adolescents living with HIV (ALHIV) worldwide. Ammon, Mason and Corkery (2018) brought to light that most adolescents on antiretroviral therapy have worse treatment adherence, viral suppression and mortality as compared

to adults. The World Health Organization (WHO) report (2018) on adolescent's advocacy, described Adolescents as a stage of human development characterized by numerous life changes and challenges including the physical, emotional and social aspects.

The MoHSS psycho-social support guideline for people with life limiting illnesses (2014) recommends social workers to make meaningful contributions towards the management and treatment of HIV particularly among adolescents who are viewed as a special population requiring special interventions. This contribution is deemed vital as part of the integrated and comprehensive HIV care and support services. Omuthiya district had a total number of 569 ALHIV who are enrolled to care at various health facilities (Quantum system, March 2021). One of the programs that the district is currently embarking upon as an effort to promote adherence amongst ALHIV is the facilitation of Teen clubs (support groups) at all health facilities. In addition, Biadgilign and Reda (2011) advice that in order to ensure adherence to treatment and retention, it requires an understanding of multiple barriers that patients face as it is vital in the development of interventions that overcomes identified barriers. The needs for ALHIV with poor adherence are poorly understood in Omuthiya district hence this study aims to explore barriers to ART adherence amongst these adolescents based on the uniqueness of the district.

1.3. Problem statement

The problem which led this researcher to explore this study was the observed increase in number of adolescents' deaths in the Northern parts of Namibia. Poor therapy/treatment compliance has been a major challenge observed from practice amongst ALHIV in Omuthiya district. Moreover, this occurrence has not been explored through scientific qualitative studies to provide evidence based findings which assist in improving the existing and or initiating adherence promotion programs based on research findings. Namibia as a country faces many challenges in addressing HIV-AIDS epidemic control goals set by UNAIDS but they are striving in achieving the targets among children living with HIV (Tendane, 2022). The MoHSS National Strategic Framework on HIV/AIDS response (2017) indicates that antiretroviral therapy (ART) coverage amongst adolescents in Namibia is 76% among girls and 84% among boys which are both below the national targets which is 90%. Despite interventions directed towards promoting adherence among ALHIV in Omuthiya

District, there is realization from practice that adherence to therapy is still an issue of concern especially amongst adolescents aged fifteen to nineteen (15-19). The Omuthiya ART District Coordinating Committee is involved in planning the treatment adherence programs for adolescents such as Teen clubs' meetings and the outcome so far has been satisfactory (Eliphas, 2017). However, more prompt interventions are still needed. Furthermore, there is limited evidence based protocols in place on how the district should go about tackling and managing this phenomenon of poor treatment adherence.

Therefore, this study sought to fill the gaps in knowledge with regard to perceived barriers to therapy amongst the selected population. The study was conducted by a social scientist, analyzed and interpreted from the social welfare perspective of which it has not yet taken place in the district and specifically Oshikoto region at large. Moreover, there was gap in knowledge identified on how ALHIV wishes to be supported through adherence promotion initiatives/programs.

1.4. Purpose of the study

It is the broad statement of desired research outcomes (Kumar, 2011, P 11). The main purpose of this study was to explore and identify perceived barriers to ART adherence amongst ALHIV in Omuthiya district and recommends for possible need-based interventions to promote adherence.

1.5. Objectives of the study

These are specific aspects of the research topic to be investigated and established (Kumar, 2011, P 62). These were:

- To explore perceived barriers to antiretroviral therapy adherence amongst adolescents in Omuthiya district, Namibia.
- To identify available support system for ALHIV in order to address barriers to treatment adherence.
- To examine ALHIV attitudes and behaviors towards antiretroviral therapy adherence.
- To explore Health Care Worker's perceptions on barriers to ART adherence amongst ALHIV.

1.6. Significance of the study

Therefore, this study adds value to practical knowledge with regard to barriers that impede therapy adherence amongst ALHIV in Omuthiya district. Additionally, this study also assists policy makers with policies formulation with regard to ensuring therapy adherence as well as those directed towards improving the provision of Adolescents friendly health care services. Furthermore, this study shed light on possible ways to address barriers to treatment from participants' perspectives. This is in line with an African proverb that states that '*Nothing for us, without us'*.

In addition, these research findings are valuable in planning, monitoring and evaluation of adherence promotion activities as well as crafting preventative measures of poor adherence to therapy in the district based on the identified perceived barriers. The findings are not only helpful for the Social Workers in rendering in-depth psycho-social support services to this key population. The findings will enable other Health Care Workers such as Nurses, Health Assistants and Doctors who are involved in continuous service provision to ALHIV to better understand some of the barriers to therapy and be able to render focused services accordingly. Besides, the findings have high propensity to equip the Omuthiya District ART Coordinating Committee with evidence based factors impeding adherence for better program planning, monitoring and evaluation.

The findings are also useful to donors who are involved in funding adherence promotion initiatives for ALHIV in the district. They assist in ensuring that the funds are directed towards critical areas where such assistance is most needed. In addition, this study adds input to the literature available on ALHIV compliance to therapy. From the theoretical perspective guiding this study, the study unveiled keys systems that are fundamental in the promotion of therapy adherence amongst ALHIV and how best to engage and support them.

1.7. Limitations of the study

Due to the sensitivity of the nature of the research, ethical clearance from the University of Namibia research committee was obtained and only then the researcher went ahead seeking for ministerial, regional and district permission to conduct the study. The researcher had fear of possible refusal to take part in the study either by the

selected participants and or guardians, but fortunately it was not encountered as both understood the aim and objective of the study and ethical principles guiding the study.

The findings may not be fully generalized to other health district since the study is sought to understand perceived barriers to ART adherence amongst ALHIV specifically in Omuthiya district with its unique demographic and socio-economic distinctiveness. However, the findings can be used as a baseline study for future studies. The findings can also be reflected upon in planning and monitoring programs designed to promote adherence among ALHIV. The sensitivity of the topic resulted in some form of uncertainties of which ethical issues were considered. Additionally, coherent information on the purpose of the study as well as reassurance of the participants was given and ensured. In general, qualitative studies are criticized for being subjective as it largely depends on human behaviors. This critic may have an impact on the trustworthiness of the findings. Nevertheless, the researcher applied and maintained the principle of objectivity as possible throughout the study.

1.8. Delimitation of the Study

This study was conducted in greater Omuthiya area (at health facilities within peri-urban areas) at the initial selected health facilities. The selection of the population was determined by history of poor treatment adherence (records available) as well as the sampling type.

1.9. Definition of key Concepts

Barriers

These are obstacles and circumstances that prevent patients from fully adhering to their treatment. Barriers can also be defined as problems and challenges that interrupt successful treatment outcomes. Barriers can also be factors that disrupt communication. Barriers can also include factors that can make a situation difficult and impossible (Learners dictionary). In general, barriers are obstacles and limitations that lead to non-compliance. For the purpose of this study, it thus aims to identify and explore obstacles and limitations contributing to poor treatment adherence amongst the identified population.

Adolescents

According to MoHSS (2014), adolescents are individuals between the ages of 10-19. They are further classified into two categories namely as younger adolescents for those between the ages of 10-14 as well as adolescents from the age of 15-19 (ART guideline, 2019). Adolescence is the period of life characterised by different health and developmental needs and rights (WHO, 2014) whereby adolescents learn how to manage their own emotions and relationship with significant others. The great majority of adolescents fall under the age-based definition of a child as adopted by the United nation convention on the rights of the child, as the person under the age of 18 (WHO, 2014). However, the term adolescent is defined differently in different countries

Adherence to treatment

In simple terms, adherence is defined as the extent of which the patients on treatment follow all the instructions pertaining to their treatment (ART guideline, 2019). In other words, it is when Adolescents are complying with all the dos and do not's directives of the treatment they are taking. Also, it is when the patient's treatment taking behaviours coincides with the instructions of the health care provider. The extent to which patients follows given medical instructions (ART guideline, 2019). The extent to which a person's behaviour corresponds with agreed recommendations from a health care provider in respect to taking medications, following a diet and or implementing lifestyle changes (Integrated guideline, 2016).

Poor treatment adherence

Refers to when a patient is unable or not willing to take treatment as prescribed. Non adherence and poor adherence are similar and often used interchangeably (ART guideline, 2019). The degree of non-adherence to treatment is common internationally (MOH S.A, 2016) and the consequences is worrisome. Therefore, interventions to improve the situation of poor adherence to treatment are highly recommendable as it can result in drug resistant to first line regimens, morbidity, mortality and increased health costs due to compromised treatment effectiveness.

Psycho-social support

This can be interpersonal strategies and techniques that are targeting an individual's biological, behavioural, cognitive, social and emotional factors with an overall goal to

promote their health and social functioning as well as mental well-being (Konji et al, 2020).

CHAPTER TWO: LITERATURE REVIEW

2. Literature Review

2.1. Introduction

This chapter presents the review of the literature essential to comprehend the worth of this study. Literature review is obtained through reading what has been published that is relevant to the chosen research topic (De Vos, Delport, Fouche and Strydom 2011). The primary purpose of the literature review is to discover connections, contradictions and any other relations between different research results by comparing various investigations (Babbie and Rubin, 2011). For the purpose of this study, the literature review will therefore examine and focus on diverse barriers associated with poor antiretroviral therapy (ART) adherence amongst adolescent from wide perspectives of previous studies conducted on the same topic. This will enhance the context knowledge. In the same vein, adherence promotion initiatives will be covered. Moreover, this chapter will also present the theoretical frameworks guiding the study. This will enable readers to understand significant themes that set the context of the topic.

2.2. Related Literature

Globally, HIV morbidity and mortality amongst Adolescent is increasing (MoHSS, 2015) & Galea (2018). This phenomenon can be reduced by increasing the ART coverage among the affected population (WHO report, 2013). According to Ammon, Mason and Corkery (2018) highlights that adolescents acquire HIV either vertically, from their mother also known as mother to child transmission or horizontally through sexual contact or risky behaviour. In simple words it means Adolescents who are currently living with HIV some got infected through their mother either during birth and or breastfeeding whilst others got infected through behaviours not linked to their mothers but rather self-regulated behaviours. By making reference to the National guidelines on Adolescents living with HIV (ALHIV) (2019), Namibia is one of the countries with the highest HIV prevalence in the world, with a prevalence rate of 22% of which ALHIV represents a growing proportion of this percentage. It is further indicated in the National ART guideline (2019) that an estimated number of ALHIV in Namibia was around 11057. However, this number has increased over years as Tendane (2022) reported that 11727 children and adolescents younger than nineteen (19) years old are receiving antiretroviral therapy in Namibia. To add on, the ART

guideline (2019) and Tendane (2022) further indicated that the majority of the ALHIV in Namibia includes the ones who were born with HIV, acquired it during breastfeeding or later on in life through other means such as those that got sexually infected through early sexual debut and sexual related abuses. Nonetheless, with the introduction of Anti-retroviral therapy (ART) programme in Namibia that started in 2003, many children born with HIV benefited from care and treatment services of which the majority of them are now adolescents who are faced with diverse challenges associated with their transitional stage as well as treatment adherence challenges. Equally, these ALHIV navigate the complicated world of friendships, relationships and life in general (Tendane, 2022). Therefore, the Adolescent guideline (2019) is recommending for special considerations of psycho-social aspects to be integrated as part of treatment to enable ALHIV to thrive in many aspects of their lives including the promotion of adherence to treatment.

Supplementary, the Adolescent guideline (2019) highlight that although there are Adolescents known to be living with HIV, sadly there is a proportion of ALHIV that are still undiagnosed and thus are unable to access treatment and care services which is a disturbing reality. One might wonder why this is the case of which some of the contributing factors to this occurrence is associated with the low testing rate among adolescents (MoHSS, 2019). This then calls for multi-sectored interventions to ensure that future generations of ALHIV have access to health care services which is also one of the ministerial strategic core values of the Ministry of Health and Social services.

Adherence to medications is a complex dynamic behaviour that is influenced by multiple risks factors ranging between individual, family and community/institutional levels (Becker, 2019). According to the Namibian National strategic framework on HIV and AIDS in Namibia (2018), it pointed out that some of the gaps and challenges identified with regard to Anti-retroviral therapy (ART) amongst ALHIV is that their unique issues and needs are not adequately addressed, particularly with regard to disclosure, adherence to treatment, psycho-social support services, sexual and reproductive health needs. What's more, the similar framework (2018) indicates that HIV prevalence rate among young women is about twice high as that of young men in Kavango and specifically in Oshikoto region where this study will be undertaken. Furthermore, ART coverage among adolescents is 74% among girls and 86% among boys. Adolescent’s girls are especially more affected by the epidemic as compared to

male counterparts with reasons driven by physical, cultural and structural barriers of HIV prevention (UNICEF, 2021). However, there are limited studies in Namibia supporting why it is the case that the coverage is high among boys than girls.

Additionally, the national strategic framework (2018) bring to light that ART coverage is high among younger adolescents aged 10-14 with 92% among girls and 94% among boys as compared to treatment adherence among adolescents aged 15-19 years. Also, it has been noted with concern that there has been a decline in ART coverage and treatment adherence amongst adolescents aged 15-19 with girls at 61% and boys at 72%. This shows that treatment adherence problems are commonly pragmatic among female adolescents than their male counterparts. Furthermore, literature describes HIV infected adolescents as having unique social and psychological issues that often negatively affect their adherence to treatment and consequently leads to poor health outcomes (Beima-Sofie, Brandt, Hamunime et al., 2017).

By making reference to a study conducted in South Africa on barriers to treatment among ALHIV aged 12-20 by Maskew et al., (2016), it discovered that Adolescents living with HIV experience poor ART outcome as compared to adults presenting a national challenge to UNAIDS goal of 90/90/90. Consequently, Adolescents have been identified as a vulnerable population requiring priority in the promotion of treatment adherence as they are confronted with a burden to cope with the clinical and psycho-social impacts of HIV. Furthermore, the same study (2016) reported that ALHIV experience numerous known economic barriers to accessing HIV care including the cost of transport and the distance to their respective health facilities.

The Namibian Adolescents living with HIV guideline (2019) describes adolescence as a difficult human developmental stage whereby children are transitioning from childhood to adulthood. This means that during this evolution, adolescent's experiences physical and cognitive changes that affect their social functioning and therefore as part of facilitating treatment and retention to care amongst this key population, it is crucial that they are screened and treated in a holistic approach including assessing their social circumstances, especially their mental health issues. It is further advised that special considerations should be given to ALHIV in rural areas who are more underprivileged than their counterparts living in towns.

Historically, according to WHO (2013), it is believed that between the year 2005 to 2012, HIV related deaths amongst adolescents increased by 50% whilst globally, HIV related death decreased by 30%. This situation was worrisome. This change in trend (increasing deaths) was primarily associated with poor prioritization of Adolescents in HIV national plans, inadequate provision of accessible, acceptable, HIV counselling, testing, treatment as well as the lack of support for adolescents to remain in care and adhere to their ART treatment (WHO, 2013).

Despite the efforts directed towards HIV management amongst adolescents in Namibia, adherence to treatment amongst adolescents remains the issue of concern especially in Omuthiya district.

2.2.1. Adolescents living with HIV

According to Tendane (2022) there was a time in Namibia, whereby there were no medications for HIV and consequently many children lost their parents and caregivers to a disease with no treatment. This then support the notion of why many adolescents living with HIV are orphans. Additionally, Gifford (2003) brings to light that children living with HIV, who are fully aware of their status have additional emotional needs. This means that they need appropriate care and support to enable them to come to terms with HIV and live positively with it, manage stigma and discrimination and remain focused on their future without being distracted by their circumstances.

Additionally, Gifford (2003) recommends for confidentiality to be ensured at all health facilities; preferably by having a private space or room whereby adolescents can freely express their problems and be counselled in return. Moreover, Gifford (2003) reported that although children issues are often viewed as sensitive in the academic world, it is of utmost importance for more research studies to be conducted on the impact of HIV on children and explore how they are coping, investigate the relevance and effectiveness of HIV programs for children, design ways to identify and assist more vulnerable children and monitor the immediate and longer term outcomes of interventions. All these tasks are viewed necessary to ensure that interventions are responsive to the unique needs of children living with HIV. Thus, Gifford (2003) argument for more research to be done on the impact of HIV on children adds value to the significance of this specific study.

In general, according to Mihalyi (2021) adolescents' experiences psychological, social and physical aspects of maturation. Usually, many adolescents have unclear roles about their lives and often experience ambiguous feelings in this regard making it difficult for them to behave differently and thus advise that in dealing with adolescents, a thorough assessment of their behaviour is needed before drawing conclusions that might be misleading in order to understand the contexts of their behaviours and be able to help them holistically. Adding on the behaviour of ALHIV, Ikeakanam (2020) support the thought of conducting a behavioural analysis amongst ALHIV as the study reveals that some of the ALHIV are battling with mental health issues which means that no matter the level of support and education that is rendered to them, they are more likely to have poor adherence as they do not purely get the message and sometimes they easily forget. Thus, it is paramount that ALHIV with additional needs such as those that are challenged mentally, to be supported accordingly. Moreover, the heterogeneity of adolescents implies that they are not the same (WHO, 2013). This means that from their mode of infection (vertical/horizontal), age, roles and responsibilities in their family and community and transitioning in adulthood differs. It is therefore recommended that service delivery interventions should take this into account as well context-specific aspects of their lives.

2.2.2. The importance of ART adherence

As indicated in the adherence counselling booklet (2012) titled 'why I take medications', it is clearly explained that the medications that is taken helps people to have many strong 'body soldiers' which is defined as body parts of the body that help keep individuals from getting sick and when they happen to get sick, the 'body soldiers' speedy up the recovery. In others words, the 'body soldiers' protect the body against illnesses and it is for such simple reason that it is being referred as such. The booklet, which is normally used for adherence counselling with ALHIV further stipulates that when ALHIV takes their medications well, it enable them to have many strong body soldiers that keeps them is a very good health status.

Moreover, the booklet (2012) emphasised that when medications is taken accordingly, it keeps the 'bad guy' sleeping under the medicine blanket. This means that, the 'bad guy' as referring to opportunistic illnesses cannot hurt the body soldiers and thus the body will have many strong body soldiers. It is further recommended that the treatment need to be taken at the right time every day in order to keep the 'bad guy' sleeping. In

simple terms, it is important for ALHIV to take their treatment everyday as prescribed as they are practically referred to like legs of the chair. Meaning, if one leg is taken away, the chair is likely to fall down and vice versa. If the medication is not taken for whatever reason, it is likely that the 'bad guy' will be awake disturbing the body soldiers and resulting in negative health outcomes. Moreover, Tendane (2022) advised that for chronic medications such as HIV, the medications should be taken every day to keep the virus under control and to remain healthy. UNICEF (2015) further adds that when ART is taken accordingly, the level of HIV virus in the body is kept low and the person will live longer and healthier.

2.2.3. Barriers affecting treatment adherence amongst adolescents living with HIV

Maskew et al., (2016) revealed that although usually retention to care is one of the goals of HIV treatment programs, there are several indications that ALHIV are receiving poor treatment outcomes as compared to adults who are on antiretroviral treatment. This conclusion was drawn from factors such as higher rates of mortality, loss to follow-ups and poor viral suppression amongst ALHIV in comparison with adults. Given this situation of poor ART outcome amongst ALHIV, Maskew et al., (2016) then emphasized that it is paramount for health care facilities to understand barriers associated with poor treatment adherence as a matter of urgency as this will result in the identification of specific factors that will then enable HIV programs to target result oriented interventions.

The following are some of the barriers affecting the treatment adherence of ALHIV in Namibia (ART guideline P.45, 2019):

- The loss (death) of parent (s)/guardian(s) negatively impacting the support system
- Treatment fatigue especially amongst adolescents who may be taking treatment for a longer period of time. This may also result in poor interest to continue taking treatment.
- Pill burden especially in instances whereby a dose is more than one tablet.
- Medication side effects such as upset abdominal and fatigue.
- Issues surrounding non-disclosure in an effort to avoid stigma and discrimination.

Having highlighted some of the barriers contributing to poor treatment adherence in Namibia, the Adolescent guideline (2019) further stresses that treatment adherence counselling should focus on identifying reasons of poor treatment adherence in order to render appropriate support rather than reprehension. Moreover, it has been discovered in the Adolescent guideline (2019) that sometimes children may have history of good treatment adherence and surprisingly they can start defaulting when they reach adolescent stage (15-19) due to multi-faced factors. Nevertheless, this calls for Health care workers to anticipate it and that it should be discussed as part of the treatment plan. In other words, health care workers involved in the treatment care for Adolescents living with HIV are advised to be aware and attentive towards diverse factors that may interrupt the treatment adherence among this specific key population rather than being generally too judgemental and concluding that ALHIV merely do not want to adhere to treatment.

According to Shalihu (2011) in a generalised study conducted on barriers to ART adherence amongst inmates at Windhoek central prison, it was discovered that stigmatization, lack of support, lack of adequate information on ARVs, lack of watches/clocks and lack of sufficient nutritional meals were some of the factors contributing to poor treatment adherence amongst inmates. Additionally, Shivute (2019) reported that the most common reasons for adolescents missing their HIV medications in a study conducted at Katutura hospital were forgetfulness, lack of transport money to go to the ART clinic, shortage or no food and lastly due to stigma (their peers laughing at them).

Additionally, Maskew et al., (2016) identified the following as barriers to treatment amongst ALHIV aged 12-20 in South Africa which is not far from the barriers identified in Namibia. These barriers include:

- Long travelling distance and high transport fares to the health facilities
- Fear of being seen at the clinic by friends or members of their school
- Being taken care of by an elderly as a guardian/treatment supporter
- long waiting periods at the clinic
- Having a caregiver with financial difficulty
- Treatment fatigue
- Lack of interest in the treatment

- Not believing/convinced that ART can help
- Unfriendly health care workers' attitude

Furthermore, other barriers to treatment are being classified into the following broad categories such as:

(i) Patient related factors (cognitive, emotional, behavioural and life stages issues)

According to an evaluation study on the psycho-social adjustment and self-esteem of prenatally HIV infected adolescents by Orawan et al., (2018) it discovered that these adolescents were at high risk of developing low self-esteem and greater psycho-social problems as compared to their peers who are HIV negative. Furthermore, the study suggested that adolescents living with HIV who are found to be challenged with low self-esteem can benefit from self-esteem enhancing programs and in the process equipping them with personal skills that will enable them to deal with the psycho-social difficulties they are facing associated with taking treatment.

In addition, the same study also revealed that HIV infected adolescents are confronted with emotional and behavioural problems such as anxiety and depression which in turn interferes with their self-esteem and can negatively affect full compliance with their treatment. Again, adolescence stage on its own is a critical and vulnerable stage in the development of self-esteem and body image as the physical and psychological changes increases the focus on physical appearance and peer acceptance of which can be emotionally overwhelming to some Adolescents. In simple terms, this means that negative self-image can have a potential effect on the psychological and behavioural problems directly related to HIV infection. Equally, HIV infected patients can be at risk of low level of self-esteem. Therefore, it is the responsibility of health care workers to provide comprehensive care; not only to provide medications but to also render the necessary emotional support (ART guideline, 2019).

It is a known fact that some adolescents keep their HIV status as a secret with fear that they will be treated differently by others especially their peers the moment they discover that they are HIV positive and on treatment (Madiba and Mokgatle, 2016). In other words, adolescents maintain secrecy over their status in order to be accepted by their peers and also to protect themselves from stigma and isolation. Furthermore (Madiba and Mokgatle, 2016) also discovered that some adolescents find it difficult to

disclose their HIV status to their intimate partners for various reasons; although it is necessary as part of HIV transmission prevention (index testing). Moreover, some Adolescents may decide to keep their status as a secret as a results of directives from their caregivers who may hold negative attitudes towards disclosure and also with fear of being exposed as their biological parents/guardians. From this point, it is clear from literature that limited data is available in Namibia on the experiences of HIV disclosure amongst adolescents from their parental perspectives.

However, Ikeakanam (2020) study on the experiences of caregivers on disclosure of ALHIV, it was revealed that most of the Caregivers of ALHIV often delay the disclosure process due to many factors. Some of these factors include fear for stigma, caregivers not having adequate disclosure skills, negative emotional reactions such as anger, blame, hate, judge and reject. It was also found that most of the caregivers felt it is solely the responsibilities of the Health care workers to do disclosure and also that some of the caregivers believed that when they disclose the HIV status of their ALHIV, automatically they disclose their own status as well.

Other additional reasons identified by Ikeakanama (2020) for delaying the disclosure was associated with the perceptions among the caregivers that their ALHIV were too young and not mature enough to understand the issue of HIV, fear that they might end up telling everyone that them and their parents were HIV positive and some caregivers had fear to cause trouble and confusion. WHO (2011), advises that disclosure should be done incrementally to accommodate cognitive skills and emotional maturity of children as it can promote good treatment adherence.

The National Adolescent guideline (2019) identified depression (a mood disorder that causes constant feelings of sadness and loss of interest) is an additional patient related barrier factor that can also contribute to poor treatment adherence and therefore recommends health care workers to screen patients with poor adherence especially adolescents for depression as an effort to support treatment adherence. In addition, it is suggested that the screening of Adolescents for depression should include assessing symptoms such as irritability, tiredness, anger, lack of energy, sleeping issues, unhappiness amongst others (ART guideline, 2019).

Other patient related barriers can also include denial of HIV status, lack of information and misinformation as well as misconception about HIV in general. In contrast,

according to the study conducted by Mazimbuko (2008) with adult ART patients at Oshakati hospital, the majority of the participants disagreed that the lack of information was associated with poor treatment adherence. Meaning the lack of information is associated with adherence in adolescents and less likely with adults taking the same treatment. Another patient related barrier to poor treatment as reported by caregivers in Ikeakanam (2020) study is that some ALHIV simply refuse to take their treatment because they fail to understand the need to take treatment when they are not sick. This argument was also supported by Kallem, Renner, Bhebremichen and Paintsil (2010) as cited by Ikeakanam (2020) who highlighted that when ALHIV takes their treatment well, they become asymptomatic and often they do not understand the importance of visiting the health facilities as scheduled for routine check-ups as well as continuous taking of medications. This is reported to result in some ALHIV basically ceasing to take treatment as they are not sick and some because disclosure was not done properly.

(ii) Family related barriers

Biadgilign and Reda (2012) reported that children living with HIV can be vulnerable as their treatment adherence largely depends on the support of their caregivers. For instance, if the caregiver is taking the same treatment and battling with diverse psycho-social challenges, it is likely to yield to negative influences on the child's adherence to treatment as the level of support can be minimal especially if their caregiver feels overwhelmed by personal pressures. Surprisingly, Biadgilign and Reda (2012) uncovered that some of the Caregivers hides the HIV infection to their children and delays the disclosure processes due to personal reasons. This type of behaviour on the side of the caregiver has been found to be one of the factors negatively affecting adherences to treatment amongst children and adolescents.

Additionally, it is a known fact that starting disclosure early as possible from 8-9 years and combining it with the necessary support enhance treatment adherence in children (Biadgilign and Reda, 2012). Further, Caregivers lack of information about HIV and treatment (ART) is another family factor associated with poor treatment adherence amongst children. This discovery is also supported by Galea et al., (2018) study that revealed that the lack of information about HIV on the side of the caregiver was one of the factor associated with poor treatment adherence amongst adolescents as some

of the caregivers who were participants in the study did not even understand the concept of adherence itself and the importance of adhering to treatment.

Moreover, the study reported evidence of misunderstanding by some the caregivers of ART treatment whereby some caregivers who are entrusted with the responsibility of ensuring that their adolescents takes their treatment correctly were the ones giving medications wrongly such as combining missed doses into a single dose which can consequently leads to severe medications side effects. Also, another practical example discovered was that the medications that is supposed to be taken in the morning or the previous day is then combined with the evening dose or the following day.

Overall, literature is highlighting that patients do not choose not to take their treatment accordingly but it could arise from the lack of information/education. Another family related barrier reported by Ikeakanam (2020) is the lack of parental involvement of which the study brought to light that some of the caregivers of ALHIV only learned and realised that their ALHIV were not taking treatment accordingly upon being informed by the Health care workers that the child has been noted to have high viral load which is one of the signs of poor treatment adherence according to ART guideline (2019).

(iii) Stigma and discrimination related barriers

HIV stigma is defined as the process of devaluation for people living with HIV (UNAID, 2016). In contrast, discrimination follows stigma and involves unfair and unjust treatment of an individual based on his/her HIV status (UNAID, 2016). HIV Stigma and discrimination involves unfavourably attitudes, abuse, beliefs and policies directed towards people living with HIV (UNICEF, 2015). Besides, stigma and discrimination involves the fear of revealing one's HIV status to intimate partner especially among adolescents (Biadgilign and Reda, 2012). In simple terms, HIV stigma and discrimination also entails unfair and maltreatment directed towards a person because of his/her HIV status. According to Bauleth et al., study (2016), it highlighted that people on ARVs are still being stigmatized and discriminated based on their HIV status and thus call for HIV programs to lay a special emphasis on reducing stigma and discrimination against people living with HIV.

With reference to the UNAID report (2016), it states that stigma and discrimination is one of the challenges affecting people living with HIV worldwide, compromising their

ability to access health care services including treatment and care and consequently detrimentally affecting the national response to HIV. The report further revealed that there is a lack of HIV specific anti-discrimination protection laws for people living with HIV in Namibia including adolescents. On the other hand, Article 10 of the Namibian constitution is one of the legal documents advocating for freedom from discrimination. However, the availability of laws is associated with the widening of access to prevention and health care services, improving the quality of treatment and enhancing the social support of infected and affected individuals thereby promoting their human rights. Overall, it has also been discovered that the stigma of HIV can be more severe than that of other illnesses creating barriers to treatment initiation and support for adherence that might be available (ART guideline, 2019). In addition, stigma and discrimination can be worsened as the result of myths in the communities. For instance, HIV being viewed as a sexually transmitted illness of which sex is already a taboo topic within many cultures and also a behaviour that is disapproved by many especially when young people are involved.

(iv) Socio-economic barriers

Most of the patients who fail to collect their ARVs treatment on a given follow-up date often are challenged with financial constraints, distance barriers and lack of transport to and from health facilities (Biadgilign and Reda, 2012). In agreement is Van Wyk and Davids study (2019) which established that a lack of financial support can negatively affect ART adherence as sometimes adolescents are not in position to provide for their transport money to go to the clinic for their follow-ups. To add on, it was found that some patients are confronted with situations whereby they have to choose between using the little money they have to pay for transportation to the facility or to use that same money to buy food or other basic necessities such as sanitary pads especially with female adolescents.

Other studies have also shown that transport constraint is considered as one of the serious challenges that affects ART adherence among patients with poor socio-economic background. According to Biadgilign and Reda (2012) it was discovered that as an effort to address socio-economic barriers to ART adherence, some patients engage in deliberate strategies to prioritize adherence which involves borrowing and begging transport funds, engaging in risky behaviours such as stealing and or unsafe

sex and some opt to do without medications by staying at home not taking their treatment.

Furthermore, it was reported that self-discontinuation and refusal by some patients to take the prescribed treatment as well as the belief that medications need to be taken after meals resulted in some patients skipping to take their medications when food is not available. This consequently interferes with treatment adherence. Nonetheless, it is not an obvious fact that patients in developing countries, rural communities or from poor socio-economic backgrounds are always challenged with socio-economic barriers as there those who are able to achieve the same maximum treatment adherence similarly to those in developed countries or with a better socio-economic situation (Biadgilign and Reda, 2012). Equally, this means that adolescents living with HIV from poor socio-economic backgrounds are as well able to fully adhere to treatment if adequate support is made available.

(v) Medications related barriers

Even when medications are easy to take especially the newly launched paediatric formulation of dolutegravir (pDTG) for young children weighing between 3-20 kg, it can still be hard for some children to keep taking it every day due to various factors (Tendane, 2022) Also, the commercial characteristics of medications such as the tastiness, the size of the pill, pill burden, availability of liquid formulation, interference of medications with social life and adverse effects such as nausea and vomiting can have a negative impact on adherence especially amongst adolescents (Biadgilign & Reda, 2012). Additionally, Treatment fatigue can have a negative impact on the treatment adherence (ART guideline, 2019). However, good treatment adherence is associated with the belief of a positive impact of medications on the quality of life of the patients (Biadgilign and Reda, 2012). In other words, when patients have a positive mindset towards taking their medications, they are more likely to adhere to treatment as they fully understand the positive impact it has on their wellbeing instead of being too pre-occupied with the size of the pill and how it tastes.

(vi) Health care and system related barriers

According to Van Wyk and Davids (2019), long waiting hours at the health facility without being attended was identified as one of the factors deterring adherence. This was further indicated that on the day of the appointment, adolescents might find themselves being absent from school or missing most of their lessons as they spend more hours at the hospital before they are given their treatment. Additionally, it was revealed that some adolescents fear to go for their scheduled visit at the health facility with fear that the flow of patients at the clinic might lead to possibilities of accidental disclosures as the waiting area clearly expose them that they came to collect their ART treatment.

Also, according to the ART guideline (2019), it stipulates that some Adolescents might be possessed with fear of who they are going to meet at the health facility resulting in some opting to rather stay away from collecting their medications as they are not emotionally ready to be seen by certain people. Missing and misplaced files as well as poor recordings at the health facility can also contribute to poor treatment adherence (ART guideline, 2019).

Structural factors not related to patient and medications barriers can also have a negative impact on adherence (Biadgilign and Reda, 2012). This is also referred to as external forces; as patients have less control over it although they are directly or indirectly affected. These forces may include negative health care workers' attitude, opening hours, privacy at ART clinics and lack of adherence monitoring mechanisms etc. Moreover, the differential treatment (negative judgements) and verbal abuse by health care workers when adolescents miss follow-ups or defaulted may also discourage them to continue adhering to their treatment (Galea, 2018).

Additional health service factors also include the level of experience of the health care providers, the communication skills between the health care worker and the patient as well as health care provider personal beliefs (Biadgilign and Reda, 2012). it is therefore recommended that a multi-disciplinary teams experienced in HIV management, adherence support and monitoring mechanisms should be in place at all health facilities rendering services to ALHIV as it is one of the important predicators of adherence to medications (ART guideline, 2019). Also, Health care workers are urged to continue rendering adolescent friendly healthcare services and not to get tired of serving them with their unique circumstances (Tendane, 2022).

(vii) School/education factors

Some adolescents reported that they have poor treatment adherence as they raised concern over the commitment with their school work, not having an open communication and trusting relationship with their teachers, negative teachers' attitude that they find it difficult to seek for permission to go to the hospital and in return sometimes end up missing their given follow-up date at the clinics (Van Wyk and Davids, 2019). In other words, some adolescents find themselves in a challenging situation between school commitment and the need to attend to clinic appointments. Also it was discovered that there is fear amongst adolescents' learners living with HIV of not wanting to miss out on lessons whilst attending to the given follow-up at the facility as they feel that they will miss out on the lessons whilst they are being attended at the hospital. Other participants who took part in the study also reported fear of disclosing their given follow-up to their teacher as they associate it with potential unintended disclosure that may lead to potential stigma and discrimination within the school environment (Van Wyk and Davids, 2019).

According to an integrated guideline for HIV, TB and NCDs in South Africa (2016, P13-14) these were some of the combined patient-related and provider-related (structural) barriers to linkage, adherence and retention in care:

Table 1: Barriers to linkage, adherence and retention

Barriers	Examples
Cognitive	Knowledge and understanding of the disease, the importance of adherence, the potential side effects, the perceptions and beliefs of health care systems.
Affective	Depression, anxiety, Denial, lack of motivation, reduction of self-worth, stigma.
Behavioural	Forgetfulness, substance abuse, lack of interest to continue taking treatment,

	Attitudes of Health care workers towards patients, level of engagement and empathy towards patients.
Medical	Pill burden and treatment adverse effects
Socio-demographic	Socio-economic status (Level of education, transport funds, stigma, non-disclosure of status
Family/social support	Lack of family support, Dependency on others
Intervention quality	Inadequate health education, lack of assessment and understanding of patient's reasons for non-adherence, weakness in identifying patients at risk, poor management of medications side effects, lack of tools to guide HCWs on ways to support patient's adherence, Lack of confidentiality, poor tracing systems.
Training	Inadequate training and orientation of staff in educating and supporting patients with adherence problems.
Organizational	Long distances to health facilities, long waiting time, lack of coordination and integration of services, medications stock-outs, inflexible clinic hours

2.2.4. Adolescents' friendly services

Adolescents friendly services entails rendering services to adolescents in a way that is responding to their unique needs and granting them an opportunity to express them freely with regard to the treatment they are receiving (WHO, 2019) for instance,

without being judgemental of who they associate with. It also involves the meaningful engagements of adolescents in the planning, monitoring and evaluation of HIV programs and ensuring decision making with regard to their own care. For the Adolescents health services to be considered as friendly, (WHO, 2019) specified that, the services should be acceptable, accessible, equitable, appropriate and effective.

Literature indicates that often in many facilities, adolescent health services are fragmented and consequently are ineffective in addressing causes of poor health outcomes amongst adolescents living with HIV. Thus, it is recommended that adolescent health friendly services should be regarded as a systematic way of delivering services, be mainstreamed and integrated into quality of care policies and strategies within HIV programs for adolescents. Lack of adolescents friendly services and support is one of the factor attributed to poor treatment adherence and consequently HIV related deaths (ART guideline, 2019). UNICEF (United Nation Children's fund) (2015) further defines adolescent friendly health services (AFHS) as a comprehensive understanding of what young people in any given society or community want and need as well as showing respect to realities of their diversities.

2.2.5. Importance of psycho-social support services in the promotion of adherence among adolescents

According to a scoping review by Okonji et al., (2020) mental health disorders including high level of anxiety and depression among adolescents living with HIV can significantly contribute to poor treatment adherence and retention in care. Hence, the need for comprehensive psycho-social support services interventions in addition to the standardized ART services to enable ALHIV to cope and adapt with the intense stigma and discrimination associated with HIV infection.

Furthermore, the review found out that there is evidence supporting the role of psycho-social support services in promoting adherence and retention in ART amongst adults. However, there is little evidence on the role of psycho-social support service in promoting adherence and retention among young people of which it was then recommended that future researchers should consider incorporating aspects of psycho-social support interventions and approaches specifically for adolescents. The same study also documented that although barriers to ART is also noted in adult population, adolescents face greater risks of mental and behavioural health problems which

constitutes additional barriers creating the need for psycho-social support provision. Additionally, the psycho-social support services are described as a package which includes counselling, cognitive behavioural therapy and peer support that is rendered with the aim of promoting HIV disclosure and communication, support adherence to medications, address emotional related distresses as well as emerging sexuality needs (Okonji et al, 2020).

According to the study conducted by Gentze (2018) on mental health among children and adolescents living with HIV, it discovered that mental health issues affecting this specific population are poorly understood despite improvement with their survival. This entails that little is done in practice to explore mental health issues which is a vital component in enhancing ART treatment adherence. Furthermore, the study identified gaps in knowledge when it comes to social support, that studies are needed to identify the types, sources of support and also to assess whether all ALHIV have access to social support. However, the study supports the sentiment that ALHIV have more emotional and behavioural problems as compared to their peers that are not living with HIV.

2.2.6. The relationship between HIV disclosure and ART adherence

Disclosure is defined as acquiring knowledge about one's HIV status or informing others about one's HIV status (Ammon et al., 2018). It is believed that adolescents who do not know why they are taking medications are more likely to miss doses and those that are unable to inform their family and friends about their HIV status are more likely to hide their medications subsequently interrupting their treatment adherence as they are not comfortable being seen taking their medications.

HIV disclosure is regarded as a critical component of successful treatment adherence (WHO, 2013) as it creates an enabling and trust environment. Evidence from an analysis on HIV disclosure in Namibia indicates that knowledge about own HIV status is vital in the management of HIV amongst adolescents (Beima-Sofie, 2017). This report further highlighted that a healthy disclosure can improve physical and psychological health as well as treatment adherence. In agreement with this view, Madiba and Mokgatle (2016) also discovered that disclosure is necessary as it enable adolescents to learn to accept and live with HIV and develop the desire to be healthy and normal like other people specifically their peers who are not living with HIV.

Additionally, the same study also revealed that adolescents found their treatment meaningful and thereafter improves adherence to treatment after disclosure processes has been carried out.

Conversely, Madiba and Mokgatle (2016) reported that disclosing of an HIV status to adolescents was found to be one of the global health challenges as many adolescents were believed to be unaware of their HIV status (diagnosis) shockingly including those that visits the health facilities regularly and are taking ART. Moreover, several barriers contributing to children not knowing their status were identified including caregiver's fears, lack of knowledge and tools on disclosure by the Health care workers. Also, most often, Caregivers are reluctant to disclose HIV status to their children with reasons associated with potential to experience HIV stigma, guilt regarding transmission, uncertainty on how to disclose, fear for negative child reactions and questions they may ask as the results of disclosure.

Thus, it is recommended that there should be interventions in place to address Caregivers fears as well as standardized disclosure tools for health care workers as both they will contribute to effective treatment outcomes for children (Madiba and Mokgatle, 2016). Overall, it is evident from literature that when children have knowledge about why they are taking medications, specifically ART they are more likely to adhere to treatment (ART guideline, 2019).

2.2.7. Interventions to improve adherence

As earlier presented, it is evident from literature that there are diverse barriers that affects adherence to treatment. Thus, this section will echo some of the interventions that can aid to address barriers affecting adherence to treatment amongst adolescents as it is also recommended by WHO (2013). Interventions to improve adherence can be initiated by adopting systems that delivers good quality, health care and social support for adolescents as a matter of urgency. For this reason, Health care workers are urged to develop adherence monitoring tool that will be monitored closely with the patient's clinical outcomes (Biadgilign & Reda, 2012). It is further advised that interventions need to take into account underlying socio-cultural, economic, political, legal and other contextual factors (UNICEF, 2015).

Additionally, continuous research studies on the area of ART adherence, patient behaviours and adherence support is needed. Also, diagnosing health problems

affecting ALHIV such as depression, cautioning the use of substances (alcohol and drugs), providing adolescents friendly services, enhancing family and community support are additional mechanisms that can assist with improving adherence (Biadgilign and Reda, 2012).

According to WHO (2013), it alluded that one of the best practice intervention to improve adherence amongst ALHIV is when efforts are directed towards those identified with adherence problems. Other ways to improve the adherence amongst adolescents living with HIV includes community based health service delivery and training of health care workers on service provision for adolescents (WHO, 2013).

Moreover, Maskew et al., (2016), recommends that behavioural facility interventions such as peer social support groups, adherence clubs as well as evaluating the effectiveness and potential impact of various intervention approaches are some of the efforts that health facilities can embark upon to promote adherence among ALHIV. Also, because adherence to ART is a complex matter, it is necessary that a multi-faceted approach acknowledging changing barriers to accessing and remaining to care is required in designing and implementing adherence interventions for adolescents.

According to UNICEF (2021) Prioritization of particular growing needs of adolescents is vital in achieving the global aim of ending AIDS epidemic by 2030 as it was discovered that an intensified focus on adolescents' needs can result in improved treatment outcomes. Also, a review recommends for the provision of dedicated care and support services to ALHIV as well as to accelerate research work that will scale towards evidence-driven interventions addressing the emerging needs of ALHIV.

Galea et al (2018) study concluded the following as some of the practical strategies to improve treatment adherence amongst adolescents:

- Storing medications at a noticeable location to serve as a visual aid to take the treatment
- Taking treatment with different food/drinks to mask the flavour and increase the tolerability
- Having future plans such as professional careers (visualise the future)
- History of declining health associated poor adherence. In other words, having fear of getting sick in events when medications are not taken accordingly.

- Adult/caregivers support in terms of reminding and monitoring adolescents with their intake of medications.
- Rewarding adolescents with the things they want such as clothing and creating awareness that in event when they stop adhering, they will also lose the awards.
- Comprehensive continuous education about ART, the importance of adherence and the consequences of non-adherence.
- health care workers to render intensive support to identified adolescents with serious adherence problems
- Peer support (establishment of teen clubs)

UNICEF (2021) also added the following detailed interventions to improve adherence among ALHIV:

(i) **Peer based group interventions:** This entails connecting ALHIV with each other through the provision of platforms for coping with shared challenges and offering support to one another in the process (UNICEF, 2021). The participation of ALHIV in peer group was found to have a positive impact on retention to care, improved adherence as well as viral load suppression.

(ii) **Adolescent's friendly health services**: These are services at the health facilities designed for ALHIV aimed at addressing their needs by ensuring accessibility and quality health care services. Available data suggest that quality friendly health services to ALHIV improve clinic attendance as well as viral load suppression.

(iii) **Community based interventions**: This involves taking the services closer to where ALHIV lives (UNICEF, 2021). This includes but not limited to community based treatment supporters, community adherence clubs, school based initiatives etc. This too, once provided consistently over time has been found to yield fruitful results with regard to treatment adherence.

(iv) **Social protection and economic strengthening:** According to UNICEF (2021), this intervention is critical to ALHIV who face diverse social challenges such as poverty, food insecurity, domestic violence amongst others that can have a negative impact on their cognitive, social-emotional and behavioural capacities that support their health and well-being. The provision of livelihood support has been found to provide potentials in improving adherence and viral load suppression specifically when combined with the

provision of psycho-social support services to both the ALHIV and their caregivers.

(v) **ALHIV engagement and advocacy:** In order to bring about social change amongst ALHIV, it is beneficial for them to be included in planning and decision making that affects their lives (UNICEF, 2021). This goes well with the 'Ubuntu' perspective that says nothing for us without us. Meaning, decisions about their treatment adherence should include them as they know themselves better especially concerning their barriers they are facing. Evidence also suggests that when ALHIV are fully engaged in decision making, they are at a better position to challenge the health care systems such as holding the health care workers accountable to provide quality health care services (UNICEF, 2021). In addition, by ensuring that ALHIV are involved in decision making amplifies adolescent's voices and provides opportunities to certify that services are congruent with their emerging social needs.

As part of the interventions to improve adherence, the following adherence monitoring strategies and interventions are crucial (Integrated guideline, 2016):

- Self-reported adherence should be obtained routinely form all patients
- Self-monitoring techniques should be in place
- WHO recommends for viral load monitoring
- one on one ART health education
- peer support
- interactive reminder devices such as pill boxes, communication technologies such as weekly messaging

2.2.8. Attitudes/roles of the health care workers in the promotion of treatment adherence amongst adolescents living with HIV

According to WHO (2013), HCWs need to possess attentive listening skills, speak plainly and be aware that not all adolescents find it easy and comfortable to openly discuss their situations with the HCWs as they may appear as strangers to them. It is therefore paramount that the HCWs should be trained and oriented on how to provide Adolescents health friendly services.

Negative attitudes of the health care workers can negatively affect Adolescents adherence as comparing to the effects it has in adults (WHO, 2013). In this regard,

health care workers are then advised to listen attentively, speak clearly, take into account adolescent's diverse needs and keep in mind that some adolescents may not be free/ at easy to express themselves to the health care workers. Thus, it is the responsibility of the health care workers to assess for potential barriers, make appropriate referrals and give education on the importance of treatment adherence to all patients receiving ART services including critical population such as adolescents (ART guideline, 2019).

In addition, health care workers should regularly enquire about patients' experiences with taking medications, concerns and expectations about treatment in general. It is also the responsibility of the health care worker during the initiation of treatment to include strategies to support adherence as part of the treatment plan as well as sharing information about possible side effects of medications. When concerns about adherence emerge, a patient should be seen and contacted (telephone, text message) frequently to assess adherence and decide on the need based interventions to improve and support adherence.

WHO (2013) recommends that the training of the health care workers should particularly focus on the following primary areas as an effort to improve adherence amongst adolescents living with HIV. These are:

(i) **Primary care**: chronic illnesses including the emotional illnesses and coping with their feelings, sexual and reproductive health issues as well as sharing information on nutrition. This entails how to live a healthy lifestyle and why ART adherence is important.

(ii) **Prevention**: health education on risky behaviours such as indulging in substance abuse and enhancing adolescent's communication skills.

(iii) **Mental health**: Positive and negative coping styles, depression and mental health issues, dealing with the history of abuse, dealing with bereavement of a loved one.

(iv) **Disclosure**: supporting adolescents to disclose to significant others in order to obtain the support they need including their sexual partners as an effort to contribute to safer sex and HIV prevention.

2.2.9. Roles of Parents/Caregivers in treatment adherence

Behind every ALHIV who has learned to keep taking his or her medications every day and who has a positive self-image, is a supportive Caregiver (Tendane, 2022). Caregivers play a vital role in the promotion of treatment adherence amongst adolescents living with HIV (Khodel and Sochanny, 2011). It is believed that caregivers are responsible for reminding and assisting adolescents to take their treatment frequently and to ensure that they go back to the health facilities for refill and monitoring by accompanying them especially the younger adolescents. In addition, low adherence amongst adolescents at times can be a marker of serious family dysfunction including parental mental health problems, substance abuse, violence, child abuse and neglect as well as many others. (Daniella et al, 2008).

In situations like this, efforts directed towards improving adherence amongst adolescents surrounded by the given social circumstances may be ineffective and extremely challenging. Thus, interventions should also include addressing parental challenges in order to create a healthy environment that will promote adherence to treatment. Previous studies have also indicated that caregiver-child education is one of the essential components in establishing good medication adherence amongst children (WHO, 2013).

According to the study conducted by Van Wyk and Davids (2019), it discovered that family factors play a critical role in the promotion of adherence amongst adolescents. A practical example shared is that some of the adolescents cited negative relationships with their non-biological caregivers that results in them defaulting their treatment as an effort to die and be with their deceased caregivers. Also, some reported that they feel like outcast within their family because they are the only ones who are taking treatment.

2.2.10. Other interventions to address to barriers to treatment

Galea et al., (2018) revealed that although there have been studies conducted globally on barriers to ART adherence amongst adolescents; the implementation of interventions remains elusive and no gold standards exist. Thus, a contextualized understanding of factors associated with non-adherence including multi-sectored social analysis is an essential step in designing suitable interventions. Furthermore, it is vital to take into account diverse factors associated with poor treatment adherence

amongst adolescents, there is no simple intervention that is applicable to all adolescents' scenarios hence it is vital for a number of strategies to be employed in improving adherence (Danielle et al., 2008).

Firstly, the assessment of low adherence and identification of barriers to treatment should be conducted. Sharing the same sentiment is Ammon et al (2018) who cautioned that adherence assessment is vital in the management of HIV amongst adolescents and that it should be conducted frequently. It is further said that assessment can be done subjectively by obtaining adherence reports from the patients themselves and their caregivers or alternatively through objective pill counts and conducting viral load tests.

In addition, this process need be done without directly confronting the concerned adolescents or being judgemental. However, acknowledging their challenges with adherence will encourage them to open up and form a supportive relationship with the health care provider in improving their adherence. Secondly, after the identification of barriers to treatment is done, the next step should be to systematically address the identified barriers. For instance, if a certain adolescent has been poorly adhering to their treatment due to unresolved grief of a loved one, then bereavement support should be rendered.

Thirdly, educational intervention is another strategy to improve adherence. This involves providing adequate general information about HIV, the prescribed treatment (required doses, daily schedule and side effects) as well as the importance of adhering to treatment (Daniella et al., 2008). Continuous health education is recommended frequently especially for adolescents who have been diagnosed with HIV at a tender age (whereby key information may have been directed towards their caregivers) to assess their present level of understanding.

Moreover, general ideology shown to improve patient's understanding of their illness includes sharing information in a friendly manner rather than business-like, giving instructions clearly and concisely in line with the cognitive abilities, stressing the importance of the suggestion, avoiding complex medical terminologies and most importantly ensuring that the patient and family expectations has been met.

Additionally, it is worth noting that with limited resources available, adherence interventions need to be designed to address different contexts and it should be

continuously monitored and evaluated for effectiveness and sustainability (Ammon et al., 2018). Also, strategies to improve adherence will be fruitful in events whereby there is an increased knowledge of the factors impacting ART. Literature also indicates that although huge resources is spent on conducting viral load tests to assess adherence level clinically, less attention is paid on interventions to explore root causes of adherence amongst adolescents.

(i) **Organizational intervention:** Organizational strategies can also assist to promote adherence among adolescents such as clustering adolescent's appointment with that of their treatment supporters (for those taking the same treatment) or giving them on days that they do not have busy school schedules. Also, health care workers should try where possible to make medical regimens simple as possible, for instance to take a dose once or twice instead of more frequent doses. Again, by making use of new technologies such as alarm on their watches for those with watches, reminders through cell phones or pill boxes with pages may be particularly appealing especially for adolescents (Daniella et al., 2008).

(ii) **Behavioural strategies and problems solving skill**: This involves visual reminders such as leaving the medications on a table whereby it is clearly noticeable. Previous studies have also established that most of the adolescents find it easier and helpful if they pair taking their treatment with some of their daily routine such as taking it with breakfast, soon after they brush their teeth, when wearing their school uniform etc. Overall, working closely with adolescents with poor adherence to treatment allows health care workers to reinforce problem solving skills amongst the concerned population (Daniella et al., 2008).

(iii) **Peer support**: Peer support amongst adolescents living with HIV can contribute to acceptance of the treatment (Daniella et al., 2008). Emotional support from peers can enable adolescents challenged with adherence problems to regain their strengths (build resilience). The establishment of the peer support groups can extend the efforts of the health care worker to ensure treatment adherence (WHO, 2013). It is also recommended that engaging adolescents in matters that concern their treatment is essential in promoting

adherence as nobody understands their problems better than themselves and that their active involvement promotes self-development.

(iv) **Motivational enhancement theory -** Another structural intervention identified from previous studies that has been found to be effective in dealing with those with poor treatment adherence is what is referred to as motivational enhancement theory (Daniella et al., 2008). With this intervention, it is based on a non-judgemental approach characterized by empathy and respect, warmth, curiosity (interest in the adolescent's view), humility (eagerness to learn more about adolescent's perspectives) and many other efforts revolving around understanding and accepting the adolescent's view rather than forcing them to change attitudes and behaviours associated with poor treatment adherence.

With this theory, it is then concluded that enhancing motivation can take time and that it is not achieved through coercive education but rather by encouraging the concerned adolescents to focus more on the reasons why their adherence is poor. Theory has also indicated that motivation enhancement is based on the adolescent's readiness to change which is normally characterised by five motivational stages as summarised by Daniella et al., (2008) as follows:

- Pre contemplation: denial of any problem
- Contemplation: Acknowledging the problem but does not see the need to change.
- Preparation: acknowledging the need to change but not ready to change yet
- Action: ready to be assisted/helped
- Maintenance: want help to maintain changes.

This means that adolescents go through these stages differently and it is therefore the responsibility of the health care provider to adapt interventions according to the presenting stage of the adolescents and by employing therapeutic interventions such as using open ended questions, reflective listening, affirmation and eliciting mixed feelings in adolescents. Another useful technique is to address the pros and cons of adherence and summarize adolescents' perspectives aloud with them.

ALHIV need to be engaged in their HIV care and treatment (WHO, 2013). Also, government and organizations need to tailor programs that are responsive to specific needs of ALHIV. At the same time, institutions should identify and address barriers to effective treatment adherence which can also include the training of health care workers to equip them to be able render services in line with unique needs of ALHIV.

Suggestion for the improvement of services

- Age appropriate support
- Provision of material assistance such as food and clothing, support for orphans
- Protection from stigma and discrimination
- Comprehensive health education
- peer support

Findings: With majority suggesting age appropriate support, being seen on their day separately from adults and more of the peer support.

2.2.11. The relationship between social support and emotional problems such as anxiety among ALHIV

According to Besthorn et al., (2018) a gap in the body of knowledge was identified when it comes to mental health of children living with HIV in Southern Africa specifically that none focused on anxiety, social support and HIV related stigma. This is despite the growing body of research on diverse challenges affecting children living with HIV.

Previous studies have demonstrated that majority of children living with HIV lives in impoverished rural communities with limited resources of which in return these circumstances affects them for instance missing their follow up at the hospital due to transport money constraints or not having food to eat prior to taking their medications (Besthorn, et al., 2018). Apart from having to deal with HIV as a chronic illness, ALHIV faces diverse psycho-social challenges including maintaining adherence to treatment, disclosure issues, negotiating sexual relationships whilst at the same time undergoing physical and developmental changes associated with the transitional stage. This study discovered that children living with HIV need continuous provision of social support thus strongly demonstrating the need for regular social support

assessment especially for children from deprived backgrounds. The need to have a universal screening for mental health for children living with HIV was established.

According to Bhana et al., (2020) in a systematic review of mental health interventions for ALHIV in low and middle income countries, it revealed the relationship between HIV and mental health as bidirectional. This means that HIV imposes psychological distresses amongst this population and also adolescents with mental health disorders are at high risks of contracting HIV due to reduced cognitive reasoning. This review further warns that not all ALHIV has mental health difficulties but an unequal number experience numerous emotional and behavioural challenges associated with disclosure discomforts, stigma and fear of negative reactions from others including the fear of being bullied.

Furthermore, these ALHIV are confronted with feelings of shock, anger, guilt and shame of having a lifelong illness which consequently strain them emotionally and results in mental health challenges. Namibian ALHIV were found to have greater emotional, behavioural and conduct problems as compared to case controls such as in Cape town whereby most ALHIV were found with significantly poor functional competence and self-concept as well as higher levels of depression, anger and disruptive behaviours. Additionally, mental health symptoms were found to be caused by socio-demographic factors and stressful life events such as the death of a close relative including parents. However, with an improved child-parent relationship as well as support from peers was found to enabling factors to address mental health issues amongst ALHIV and enhance psycho-social adjustments (Arvin, 2020).

2.3. Theoretical Framework

2.3.1. Social work as an evidence based practice

The study is conducted from a social work perspective. According to Babbie and Rubin (2007), Social Workers are required to employ the best scientific evidence available as part of the problem solving interventions with individuals, families, groups and communities as illustrated below in order to render comprehensive social welfare services.

In addition, the Code of Ethics for Namibian Social Workers association specifically requires social workers to keep current with, critically examine practice related research in the professional literature and to include evidence based knowledge as part

of knowledge base for practice. Hence, this study will add value to social work as an evidence based practice.

2.3.2. Theoretical Framework

This study will be based on the Ecological systems perspective. The Ecological systems theory was developed by a Russian theorist Urie Bronfenbrenner during the 1970s. This theory argues that human development is being influenced by different types of environmental systems and levels ranging from people and institutions; immediately surrounding an individual up to the societal forces. Literature further indicates that, this theory was developed after gaps in knowledge was identified which proves that human studies were more focused on the internal world of an individual and in return ignoring the contexts within which the particular individual lived (Jaeger, 2012).

Historically, the Ecological theory was wedded to the system theory as it was deemed necessary enhancing in many important ways (Galea, 2018). That of; Ecology is the science that is concerned with the adaptation fit of organisms and their environment whilst Systems are concepts used to better understand how people achieve a goodness fit of various aspects within their environment. Social scientists are sensitized by the Ecological systems theory to realize that interpersonal relationships including the simplest parent-child relationships does not exist in a social vacuum but rather it is rooted in social structures of the larger society.

Additionally, the Ecological system theory dispute that it is not always possible to understand human behaviours and changes over time without studying the basic varied elements of their surroundings they lived in. In the context of this study, this implies that it will be valuable to take into account various systems within which Adolescents interact with and of which in return might have a direct or indirect impact on their treatment outcomes. These systems include amongst others their immediate family, health facilities and respective communities.

According to Galea, (2018) the Ecological systems theory will facilitate a multi-level social analysis which will offer opportunities to understand diverse factors associated with poor treatment adherence amongst adolescents and also to assist in mapping out critical areas requiring immediate interventions. In shedding more light in the perspective of this study, this theory further argue that adherence problems cannot be

exclusively viewed at an individual level but rather at a macro level with different systems involved. Also, not exempting individual factors but taking into account how individual factors are affected and how they are affecting other environmental factors.

Still on the theoretical perspective, Becker (2019) in a cross-sectional study investigating barriers to ART adherence among HIV infected women in rural Eswatini using a mixed method approach, it discovered that improving ART treatment adherence and reducing morbidity goes beyond exploring and addressing individual level influences on health by extending the interventions on examining external environmental factors within which individuals interacts with. It is further stated (Becker, 2019) that it becomes a public health concern if there is no knowledge generated on the barriers affecting treatment at an individual as well as at broader perspectives as the planning of adherence promotion initiatives and programs will lack necessary scientific evidence that will reveal diverse challenges to treatment especially for this vulnerable population. The system ecological theory has been used by researchers in public health and social sciences to describe factors within multiple domains that put forth an influence on individual health outcome (Becker, 2019).

Adherence to prescribed treatment is a momentous element of effective clinical HIV treatment and care (Becker, 2019) as it is crucial for overall viral suppression that leads to an improved general health. Contrastingly, poor adherence to prescribed treatment is associated with reduced efficiency of viral suppression and increased risks of opportunistic infections that may result in mortality.

2.4. Summary

In summary, it has emerged from literature that treatment adherence amongst adolescents is of concern as compared to that of adults. This means that strategic interventions are needed to promote treatment adherence. It also came out that the issue of treatment adherence is influence by diverse factors (barriers) and it is therefore the responsibility of key stakehs involving the parents, adolescents themselves, health care workers as well as the community at large to address barriers associated with poor treatment adherence. This will assist in creating adherence programs that are need based.

Additionally, the ART guideline (2019) presents that adolescent appeared to be under-served in many settings and across HIV cascades resulting in them having significantly

low access to ART services, high risk of lost to follow-up, minimal treatment adherence and increased need to receive psycho-social support services. In light of the said circumstances, it is therefore recommended that adolescents should receive comprehensive health care and social support to address their unique challenges.

CHAPTER 3: RESEARCH METHODOLOGY

3. Research Methodology

3.1. Introduction

Research methodology entails information outlining how empirical work was conducted. This study of barriers associated with poor treatment adherence amongst Adolescents living with HIV (ALHIV) was conducted in Omuthiya district at selected health facilities that provides HIV care according to the latest National ART guideline (2021).

3.2. Research Approach

This study employed a qualitative research approach which is a way of exploring and understanding the meaning of individuals or group certain phenomenon in a natural setting and tries to make sense out of such phenomenon (Creswell, 2007). Qualitative design was viewed appropriate for this study as it enabled the researcher to understand barriers to treatment affecting Adolescents living with HIV (ALHIV), explored deeper meanings and participant's experiences attached to their daily life of taking ART treatment. The researcher kept focus on learning the meanings that participants had about the barriers to treatment and not necessarily the researchers' personal perspectives and knowledge from the literature reviews. The qualitative research is classified as unstructured, as it allows flexibility in all aspects throughout the research processes (De Vos et al., 2011).

3.3. Research Design

An exploratory research design was used to explore barriers associated with poor treatment adherence amongst adolescents as well as exploring the experiences of health care workers in rendering services to adolescents. Exploratory studies are conducted to gain insights into a situation (Blaikie, 2000 in De Vos et al, 2011). Exploratory studies attempt to address a 'what' research question using a qualitative approach. The need to conduct exploratory studies usually arise out of a lack of basic information on a new area of interest and the aim is to get to know the underlying issues in order to be able formulate scientific problem solving strategies.

3.4. Population

The population of the study consisted of all Adolescents living with HIV (ALHIV) residing in the greater Omuthiya district area from which a sample of participants of

(ALHIV) with history of poor treatment adherence and seen on several occasions for adherence counselling and those known with vulnerable social conditions that are at risk of developing suboptimal adherence to treatment was selected. The selection of eligible participants was done with the assistance of the Nurses in charge of the selected clinics as well as Health Assistants who are highly involved in rendering regular adherence counselling to ALHIV identified with poor treatment adherence. Health care workers also formed part of the study participants as key informants in order to gain their insights into the matter. Selected participants were then given detailed information about the study before their informed consent and that of their Caregivers (where required) could be obtained. The interviews were scheduled on the ALHIV treatment follow-up dates and it took place at the facility where they are receiving their treatment to avoid additional transportations costs in the process mainly because of the study.

3.5. Sampling

The researcher employed purposive sampling technique to recruit participant for the study as it was proposed. According to Cresswell (2014), purposive sampling refers to intentionally selecting participants based on their characteristics, knowledge, experiences, or some other criteria. The following clinics were also purposively chosen: Omuthiya, Amilema, Onyuulaye, and Onkumbula. These were chosen because they had a high number of adolescents with history of poor treatment adherence and of which the need assessment conducted in 2020 by the I-Tech Nurse mentor recommended the identified ALHIV to receive psycho-social support services by the Social workers.

The research team only consisted of the principal investigator (researcher) who worked closely mainly with the Health assistants working with ALHIV and Nurses in charge at ART site to identify eligible participants. Consequently, six (6) Health Care Workers (3 health assistants and 3 Nurses) as key informants and ten (10) ALHIV were recruited as participants of the study.

After the identification of the participants, the researcher emphasised that participation in the study was entirely voluntary, that the in-depth interviews planned was confidential and that they had rights to refuse not to take part in the study and that their decision was not going to affect in any way the health services they are receiving.

Afterwards for those that agreed to take part in the study, their informed consent was then obtained with that of Caregivers where it was required.

Sampling eligibility criteria:

- ALHIV aged 15-19, both male and females, fully disclosed.
- ALHIV on ART for longer than a year, receiving treatment at the selected health facilities
- ALHIV noted with social challenges and at risk of developing suboptimal adherence, record of high viral load (over 1000 units), seen on several occasions for adherence counselling (frequently missing doses and follow-ups at the clinic, difficulties to take treatment at the given time as well as reported tendency of refusing to take treatment).
- HCWs as key informant those that are rendering services to ALHIV with minimum of two (2) years' work experience.

The targeted population was deemed necessary to achieve the aim and objectives of the study as they assisted in giving comprehensive answers to the set research questions.

3.6. Research instruments

The study used in-depth interview to facilitate the process of data gathering because the interview method was convenient for the respondents and ensured data collection without compromising the respondents' confidentiality considering the sensitivity of the research topic. These were a set of semi-structured open ended questions that guided the researcher during interviews and facilitate the process of probing for deeper meanings. Both categories of participants had theirs and they differed slightly. The interview guide for Adolescent was initially developed in English but it was later translated in the local language to make it easier for the adolescents to express themselves accordingly. Interview guide was selected as the research instrument in order to assist the researcher to be able to find answers to the set research objectives.

3.7. Data Collection Procedures

This qualitative study was conducted in Omuthiya Health District between April and July 2022. Ethical approval was granted from the research committee at the University

of Namibia, Executive Director of the Ministry of Health and Social Services, Oshikoto Regional Health Directorate Office as well as the office of the Senior Medical Officer (SMO) of Omuthiya district then Omuthiya district coordinating committee. Communication was further extended to the selected health facilities in-charges through the office of the Primary Health Care Coordinator. Based on the findings of the pilot study, the in-depth interview guides were refined in preparation of embarking upon the main study. These guide featured barriers, attitudes and adherence initiatives from both the ALHIV and HCWs perspectives.

The researcher conducted 6 interviews for health workers and sent in 10 questionnaires to gather the information.

3.7.1. Pilot study

The research instruments were pilot tested with participants who met the selection criteria to ensure the validity of the findings and to make necessary amendments before embarking upon the main study. Pilot study which is also referred to as 'a dress rehearsal' for the main study (De Vos et al., 2011) attempts to bring possible deficiencies to the fore timely and thus was conducted to assess the feasibility of the study and to test the appropriateness of the interview guides.

It was conducted with three (3) ALHIV and two (2) HCWs who met the eligibility criteria. The sampled population strictly did not take part in the main study. The purpose was to test the research instrument (interview guides) for both participants, analysis methods and to make any other logistical adjustments where necessary. The researcher reviewed the findings and reflected on the sensibleness of the study. The study protocols were then established before embarking upon the main study.

3.8. Data collection methods

In-depth interviews were employed as a data gathering method. This method was chosen as it allowed the researcher to collect data on individual's personal history, perspectives and experiences especially that the research topic is sensitive in nature. The researcher kept in mind the strategies for ensuring trustworthiness of the data gathered by maximizing objectivity at all levels and consequently reducing biases. To ensure trustworthiness, theoretical triangulation; participant validation was adopted to enhance credibility and dependability (Morse, 2015).

Nonetheless, ten (10) in-depth interviews were conducted with ALHIV at the health facilities were they are receiving treatment. Six (6) key informant interviews were also conducted comprising of three (3) Nurses involved in treatment and care as well as three (3) health assistants who are involved with the provision of adherence counselling. Keys informants were mainly involved in order to share their experiences, observations and reflect on their perspectives on ART barriers at their respective health facilities. Informed written consent was obtained first before the arrangement of the in-depth interview. The interview guides for ALHIV were translated in the local language (Oshiwambo) since not all of the participants are fluent with the official language (English). These interviews recordings were transcribed verbatim in Oshiwambo and then translated again in English before data analysis and interpretation. The information shared (recordings) was stored in a confidential manner.

The interview guides enabled the researcher to probe further on the subject area and also to ensure that the participants understood the questions the way they were phrased and coherent answers were provided. Data was collected from the Ecological-system theoretical perspective that was developed during the 1970s by a Russian theorist Urie Bronfenbrenner. The theory is suitable to study the behaviours when multi-sectored systems are involved. Adherence to medications is a complex dynamic behaviour that is influenced by multiple risks factors ranging between individual, family and community/institutional levels (Becker, 2019).

In- depth interviews were used for both participants as they are suitable and useful when detailed information is needed to explore people's thoughts and behaviours with regard to an identified social phenomenon. The interviews were audio recorded whereby it captured participant's experiences. The researcher took note of general observations and additional notes that were incorporated during data analysis.

The following uniformity guided the in-depth interviews:

- Initially, appointments for interviews were scheduled with the assistance of the Nurse in charges as well as Health Assistants of the selected health facilities

- The purpose of the study, criteria for selection, duration of the interviews and audio recordings was discussed with the selected parents and caregivers were it was required. Written informed consent was then obtained from all the 10 ALHIV.

Parents and caregivers were selected because in certain instance where parents were not available due to death, care givers were there to take part in the study.

- Conducting the interviews in a conducive and private consulting room and appreciating participants for taking part in the study.

3.8.1. Data Analysis

According to Kawulich (2004) data analysis is the process of reducing large amount of collected data by making sense of them by organizing data, reducing data through summarizing and categorizing as well as identifying and linking patterns and themes in the data. For the purpose of this study, data was analysed using the thematic data analysis as stipulated by Creswell (2009). Interviews were transcribed before analysis. Common themes and sub-themes were drawn. Socio-demographic data were summarised to give description of the sampled population. Each interview was summarised the same way it was conducted capturing key themes related to ART treatment barriers, adherence promotion initiatives, knowledge and skills as well as attitudes and behaviours of ALHIV and HCWs. Additionally, coding was also done as part of the analysis, differences discussed and resolved. By drawing conclusions, key barriers impeding adherence to treatment were then identified.

Additionally, during data analysis, relevant quotes were grouped together and synthesized (pulling together concepts and statements from the data). Data interpretation was also done to better understand the barriers which discovered factors such as patient, family, and medications related factors. The translation of quotes was also done into English which was cross-checked for accuracy by an expert in language translation. Below is a summary of how data analysis was done as outlined by Creswell (2009):

Step 1: **Organize and prepare data for analysis** – the researcher transcribed interviews, wrote up field notes, sorted and arranged findings into different types depending on the sources. At this stage, the researcher was overwhelmed by the amount of information noted down from interviews, observations and records of feelings as it was too many and narrowing it down was a bit hectic. During this process of documentations, the researcher became aware of the nature of the behavioural patterns that existed within the study population. Also, the data analysis started emerging from this process of taking notes. This was the first formal analytical step.

During this stage, the researcher listed down all records of what has happened during data analysis to ensure that no information is lost in the process or being left out without being analysed.

Step 2: **Read the data** – conceptualizing and categorizing of data was done. Furthermore, the researcher tried to draw meanings and make sense of the data gathered by writing notes and recording general thoughts about the data. The researcher also refined key concepts that usually begins with simple observations and compiled a detailed description of what was observed during data gathering and why it mattered. The analytic insights were then tested with the new observations, problem statement revisited and in the process, the researcher gathered more data during these interactions.

Step 3: **Coding all the data** –as the process of data analysis continued, the researcher is eventually likely to see growing mass of data mostly textual materials that needs to be sorted out into categories (by topic) of individual pieces of data coupled with a retrieval kind of a system (Babbie, 2011). Coding also involved organizing the data by bracketing and writing a word to represent the category and labelling it according to the participant's actual language. This process enabled the researcher to retrieve information at a later stage of analysis as information was coded.

Step 4: **Generate a description and a theme** – During this stage, the researcher used the coding processes to generate descriptions of a setting and categories or themes for analysis that appear as major findings of the study. This was done with the intention to examine relationships between themes and then to explain why the identified themes emerged the way they did.

Step 5: **Representing the description and themes** – although there are limited set standards to evaluate the validity and authenticity of qualitative data, it was during this stage that the researcher was careful with the evidence and the methods from which the data is drawn from in order to avoid fabrication of data. As part of representing the data description and themes, the researcher then conveyed the study findings of the data analysis using the narrative passages whereby chronological events and several themes are discussed.

3.9. Ethical issues

Due to the sensitivity and the nature of the research topic, the process of obtaining the ethical clearance took time as it was forwarded to the University of Namibia Research Ethics Committe (UREC) committee for further scrutiny and thereafter amendments were done accordingly as advised.

The researcher was guided by the following ethical issues and ensured adherence thereof:

Informed consent: The main aim of the study was well explained to both participants and Caregivers to warrant their understanding and consequently make informed decision with regard to their participation in the study. Due to the sensitivity of the topic, parental consent was obtained for all the Adolescents participants.

For ALHIV, their Parental/Caregivers and individual consent was obtained in writing. HCWs informed consent was also obtained in writing. Informed consent from both concerned parties was obtained after they were all informed about the aim of the study. After they agreed to participate, appointments were made and interviews conducted at respective health facilities as per appointments schedules. The researcher emphasised to the parents and Caregivers as well as ALHIV that participation in the study was voluntary and that refusing to take part in the study was not going to affect in any way the health services they are receiving. Interviews were recorded (audio) by the researcher and transcribed verbatim.

Confidentiality: participants' privacy was prioritized. They were made aware that the information obtained will not be used for any other intentions apart from the purpose of the study. The interview recordings were kept confidential that only the researcher had access to it. Privacy protection was also assured. Each interview lasted approximately 20 minutes for HCWs and around 30-40 minutes for ALHIV.

Competency of the researcher: the researcher is well trained to conduct social science research studies and how to handle ethical issues as part of the study. The researcher is well informed on the aspects of psycho-social support services and that the role of the researcher was clear from that of a therapist.

Voluntary participation: although participants were selected as per the sampling method chosen by the researcher, their right to refuse taking part in the study was

granted with no possible consequences on the service delivery. Fortunately, no direct refusal was noted during data gathering.

Deception of participants: genuine information on the purpose of the study was given. No withdrawing of information was done to influence participants to take part in the study whereas they would have otherwise possibly refused to take part in the study. There was an open communication between participants and the researcher whereby participants were able to ask questions related to the study and presenting their issues of concerns before they made their final decision to take part in the study.

3.10. Summary

The chosen research methodology enabled the researcher to conduct the planned study effectively as initially proposed. The research participants consisted of two categories namely health care workers as key informants as well Adolescents aged 15-19 living with HIV and known with poor treatment adherence. Both participants were purposively sampled. Pilot study was conducted to ensure validity and reliability of the findings before embarking upon main study. In-depth interviews were conducted using interview guides to gather data for the study. The anticipated limitations were minimal as the researcher adhered to ethical issues guiding the study. No physical harm was reported during the study. However, on the emotional impact it is a bit challenging to rule it out but nonetheless; participants were informed of the debriefing session and its importance.

CHAPTER 4: PRESENTATION OF RESULTS AND DISCUSSIONS

4. RESEARCH FINDINGS

4.1. Introduction

This chapter entails the analysis and presentation of data gathered for the purpose of this study using a thematic data analysis; which is a nonumerical examinations and interpretations of observations obtained during data gathering process (Babbie and Rubin, 2011). Data interpretations will as well form part of this chapter. During the process of qualitative data analysis, the collected data are organized, reduced through summarization and categorization and also the patterns and themes are identified and linked (Kawulich, 2004). The findings are presented based on the key themes that emerged from in-depth interviews with sampled Adolescents living with HIV, aged 15-19 as well Health care workers who served as key informants for the study. This is

done with intent to draw deeper life meanings of barriers associated with poor treatment adherence amongst the targeted group of Adolescents living with HIV. Additionally, to enable the researcher and the public at large to acquire knowledge from the data gathered. Overall, qualitative data analysis transforms the research data into meaningful narratives and or interpretations. According to the National guideline on Adolescents living with HIV (2019), it indicates that the majority of the ALHIV in Namibia includes the ones who were born with HIV. This is being supported by the study findings as all of the participants (Adolescents living with HIV) indicated that they have been on treatment since their childhood. This gives an impression that most of them have been vertical infected (mother to child).

Furthermore, the findings indicate that majority are orphans (6/10) and cared for by Grandparents and other relatives such as Aunts. For instance participant A pointed out that; *I do not know my biological parents; I was told they died when i was still a small child. I now reside with my Paternal Uncle.* Participant B had this to say: '*My Father died, I do not know where my Mother is staying, and I stay with my Grandmother'*. Sharing the same experience is Participant D who narrated that: *'the situation got challenging when I lost my Father last year (2021), I now stay with my Grandmother'*. This can indicate that most of the Adolescents living with HIV are battling with unresolved grief of some of their biological parents and that most of them did not get a chance to receive psycho-social support services. This can also affect their adherence to treatment.

Largely, most of the participants were able to express themselves freely and openly in their vernacular language, Oshiwambo which was later translated by the researcher in English. However, some narrated their experiences briefly, whilst for others it was detailed but all in one, they were able to answer the research questions as set per objective.

4.2. SECTION A: IN-DEPTH INTERVIEWS WITH ADOLESCENTS LIVING WITH HIV AGED 15-19

4.2.1. Demographic Information of Participants

The demographic information is presented in a table below.

Table 2: Respondent Demographic Information

Age of participants	Frequency	Percentage (%)
15 -16	1	10
16 – 17	4	40
17 -18	1	10
18-19	4	40
Total	**10**	**100**

Majority ALHIV who took part in the study are between the ages of 16-17 and 18-19 years old.

4.2.2. Section A: Emerging Themes & Sub-Themes (Topics/Subjects)

Table 3: Emerging themes and sub-themes

Themes	Sub-themes
Theme 1: common barriers contributing to poor treatment adherence among adolescents	• Forgetfulness • Poor parental support • Lack of food and income at home • Lack of interest to take medications • Stigma and discrimination • Medication side effects • Discomfort to take medications in the presence of others (intimate partners, peers) • School/education related barriers • Stress related factors
Theme 2: Adherence promotion initiatives (to identify available support system for ALHIV)	• Provision of psycho-social support services • Teen club/peer support

	• Provision of health education and Adolescents health friendly services • Parental involvement • Community engagement
Theme 3: ALHIV attitudes and behaviors towards antiretroviral treatment adherence	• Fear of stigma • Lack of knowledge • Burden of adherence • False sense of good health
Theme 4: The level understanding on the importance of taking antiretroviral treatment	• Health consciousness • Effects of non-adherence

4.2.3. Theme 1: Common barriers contributing to poor treatment adherence among adolescents

Maskew et al., (2016) emphasized that it is paramount for health care facilities to understand barriers associated with poor treatment adherence as a matter of urgency as this will result in the identification of specific factors that will then enable HIV programs to target result oriented interventions. Additionally, the National guideline for Adolescents living with HIV (2019) tinted that the concerned Adolescents living HIV are faced with diverse challenges associated with their transitional stage as well as treatment adherence challenges. The Adolescent guideline (2019) then calls for special considerations of psycho-social aspects to be integrated as part of treatment to enable ALHIV to thrive in many aspects of their lives including the promotion of adherence to treatment. The following are some of the barriers affecting the treatment adherence of Adolescents living with HIV (ALHIV) in Namibia (Adolescent guideline, 2019):

- The loss (death) of parent (s)/guardian(s) negatively impacting the support system
- Treatment fatigue especially amongst adolescents who may be taking treatment for a longer period of time. This may also result in poor interest to continue taking treatment.
- Pill burden especially in instances whereby a dose is more than one tablet.
- Medication side effects such as upset abdominal and fatigue.

- Issues surrounding non-disclosure in an effort to avoid stigma and discrimination.

It is evident from this study that all the above mentioned barriers also came out as findings with the majority raising concern over poor parental support system and the issues surrounding non-disclosure in an effort to avoid stigma and discrimination. The findings correlate with the study conducted by Shivute (2019) on the same topic at Katutura hospital which identified barriers to poor adherence such as forgetfulness, lack of transport money/food and many others which also emerged as a common barrier amongst the majority of this study. Additionally, Shalihu (2011) study on the same topic but with inmates at Windhoek Central Prison identified barriers such lack of watches/clocks and stigma which also emerged from this study.

This implies that the phenomenon of poor treatment adherence due to various barriers is as well widely spread amongst adolescents living with HIV in Omuthiya District. Moreover, it is a sad reality to note that there are multiple diverse social factors involved as barriers impeding adherence ranging from patient related factors to structural factors such as the unavailability of transport to and from the health facilities.

The study clearly indicates that much more still need to be done in order to achieve optimal adherence amongst Adolescents specifically the ones. Interventions towards resolving personal/patient related and family barriers emerged as critical areas that need urgent implementation. The key inquiry under the theme was to identify barrier leading to poor treatment adherence. The following sub-themes were identified during in-depth interviews with Adolescents living with HIV identified with poor treatment adherence.

4.2.3.1. Sub-theme 1: Forgetfulness

85% of participants (n=17), reported that forgetfulness is one of the common patient related barrier leading to poor treatment adherence as they find themselves skipping to take their medications simply because they forgot.

Reasons for forgetfulness cited from the study are as follows: *'Most of the time I find myself forgetting to take my medications that I only remembers midnight but then I also do not wake up to go drink my medications but I only wait to take my medications again the following day', - Participant D.*

'Most of the time I forget to take my medications because I am staying alone, there is no one that reminds me when I forget and also when I drink alcohol' - Participant H.

'Most of the time I forget to take my medications, I remember to take my medications after the time for taking medications has lapsed. This results in me skipping medications in such instances' - Participant I'

'In days when I wake up late for school, I usually forget to take my medications and only remember about them on my way to school' – Participant B.

Forgetfulness is very common amongst adolescents as indicated per their reasoning's. It also came out that they do not have mechanisms in place as reminders. One can also tend to conclude that Caregivers are failing to fulfill their responsibility of reminding and monitoring Adolescents intake of medications at home as a control measure to ensure adherence as stated by Khodel and Sochanny (2011) that Caregivers are responsible for reminding and assisting adolescents to take their treatment regularly.

4.2.3.2. Sub-theme 3: Poor parental support

Biadgilign and Reda (2012) reported that children living with HIV can be vulnerable as their treatment adherence largely depends on the support of their Caregivers. Galea et al., study (2018) revealed that the lack of information about HIV on the side of the Caregiver was one of the factor associated with poor treatment adherence amongst adolescents as some of the Caregivers did not even understand the concept of adherence itself and the importance of adhering to treatment, which means it will be difficult for them to render the necessary support as Caregivers simply due to the lack of understanding. Another family related barrier reported by Ikeakanam (2020) is the lack of parental involvement; that some of the Caregivers of ALHIV only learned and realized that their ALHIV were not taking treatment accordingly only upon being informed by the Health care workers. Similar experiences have also been shared by the Adolescents during this specific study.

Participant A reported that he has parental care at home only that he is being disturbed by the shouting with bad words by his Grandmother (*'there is parental care at home. The only problem is the shouting with bad words by my Grandmother').* Participant B also reported to have good parental care at home; '*My Grandmother wakes me up to take my medications because she is the one who is keeping them'.*

Other Participants such as Participant E had a different sentiment. '*The parental care at home is very poor. I stay with my Father only, the two of us and most of the time I find myself alone at home as my Father goes to shebeen. Sometimes no one even notices that I am not at home'.* Participant G had this to say on poor parental care at home; '*the situation at home is not good (teary). We do not have parental care at home. There*

is no one who corrects me neither give me advice'. Participant H also reported poor parental care at home. *'I stay home alone with no parental supervision. When I forget to take my medications, no one reminds me'*.

These participants complained about poor parental care at home, that no one really care to ensure that they are taking their medications or not and also that when Caregivers are being requested by the Nurses to discuss the issue of poor treatment adherence, they fail to show up some giving reasons that they are busy at home or they have no means to reach the health facilities. Participant C felt the poor parental care at home is attributed to her Grandmother's level of literacy (*'I am also of the opinion that my Grandmother's level of understanding of my medications is very low/poor')*.

Another concern expressed at home is that majority of the participants reported that most of the time they do not have access to accessories such as a watch/clock or a cell-phone to check the time before taking their medications which result in them not always taking medications on their recommended time. This situation then forces them to rely on the sun in guessing the time. Participants had this to say; *'When my Grandmother is not at home, I check the time for taking medications with the sun'- Participant B. 'Mostly, I check for the timing with the sun set because I do not have a cell-phone neither a watch, sometimes I find myself taking medications on different time slots when my father is not around at home because he is the only one with the cell-phone where I can check the time' – Participant E. 'I have no watch neither a cell-phone to check my time for taking medications. Sometimes I confirm the timing with my neighbors but mostly I just check with the sunset' – Participant H.* However, Participant C, D and F both indicated that they are in position of cell-phones whereby they check and confirm the time for taking medications.

It is clear from the findings that poor parental care is a concern for many. They are of the opinion that they are not getting the adequate support from them. Also the majority of them are challenged with not having instrument/ reminders to confirm their time for taking their medications. All these factors surrounding the care at home are then the common reason (s) for some to skip taking their medications.

4.2.3.3. Sub-theme 4: Lack of food and income at home (socio-economic factors)

Most of the patients who fail to collect their ARVs treatment on a given follow-up date often are faced with financial constraints, distance barriers and lack of transport to and from health facilities (Biadgilign and Reda, 2012). In agreement with this sentiment, is Van Wyk and Davids study (2019) which established that a lack of financial support

can negatively affect ART adherence as sometimes adolescents are not in position to provide for their transport money to go to the clinic for their follow-ups.

Majority of the residents within Omuthiya district reside in deep remote areas and depends on subsistence farming for survival. Findings indicates that it is such a sad reality that sometimes people find themselves taking medications on an empty stomach simply because there is no food at home. Additionally, some find themselves with no money to afford transportation fares to and from respective health facilities. Some participants had this to say. '*With regard to food, it is also a major barrier. This year our harvest was very poor, we did not get enough Mahangu grains as usual as it was also eaten up by the livestock. Sometimes there is no transport money to come and collect my medications from the clinic'- Participant G.*

'Sometimes I find myself in situations whereby my medications are finished but there is no transport money to go collect my medications. As a result, I then stay like that without taking my medications until I get assistance with transport money' – Participant G.

'Sometimes I fail to come collect my medications at the clinic because I find myself with no transport money as my Grandmother who is my Caregiver is not eligible for old age pension grant yet. Most of the time when I get money is only when I borrow for assistance from good Samaritans. Also there are times when there is nothing that I can eat before taking medications; as a result, I often skip taking my medications as it worsens the side effects. In most cases during morning hours, we usually do not have anything to eat at home as we only eat lunch and dinner' – Participant C.

The situation of socio-economic difficulties characterized by the lack of food and unavailability of transport is one of the common social problem affecting the district at large and not only for the Adolescents living with HIV. This means that, some of these issues are deep rooted in social structures for example having the poor and rich people within the same community.

4.2.3.4. Sub Theme 5: Lack of interest to take medications

Ikeakanam (2020) study found that some ALHIV simply refuse to take their treatment because they fail to understand the need to take treatment when they are not sick. This argument was also supported by Kallem, Renner, Bhebremichen and Paintsil (2010) as cited by Ikeakanam (2020) who highlighted that when ALHIV takes their treatment

well, they become asymptomatic and often they do not understand the importance of visiting the health facilities as scheduled for routine check-ups as well as continuous taking of medications. This is reported to result in some ALHIV basically ceasing to take treatment as they are not sick and some because disclosure was not done properly.

As the findings of this study highlights that all participants have been on treatment since their childhood, some indicated that they experience moments whereby there is no interest to continue taking medications due to various factors. This is what some had to say during in-depth interviews. '*I have realized that as I am growing up my social challenges are increasing resulting in me losing interest in continuing with medications sometimes to the extent that even if I know it is time to take my medications, I just skip to take my medications due to stress'- Participant F.*

'Sometimes I lose interest to take my medications resulting in me asking my Grandmother until when am I going to take the same medications' – Participant C.

'The interest to take medications often diminishes simply because I feel tired of taking medications, - Participant B.

This is telling us that, interventions directed towards keeping the adolescents motivated and with interests towards continuing to take their medications is needed.

4.2.3.5. Sub-theme 6: Stigma and discrimination

HIV stigma is defined as the process of devaluation for people living with HIV whilst discrimination involves unfair and unjust treatment of an individual based on his/her HIV status (UNAID, 2016). Stigma and discrimination involves the fear of revealing ones HIV status to intimate partner especially among adolescents (Biadgilign and Reda, 2012). This was also noted during this study that there are ALHIV whose intimate partner still does not know that they are taking medications for HIV and it is mainly due to fear of stigma and discrimination.

Additionally, it was revealed by Van Wyk and Davids (2019) that some adolescents fear to go for their scheduled visit at the health facility with fear that, the flow of patients at the clinic might lead to possibilities of accidental disclosures as the waiting area clearly expose them that they came to collect their ART treatment. Also, The National Adolescent guideline (2019) approximate that, some Adolescents might be

possessed with fear of who they are going to meet at the health facility resulting in some opting to rather stay away from collecting their medications as they are not emotionally ready to be seen by certain people.

From experience, HIV is still one of a highly publically stigmatized disease in Namibia. These includes unfavorably attitudes such as name-calling and beliefs directed to people living with HIV. However, this thought is supported by Bauleth et al., study (2016) who reported that people on ARVs are still being stigmatized and discriminated based on their HIV status and thus call for HIV programs to lay a special emphasis on reducing stigma and discrimination against people living with HIV.

Stigma and discrimination can happen at home and even at public places such as in the community, health facility or even at school. Participants of the study also shared their experience on stigma and discrimination of which they felt is one of the barriers to treatment adherence as they are made to feel bad simply because they are living with HIV.

This is what participants shared with regard to stigma and discrimination. '*My Peers at home treats me badly simply because I am the only one taking the medications. They even go as far as eating the food that is meant for me to eat before I take my medications'- Participant B.*

'*There is a certain Lady at our village who always talks about us around the community; that people from our house are taking medications for HIV simply because she got to know that my Grandmother is also on treatment. This I view it as discrimination and it makes me feel bad that some community members are stigmatizing us'- Participant C.*

'Most of the time I feel bad because my mother always shouts at me with bad words saying that among all her children, I am the only one who is HIV positive. This type of behavior makes me angry and resistant to take my medications because I also do not know how I got infected with HIV' – Participant E.

Although some people might think that stigma and discrimination directed towards people living with HIV is now an issue of the past, this study unveiled that stigma and discrimination against people living with HIV is still happening even within household

where they live and even community at large. It also came to light that some ART sites that is only providing such specific services is also contributing to stigma because everyone who is seen at that specific clinic or site, people automatically assume that they came for the ART services. Some participants indicated that they do not feel comfortable to be at ART clinic. In this regard, the clinic is perceived as an uncomfortable place since the service is being stigmatized (*'everyone knows that is an ART clinic, whereby people infected with HIV receives their treatment' claims Participant D*), thus, some participants felt it is better they stay away at home instead of coming to the clinic to publicly disclose that they are on ART treatment.

4.2.3.6. Sub-theme 7: Medication side effects

Medications offer a wide variety of benefits including the suppression of the virus in the body. However, the commercial characteristics of medications such as the tastiness, the size of the pill, pill burden, availability of liquid formulation, interference of medications with social life and adverse effects such as nausea and vomiting can have a negative impact on adherence especially amongst adolescents (Biadgilign & Reda, 2012). Additionally, some people opt to skip taking their medications merely because of the side effects/ negative experiences with the medications which in the end then serve as a barrier to effective treatment adherence.

For this specific study, some participants affirmed that: '*Sometimes the medications make me nausea but not vomiting especially after taking them without eating something, therefore I sometimes skip to take my medications to avoid the side effects'.– Participant I, Participant C and Participant D.* Also, adding on the side effects is participant A and B who indicated that medications make them dizzy and weak and as a coping mechanism, they then skip taking their medications sometimes. On the other hand, Participant E, F, G and H both reported that they did not experience medication side effects yet.

With regard to the medication side effects, this is telling us that side effects differ from person to person. Overall, it should not be the reason for one to stop taking the medications but rather one need to report the complaints in order to be assessed further because medications offer a wide range of benefits although sometimes it comes with side effects.

4.2.3.7. Sub-theme 8: Discomfort to take medications in the presence of others (intimate partners, peers)

It is a known fact that some adolescents keep their HIV status as a secret with fear that they will be treated differently by others especially their peers the moment they discover that they are HIV positive and on treatment (Madiba and Mokgatle, 2016). In other words, adolescents maintain secrecy over their status in order to be accepted by their peers and also to protect themselves from stigma and isolation. This literature is in line with this study finding as it came out that there is still quite a large number of Adolescents who are not comfortable to take their medications in the presence of the strangers. Some have fear of being stigmatized and discriminated and others have to with the level of trust.

Furthermore, Madiba and Mokgatle (2016) discovered that some adolescents find it difficult to disclose their HIV status to their intimate partners (which was also noted during this study) for various reasons; although it is necessary as part of HIV transmission prevention (index testing). Also, some Adolescents may decide to keep their status as a secret as a results of directives from their caregivers who may hold negative attitudes towards disclosure and also with fear of being exposed as their biological parents/guardians.

During in-depth interviews, participants had this to share. '*I am not free to disclose to my Boyfriends that I am taking medications for HIV and it is the reason why most of the time I hide my medications from them. Also, most of the time when I go to collect my medications from the clinic, I usually hide them and my health passport in the forest and hide' - Participant J.*

Additionally, '*I am not free at all. I do not have a trustworthy person including my intimate partner who does not even know that I am taking medications for HIV. I have trust issues because of the situation at home that made me not to have reliable people around me – Participant G. 'I am not free; I always do not want people to know that I am taking medications for HIV because I have fear of how they will react towards me although I do not specifically know what might happen (fear of the unknown)' – Participant -*

4.2.3.8. Sub-theme 8: School/education related barriers

According to Van Wyk and Davids (2019) on the day of the appointment at the clinic, some adolescents might find themselves being absent from school or missing most of their lessons as they spend more hours at the hospital before they are given their treatment. Although 50% are currently not attending school mainly because they drop out, the school going participants had this to say with regard to school/education related barriers which include being occupied with schoolwork as well as trust issues with learners and Teachers. '*Sometimes I find myself writing a test at school on the day I am scheduled for my follow-up. This situation then forces me to write the test first as my Teachers do not allow me to go before I write which sometimes when I get to the hiking point, there is no transport going the direction of the clinic and sometimes I just go back home even when my medications are finished' – Participant D.*

'*Sometimes at school, my classmates refused to be part of the group work activities with me. This makes me wonder if perhaps their refusal is because they know that I am taking medications for HIV' – Participant J.*

'The only challenge is only when asking for permission to go to the clinic, sometimes you do not want the Teacher and other learners to know that I am going to collect my medications at the hospital' – Participant F.

4.2.3.9. Sub-theme 9: Stress related factors

According to an evaluation study on the psycho-social adjustment and self-esteem of prenatally HIV infected adolescents by Orawan et al., (2018) it discovered that these adolescents were at high risk of developing low self-esteem and greater psycho-social problems as compared to their peers who are HIV negative. This is in line with the study findings as it came out that most of them narrated that they are going through stressful situations associated with them taking medications but not applicable to their peers who are not taking the same medications.

For instance, this is what some participants had to say. '*Mostly I have noted that the reason behind my poor adherence is stress when I think of my life in general. I have realized that as I am growing up my social challenges are increasing and this is not happening with my Peers that are not taking the medications. Sometimes I have the self-confidence, but whenever I take my medications and think of what my friends used to*

talk about with regard to people living with HIV, I just lose courage and I no longer take my medications'- Participant F.

'At times I am faced with mood swings and stress to such an extent that even if someone at home is calling me, I am just angry as if someone did something wrong to me, I then fails to take my medication whenever I am in this mood' – Participant J

'Sometimes I am stressed by the shouting of my Grandmother. This makes me feel bad and opt out on my medications sometimes' Participant A.

4.2.3.10. Sub theme 10: Facility related barriers

These include negative staff attitudes; lack of knowledge and skills as well as Adolescent's friendly health services. Van Wyk and Davids (2019) added that long waiting hours at the health facility without being attended was identified as one of the factors deterring adherence. The negative judgments and verbal abuse by health care workers when adolescents miss their follow-ups or stopped taking their medications may also discourage them to continue adhering to their treatment (Galea, 2018). For the purpose of this study, majority could not identify barriers that are facility related. For example; *there is no concern, Health Care Workers are attending to us well – Participant B.*

No, I did not come across any challenge with regard to the service provision at the clinic. This means that our Health Care Workers are very friendly and are well equipped with knowledge and skills. They are also giving us age appropriate type of services – Participant C.

'Everything at the Clinic is fine, I cannot complain' – Participant H.

Most of the respondents revealed that they have an outstanding experiences interacting with the HCWs when they come to collect their medications at the clinic. This they said it is in terms of them being at ease in asking treatment related questions; that they are free to express their concerns and solicit for support. Participants also highlighted that although they are challenged with diverse social challenges impeding their treatment adherence, they appreciate the supportive attitude of HCW specifically the Health Assistants who continuously provide adherence counseling and try to find ways to help them especially with the referrals to the social workers for further social interventions.

However, Participant A and E differed from others as he raised a complaint that '*When the Clinic is full, we stay for too long in the queue waiting to be attended. Sometimes, Health Care Workers are just too slow'- Participant A.*

'No there are no major issues of concern only that sometimes I wait for too long in the queues before I get treatment when I find the clinic full that day' – Participant E.

In conclusion with regard to treatment barrier, most of the participants were found to be living in vulnerable circumstances. This indicates that the poor treatment adherence is not necessarily by choice but rather this behaviour is being influenced by diverse social factors or rather the systems they interact with as clearly stipulated in the Ecological System theory, which is a conceptual framework guiding this study.

4.2.3.11. Theme 2: Adherence promotion initiatives (to identify available support system for ALHIV)

According to the Ministry of Health and Social Services on Adolescents services (2019) it made a recommendation for multi-sectored interventions to ensure that this future generation of ALHIV has access to health care services. This is in line with this study's objectives; that of overseeing how best Adolescents living with HIV can be supported to resolve barriers impeding their treatment adherence. The Adolescent guideline (2019) stresses that treatment adherence counseling should focus on identifying reasons of poor treatment adherence in order to render appropriate support rather than reprehension. This is urging the health care workers and the parents to be supportive towards the adolescents when they find themselves in situations whereby they are unable to adhere fully.

As part of the study, participants acknowledged that they face diverse barriers that obstruct their treatment adherence. Therefore, they also shared their recommendations on how best they can be supported in order to improve adherence to treatment, taking into account their unique needs and social circumstances. Their experience also goes well with the 'Ubuntu' perspectives of '*nothing for us, without us'*. According to Gentze (2018), it was recommended that studies are needed to identify the types, sources of support and also to assess whether all ALHIV have access to social support.

Below are some of the multi-sectored adherence promotion interventions:

4.2.4. Provision of psycho-social support services

Psycho-social support services are defined as interpersonal strategies and techniques that are targeting an individual's biological, behavioral, cognitive, social and emotional factors with an overall goal to promote their health and social functioning as well as mental well-being (Konji et al., 2020). According to Gifford (2003), Adolescents living with HIV, who are fully aware of their status have additional emotional needs and thus need to be provided with psycho-social support services. This means that they need appropriate care and support particularly at home to enable them to come to terms with HIV and live positively with it, manage stigma and discrimination and remain focused on their future without being distracted by their circumstances. Okonji et al., (2020) recommends for comprehensive psycho-social support services interventions in addition to the standardized ART services to enable ALHIV to cope and adapt with the intense stigma and discrimination associated with HIV infection.

In light of this, participants had this to say on the provision of psycho-social support services. '*I personally need continuous emotional support when I come to collect my medications. Also, for us coming from poor socio-economic backgrounds and having challenges with food, it will be best if we are to be given food like what Project Hope/Catholic Aids Action was doing when we use to get cooking oil and Maize meal. It really helped us a lot'- Participant C.* Also supporting the provision of food is participant B *'We should be served with refreshments during our teen club meetings'.*

Further on the provision of psycho-social support services is participant F who suggested that *'I need someone who is not part of my family but at least someone from the hospital like the way I am talking with you now whereby I will be going to seek help and for me to narrate my issues of concern and in return this person will encourage me and instill me with hope on how to go about addressing my social challenges. I need a trustworthy person at the clinic like the way we have Guardian Teachers at school'.* Moreover, supporting the sentiment of emotional support to be made available at the clinic is Participant G who is of the opinion that '*I Participant J also felt 'I need continuous home visits for psycho-social support services to enable me to continue adhering to my medications'.*

4.2.5. Teen clubs/peer support

Peer support entails connecting ALHIV with each other through the provision of platforms for coping with shared challenges and offering support to one another in the process (UNICEF, 2021). The participation of ALHIV in peer group was found to have a positive impact on retention to care, improved adherence as well as viral load suppression.

Participant A wishes *'to be meeting regularly with my peers who are also taking the same medications, I feel good when I mingle with others during teen meetings as we share common challenges'.* The idea was also supported by Participant B that*; 'we, Adolescents to still be attended on our separate day not with adults, namely Fridays to enable us to engage freely with our peers.* Overall participants expressed that associating with others (peers) with similar characteristics (also on treatment) boost their self-confidence as they aloud that it gives them a sense of belongings; that they are not the only ones battling with HIV. This also goes well with an African proverb that state that '*a problem shared is a problem solved*'.

4.2.6. Provision of health education and Adolescents health friendly services

Adolescents friendly services entails rendering services to adolescents in a way that is responding to their unique needs and granting them an opportunity to express them freely with regard to the treatment they are receiving (WHO, 2019); without being judgmental of who they associate with. Also, it involves the meaningful engagements of adolescents in the planning, monitoring and evaluation of HIV programs and ensuring decision making with regard to their own care. This means that, the services should be acceptable, accessible, equitable, appropriate and effective 'Since majority indicated that HIV is a sensitive matter, they made a recommendation for the HCWs to always ensure a safe environment that promotes confidentiality of their discussions and treatment at all times to protect them.

Participant D prefers that health education should be done on one on one rather than in a group setting '*I am suggesting that continuous health education should be given always after we are given our medications. I will also prefer that this is done on a one to one instead of a group discussion as not our personal issues are worth to be discussed in a group setting and also individual circumstances will demand for different interventions'.* Other participant recommends that:

'*We need to be attended fast, especially us that are coming from far to enable us to go back home early. I don't like it when I wait for too long at the clinic. We need to be reminded continuously during health education to take our medications on time'- Participant A and Participant J.*

'I am suggesting that continuous health education should be given always after we are given our medications and Health care workers to assist us in a friendly manner without judging us and anyone else who is able to assist me with my needs'- Participant D and Participant 1.

4.2.7. Parental involvement

It is clear from the participants' narrative that majority raised concerns with regard to parental involvement in the promotion of adherence. The following recommendations surfaced from the in-depth interview:

'It will be best if my Grandmother is informed of how my treatment is going and on how best she can support me at home'- Participant C and Participant D.

I am wishing for the good parental care to be available at home. This will give us courage to continue adhering to treatment as we face many challenges' - Participant a, B, G and J.

'I want my Father to be the one to keep my medications and ensure that I take my medications every day when he gives me'- Participant E.

'I need a watch or a phone to be checking the time for taking my medications. My Aunt to ensure that I always have food at home'- Participant H.

'Caregivers need to remind us to take medications, just in case we forget sometimes'- Participant I.

'Parental involvement is needed. Parents should tell the children as they are growing up the truth for them to understand the situation they find themselves in especially the ones that got infected from birth. Some of the children are cared for by Elderly whereby their understanding is very poor. Parents should talk to their children continuously at their level. This will enable children to also remember what they are being taught at school about HIV. Parents should talk to their children in a friendly

manner and they should refrain from making or scaring us with statements like if you are not taking your treatment, you will die- Participant F.

Participants are of the opinion that if the above-mentioned recommendations are put to task at home, it will help them to fully adhere to their treatment.

4.2.8. Community engagement

This involves taking the services closer to where ALHIV lives (UNICEF, 2021). This includes but not limited to community based treatment supporters, community adherence clubs, school based initiatives etc. This too, once provided consistently over time has been found to yield fruitful results with regard to treatment adherence.

Although majority of participants could not identify interventions to promote adherence at community level. Participant D suggest that '*we need to select people from the community that we see that they are able to assist us since not everyone from the community is able to assist accordingly and as per our unique circumstances. It is then our responsibility to choose those that we trust'*. Participant F added that *'Nurses need to do more awareness raisings meetings with all children in the community and not only for those living with HIV but rather health education in general about HIV.*

In conclusion, these are the adherence promotion initiatives identified from the study from the perspective Adolescents. This means that these are workable solutions to the phenomenon of poor adherence because it is how best adolescents feel they should be supported in the said ways to enable them to fully adhere to treatment.

4.2.9. Theme 3: ALHIV attitudes and behaviors towards antiretroviral treatment adherence (Sub theme: reluctance to take medications)

HIV infected adolescents are confronted with emotional and behavioral problems such as anxiety and depression which in turn interferes with their self-esteem and can negatively affect full compliance with their treatment (Orawan et al, 2018). An attitude is one of the factors that can also influence one's adherence behavior. This is what participants shared on their personal attitudes and that of others (peers). '*Most of us do not want to take medications. There is just no interest to take medications. Some feel the medications are not needed because they are not sick. Some feel shy because they are taking medications for HIV' – Participant A.*

‘Many of my peers do not want to take their medications because they feel that the medication is not helping, it is just a waste of their time. They see that they are doing well even without taking the medications’- Participant B.

‘*Most of my peers do not take the treatment serious when health education is given. Some feels irritated when they are being seen for adherence counseling’ – Participant F.*

Additionally, participants shared their personal experiences of how it feels to take medications daily for life. Some feels it is a burden. ‘*I feel emotionally overwhelmed because I thought a person who is HIV positive supposed to take medications for a certain time frame for example three months then they will be cleared off with HIV’ – Participant J. ‘It is tiring to take medications sometimes’ – Participant A. ‘I sometimes wonder that truly I will be taking medications for the rest of my life’ – participant F.*

However, other participant shared a different perspective indicating that they have come to terms with taking medications every day for life. ‘*I do not have a problem with it because medications are what is keeping me alive even though I forget sometimes’ – Participant I. ‘I do not have any problem or feel burdened’- Participant H. ‘I do not really have a problem with it, I usually feel good because it is the medications that are keeping me alive’ – Participant G.*

4.2.10. Theme 4: The level understanding on the importance of taking antiretroviral treatment

As indicated in the adherence counseling booklet (2012) titled ‘*why I take medications’,* it is clearly explained that the medications that is taken helps people to have many strong ‘body soldiers’ which is defined as body parts of the body that help keep individuals from getting sick and when they happen to get sick, the ‘body soldiers’ speed up the recovery. Against this background, majority of participants (8/10= 80%) indicated that they fully understand the importance of taking antiretroviral treatment as quoted below:

‘Yes it is important and needed to drink medications so suppress the virus in the body and remain healthy/ living positively with HIV’ - Participant D.

'Yes it is needed and it is important to take medications even if a person is not sick because you never know when one will get sick. Again, anyone can get sick any day'- Participant F.

'It is important and necessary to take the medications as prescribed in order to suppress the virus in the body. Even when one is not sick, the medications still need to be taken for us to remain healthy and be able to partake in developmental activities'- Participant G.

These findings are in agreement with the study conducted by Mazimbuko (2008) with adult ART patients at Oshakati hospital whereby the majority of the participants disagreed that the lack of information was associated with poor treatment adherence. In contrast, one participant (4/10=40%) lacked satisfactory knowledge on the importance of taking medications. Participant reported that sometimes they simply do not choose not to take their treatment accordingly but described the defaulting behavior as being driven by inadequate sharing of information (health education) in a friendly and conducive manner.

This is what the participant had to say. '*I only know that it is important but i am not well informed as to why. Also, I want to ask; if I continue to take my medications every day, is there any chance whereby HIV will no longer be in my body that even if I get tested for HIV, I will be HIV negative?' – Participant C.*

Largely, this participant acknowledged how knowledge is essential when it comes to treatment adherence adding that a positive interaction during information sharing between HCWs and us as patients promote and strengthen an open relationship whereby we are free to express our concerns and be guided accordingly. This is then a wakeup call for all health care workers involved in HIV management to value the importance of information dissemination when rendering adolescents health friendly services.

Moreover, it is clear from the participant's reasoning that those that understand the importance of taking medications are well informed on the aftermath of poor adherence and vice versa. On the other hand, it is clear that the level of understanding is not necessarily the major barrier as the majority of participant poses knowledge on

why they are taking medications. The resistant behavior to take medications is rather embedded in other psycho-social aspects.

4.3. Section B: In-Depth Interviews with Health Care Workers as Key Informants

4.3.1. Demographic Information of Participants (Health Care Workers)

Table 4: Demographic information for Health workers

Age of respondents	Frequency	Percentage (%)
20 – 30	0	0
30 – 40	2	33
40 – 50	4	67
Total	**6**	**100**

The respondent's gender composition is made up of four (4) female and two (2) males with qualifications in HIV management counselling and Nursing. The minimum years of experience in ART services are four (4) years and the maximum is over twenty (20) years. This means participants are well informed on Adolescents issues as they have worked within this dimension for years.

4.3.2. Emerging Themes and Sub-Themes

Table 5: Emerging Themes and Sub-themes

Themes	Sub-themes
Theme 1: Barriers to treatment adherence	• poor parental care (monitoring and supervision • Forgetfulness • Being playful • Reactions after one's HIV status disclosure • Peer pressure • Stigma and discrimination • Socio-economic factors • Medications side effects • Facility related barriers

	• Stress • School factors • Lack of knowledge and skills
Theme 2: Adherence Promotion Initiatives	• Peer support • Parental involvement • Continuous health education
Theme 3: Attitudes And Behaviours Of ALHIV Towards Treatment Adherence	• Poor commitment • Taking treatment lightly
Theme 4: Level Of Understanding On The Importance Of Taking Medications	• Social circumstances influences
Theme 5: Health care workers perspective on barriers	• Poor parental monitoring and supervision • Self-esteem issues

Participants shared their experience from the perspective of being experts. The aim was to enhance the understanding of barriers affecting treatment adherence of the adolescents living with HIV from their personal point of view as well as from the experts who attend to them frequently when they come for their follow-ups and who are well informed of their circumstances. It is the responsibility of health care workers to provide comprehensive care; not only to provide medications but to also render the necessary emotional support (National Adolescent guideline, 2019). Below are themes and sub-themes that emerged from in-depth interviews.

4.3.3. Theme 1: Barriers to treatment adherence

According to Daniella (2008) it discovered that in many instances of adherence counseling, the focus is mainly on emphasizing the implications of non-adherence rather than on exploring the drivers of non-adherence. This means that, the possibility of leaving the problem unattended is very high as much is done to address the symptoms without due considerations of the root cause of the problem. poor adherence is a common reason behind treatment failure as it can lead to drug resistant HIV that is caused by failure to achieve maximum viral suppression and therefore it is paramount that the identification of clients at risk of achieving suboptimal adherence

should be identified to enable health care workers to render tailored care through targeted interventions (Heestenmans et.al., 2016).

The National Adolescents guideline (2019) cautioned that special considerations should be given to Adolescents living in rural areas as they are more vulnerable to various barriers than their counterparts in town. The guideline further advice that it is crucial that these adolescents referred to are screened and treated in a holistic approach including assessing their social circumstances, especially their mental health issues.

Health care workers shared that Adolescent living with HIV are challenged with diverse barriers mainly ranging from personal barriers to that of family related barriers. It was discovered that although ALHIV are confronted with these issues, it is then worsened by the lack of parental support at home, says HCW 3. Tapping from the sharing of experience of health care workers, it came out that barriers affecting treatment adherence are interrelated from all the health facilities.

This can mean that ALHIV are challenged with common barriers and thus the findings of this study are significant in improving adherence promotion initiatives in other health facilities as well although there might be slight differences as HCW 6 indicated that '*barriers to treatment differ from child to child*'. Additionally, the success rate of treatment is attributed to the level of parental support. For example, HCW 3 had this to say '*You know what, the success of any child on ART treatment depends on the parental involvement. They are the ones who need to massively motivate the child to fully adhere to treatment. So, I would say most of the challenges lie with poor parental care'*.

It has also come to the attention of the HCWs that sometimes ALHIV are not being honesty with the HCWs on treatment adherence. HCW 1 gave an example that '*when we try to find out if they are taking treatment, some often lie that they are taking their medications accordingly when in reality they are not'*. Another sad reality shared is that '*some of them has been taking medications without knowing what for exactly and when they get to know, they become very angry questioning how they got infected with HIV' – HCW 3.*

4.3.4. Sub-theme 1: poor parental care (monitoring and supervision)

Caregivers play a vital role in the promotion of treatment adherence amongst adolescents living with HIV (Khodel and Sochanny, 2011). It is believed that caregivers are responsible for reminding and assisting adolescents to take their treatment frequently and to ensure that they go back to the health facilities for refill and monitoring by accompanying them especially the younger adolescents. Low adherence amongst adolescents at times can be a marker of serious family dysfunction including parental mental health problems, substance abuse, violence, child abuse and neglect as well as many others. (Daniella et al, 2008).

This is the major barrier attributed to poor treatment adherence amongst adolescents living with HIV from the perspectives of health care workers. This sentiment was supported by what participant had to say. '*Most of the Caregivers often just tell ALHIV to go and take their medications without them monitoring if the medications were indeed taken or not*'*- HCW 1.* In other words, Caregivers involvement and support is very minimal. Also supporting this response is HCW 2 '*The major barrier from my experience is the lack of support from Caregivers'.*

HCW 3 also shared the same feeling *'Most of the poor adherence situations are attributed to poor parental care at home. In most cases when we ask them especially the younger ones who usually give or supervise them when they are taking their medications, they indicate no one as most of them they are in charge of their own medications affairs'.*

HCW 5 also had this to say on poor parental care. *'Many are affected by poor parental care at home. Some are suffering more because they are not staying with their biological parents, that there is just no support at home. At times they are also suffering at the expense of their step parents and even extended family members who are mistreating these kids. Sometimes as HCWs, when we try to discuss the issues of concern with caregivers, they often insult us and never turning up at the Health facility when invited/requested. Sometimes the poor parental care is often caused by marital frustrations and substance abuse that in return affect the concerned child'.*

Adding on the barrier of Care giving at home, HCW 1 also pointed out that some ALHIV are battling with unresolved grief '*some are battling to deal and accept the death of their loved ones who in most cases were their treatment supporters, this in the process can destruct their treatment adherence as the level of care sometimes reduces and also they struggle with lifestyle adjustments'*.

This clearly indicates that interventions to improve adherence amongst Adolescents living with HIV should focus more on parental involvement.

4.3.5. Sub theme 2: Forgetfulness

HCWs acknowledged that forgetfulness is a very common barrier to treatment adherence not only amongst Adolescents living with HIV but also adults taking the same treatment. This is what they shared from the in-depth interviews. '*Forgetfulness often arises from the time that is initially agreed upon during initiation. For example, if the agreed time is 20h00 and the family usually has dinner earlier than that, it means by then the child might be sleeping already and will obviously forget to take their medications on that same day' – HCW 6.*

'Forgetfulness is one of reason we get from our ALHIV of which we regard it as normal behaviour among that age group and that they only need to be reminded by their caregivers' - HCW 4. Additionally, '*Forgetfulness is one of the reasons associated with poor adherence amongst ALHIV which is often worsened by the lack parental support. Forgetfulness is further associated with stress due to diverse social issues at home, including amongst others having to deal and accepting the deaths of their loved ones. – HCW 1.*

This finding implies that, although one of the barriers to treatment adherence is forgetfulness, this behaviour can easily be managed if there are reminders in place such as parental cross-checking.

4.3.6. Sub-theme 3: Being playful

This barrier is mostly noted with concern among boys than girls. It was said by HCW 3 that, '*Being playful is a major barrier. Most of them take their treatment well in the*

morning but when it comes to the evening, it is a major problem as they come back very late in the evening from recreational activities such as soccer and that they rarely take their treatment upon their return home more especially boys. Generally, most of them have interests to take their medications only that they are too playful that makes them forgetful which is a common barrier even with some adults'. Sharing the same sentiment is also HCW 4 who also placed the emphasis that boys are more playful then girls and this then mean that this barrier is more common in boys than girls.

4.3.7. Sub-theme 4: Reactions after one's HIV status disclosure

Disclosure is defined as acquiring knowledge about one's HIV status or informing others about one's HIV status (Ammon et al., 2018). HIV disclosure is regarded as a critical component of a successful treatment adherence as it creates an enabling and trust environment (WHO, 2013). Also, Madiba and Mokgatle (2016) discovered that disclosure is necessary as it enable adolescents to learn to accept and live with HIV and develop the desire to be healthy and normal like other people specifically their peers who are not living with HIV.

According to Ikeakanam study (2020) on the experiences of Caregivers on disclosure of ALHIV, it revealed that most of the Caregivers of ALHIV often delay the disclosure process due to many factors. Some of these factors include fear for stigma, Caregivers not having adequate disclosure skills, negative emotional reactions such as anger, blame, hate, judge and reject. It was also found that most of the caregivers felt it is solely the responsibilities of the Health care workers to do disclosure and also that some of the Caregivers believed that when they disclose the HIV status of their ALHIV, automatically they disclose their own status as well.

Against this background, it is a well-known fact that majority of adolescents react differently with feelings such as anger, blame, hate, judge and reject as revealed by Ikeakanam (2020) after they are made aware of their HIV status. It also depends on how the process of disclosure was carried out; that sometimes *'it is not done when it supposed to be or sometimes being done partially, this is mainly a shortcoming on us as health workers as we fail to monitor the whole process of disclosure' says HCW 1.*

Also supporting on the health care's shortcoming on disclosure is HCW 2 who stated that '*we often do not keep track on the disclosure processes, something that we need to take very serious; sometimes it is only done partially and it just goes on like that'.*

If proper emotional support was rendered, they are more likely to understand and accept their status including a good adherence to the medications. Contrastingly, in events where disclosure results in emotional burdens, that is when the reaction to one's status becomes a problem like how HCW 1 described some of the reactions after full disclosure is done *'they often become rebellious and in the process they stop taking their medications.*

HCW 6 had this to say *'some ALHIV often react aggressively and become resistant to take medications as they continue to wonder how they got infected. Some develops hatred and hold grudges towards their parents for being responsible to infect them with HIV. It also results in conflict and misunderstanding between the child and the parents and consequently in situations like this, they then refuse to take their medications accordingly'.*

Moreover, caregivers are somehow blamed for sometimes complicating the disclosure process because '*some of Parents/Caregivers often opt that they do not want their Adolescents to be disclosed with fear of negative reactions such as anger and also as parents they try to avoid accidentally disclosing their own status through their children and thus prefers that they are not told the genuine reasons why they are taking treatment',* claims HCW 2. This delay in disclosure can have negative impacts on the adherence level as ALHIV does not understand the importance of taking the medications they are taking.

4.3.8. Sub-theme 5: Peer pressure

In simple terms, peer pressure is doing what one is being persuaded to do because of other people's behaviour such as friends. This is how Health care workers see peer pressure as a barrier to treatment adherence: '*I would say it is mainly due to peer pressure, you know as they are growing up, they start to associate with other peers and through such interactions, they normally change their behaviour to fit in with others that they stop taking their treatment as they engage in social affairs such as going out with their friends. For example, boys going for soccer and by the time they return home, it is very late that their time for taking medications has already passed and this is obviously poor adherence' - HCW 5.*

4.3.9. Sub-theme 6: Stigma and discrimination

Stigma and discrimination includes behavior that is meant to dehumanise a person who is living with HIV. This is what Health care workers shared from experience on stigma and discrimination. '*I have come across cases of some learners in the hostel not taking their treatment simply because they are scared of others reactions towards them. One specific case is that of a female hostel adolescent who always come back with medications when she come back for her follow-ups as she does not take them at the hostel' - HCW 2.*

Additional practical examples*, 'I have come across a case whereby a learner stopped taking his treatment when he was admitted at the hostel because he did not want to be seen by others taking his medications. Also, I have come across a case whereby one learner refused to go to school camping as required during exams due to fear of stigma (fear of how he will cope with taking treatment amongst his peers)' – HCW 5.*

'Some of our children are still hiding, and they do not want to be seen / associated with HIV. We have noted that stigma is a concern at home and or at school. At the moment, there is a case of a schoolgirl who is being stigmatized at school simply because she is on HIV treatment and as a result she does not regularly take her medications'- HCW 3.

'There are few ones who will demand that their medications should be issued in medications plastics instead of the prescribed medications bottles with reasons that, they fear stigma and discrimination if they are seen carrying the bottles or if the medications makes/gives a sound whenever they are walking and worse when they are running. As an effort to avoid stigma, some prefers coming very late at the clinic hoping to find others already being attended and not at the clinic to see them' – HCW 4.

'Most of the adolescents do not want to be seen by others taking medications. Some do not even want to be seen at ART sites because they know that it is specific for ART and that everyone that visits the clinic is obviously on HIV treatment. Also, some have

difficulties informing their intimate partners about their status and often skip taking treatment to avoid being seen/known that they are living with HIV' - HCW 6.

It is clear from the findings that more girls are affected by stigma than boys. One wonder if it is because of their personality traits or there are other factors involved. This also emerged as a possible research topic that can be explored in future to contribute to literature on the topic. The fear of being seen taking medications affects adherence to treatment negatively as in the end the option of not taking medications over empower the importance of taking medications.

4.3.10. Sub-theme 7: Socio-economic factors

According to a study conducted in South Africa by Maskew et al (2016) on the same topic, it discovered that ALHIV experience numerous known economic barriers to accessing HIV care including the cost of transport and the distance to their respective health facilities. This fit in with the situation in Namibia whereby this study finding indicated that Adolescents living with HIV are coming from different social backgrounds including some with deprived resources such as money for transportation and or even food which is a basic need. The unavailability of all these can affect adherence negatively. Health care workers had this to say*; 'social problems at home such as not having food to eat before taking the medications is also one of the issues that makes the ALHIV to skip taking their treatment sometimes'- HCW 1 and 3.*

'However, there are those that fail to come for their scheduled follow-up on time with reasons that they were not given transport money by their caregivers. Sometimes caregivers do not understand the importance of the ALHIV coming to the clinic on the given date and sometimes they just do not have transport money to give them'. HCW 4, 5 and 6.

'Most of the Caregivers are subsistence farmers; depending on traditional food. In event of drought, food becomes a problem at home. Normally patients are informed to take their medications after meals, and when they find themselves with no food to be eaten prior to taking medications, some skip to take them', HCW 6. This is in line with the belief that medications need to be taken after meals resulted in some patients skipping to take their medications when food is not available. This consequently

interferes with treatment adherence (Biadgilign and Reda (2012). In conclusion, it is not an obvious fact that patients in developing countries, rural communities or from poor socio-economic backgrounds are always challenged with socio-economic barriers as there those who are able to achieve the same maximum treatment adherence similarly to those in developed countries or with better socio-economic situations (Biadgilign and Reda, 2012). Equally, this means that adolescents living with HIV from poor socio-economic backgrounds are as well able to fully adhere to treatment if adequate support is made available.

4.3.11. Sub theme 8: Medications side effects

Medications offer wide range of benefits and sometimes in the process might also give unfavorably situations to its consumers that some opt to rather not take them in order to avoid the side effects. From experience, Health care workers have noted that some ALHIV simply skip taking medications regularly with reason that it gives them additional medical complains. Some participants revealed that: *'We have attended to cases whereby ALHIV complains that sometimes they do not take their medications because it makes them sick for example having stomach aches'- HCW 1.*

'Reports that whenever they take their medications, they often get nausea, like they want to vomit of which some then stop taking treatment to avoid the problem'- HCW 2.

'complains that the medications make them moody, increasing the sexual desires, not growing according to milestones, developing skin rashes, nausea with vomiting and dizziness sometimes. This then also contribute to poor adherence as they feel when they do not take treatment, they are less likely to experience these problems' – HCW 6.

HCW 4 also highlighted that the medications are bitter/sour, sometimes if taken in big quantity, can result in ALHIV being emotionally overwhelmed and can also result in reduced interest to take their medications.

4.3.12. Sub-theme 9: Facility related barriers

Negative attitudes of the health care workers can negatively affect Adolescents adherence as comparing to the effects it has in adults (WHO, 2013). In this regard,

health care workers are then advised to listen attentively, speak clearly, take into account adolescent's diverse needs and keep in mind that some adolescents may not be free/ at easy to express themselves to the health care workers. Thus, it is the responsibility of the health care workers to assess for potential barriers, make appropriate referrals and give education on the importance of treatment adherence to all patients receiving ART services including critical population such as adolescents (ART guideline, 2019).

Majority could not identify facility barrier citing that although there use to be complains of adolescents waiting for too long in the queues waiting to be attended, this is no longer the case as Adolescents now have their separate day (Fridays), the day designated to render Adolescent health friendly services. However, HWC 6 had different sentiment pointing out that some of the Health care workers can be barriers to treatment adherence amongst adolescents living with HIV. This came from the narrative:

'Sometimes us HCWs we fail to scrutinize our way of communication to our patients including Adolescents. At times we bring our stresses from home at work that we end up shouting at patients. This make them to feel bad and some start asking themselves what is the point of taking medications if they are being shouted at upon receiving medical care'.

'Another issue we sometimes start our daily work of attending to patients very late. Giving our priority to our personal affairs first and chatting with fellow colleagues. also, some people are coming from far with limited transportation that they reach the facility late (few minutes before lunch hour) resulting in them being attended after lunch and sometimes that is the time the transport is going back to the village. Consequently, this causes confusion and panics as their wish is to go back attended and at the same time they do not want to be left behind by the village transport'.

'Sometimes as HCWs, we tend to forget that different people understand things differently; that we give information narrowly and in a hurry concluding that everyone got the message but sometimes they go struggle at home simply because they fail to grasp the key messages'.

4.3.13. Sub-theme 10: Stress

Different stressful situations can trigger poor treatment adherence depending on an individual. For the purpose of this study, health care workers pointed out stressful situations that affect adherence to treatment amongst adolescents living with HIV as part of their experiences and interactions. This is what some have to say:

'There are those who are stressed by their social circumstances at home, that there is no proper parental care, being bullied and stigmatised at home and sometimes there is no food for them to eat before they take their medications' - HCW 3.

'You know a life of a young person goes with everything that is happening around them. For example, when they are failing at school, they tend to develop inferiority feeling that what is the point of taking my medications if I am failing at school? What am I trying to achieve? Also, when they realize that others see them in a certain manner such as not being that wise enough (emotionally down) and being different simply because they are taking medications this gives them low self-esteem that negatively affect their treatment adherence' – HCW 5.

'Some are stressed due to side effects of medications, that they are tired of taking medications but still have no option of stopping treatment' – HCW 6.

This is clear that ALHIV are challenged with diverse stressful situation that can result in the lack of interest to fully adhere to their medications although the lack of interest can also be attributed to other life events that are not stressful such as this practical example that was shared by HCW 6*,'an Adolescent boy stopped taking his medications after he received his estate allowance to the extent that his interest in treatment totally got diverted'.*

4.3.14. Sub themes 11: School factors

Some adolescents reported that they have poor treatment adherence as they raised concern over the commitment with their school work, not having an open communication and trusting relationship with their teachers, negative teachers' attitude that they find it difficult to seek for permission to go to the hospital and in return sometimes end up missing their given follow-up date at the clinics (Van Wyk and Davids, 2019). Since most of the Adolescents are school going, they also face

barriers at school that affect their treatment adherence. This is what Health care workers shared from experience:

'In most cases some do not show up on their given follow-up date as they opt to go to school first on their follow-up date as they do not want to miss their lessons and as a result they always come up with excuses that they failed to come on the given follow-up date as they were busy writing the tests even when it is not true. However, there are some cases for day learners whereby some teachers allegedly refuse them permission to come to the hospital with reasons that they are missing from lessons on too many occasions'- HCW 2.

'Usually they report that they failed to come for their follow-up date on the exact date given because they were writing a test or coming late because they did not want to miss any of their lessons'. - HCW 3.

'I realized that most of them have difficulties disclosing to their Life skills teachers so that when they need to come to the clinic for their follow-up, they do not need to struggle asking for permissions. Also, there are those who will come a day after their follow-up date with reasons that they were writing their examination which is an understandable reason at least'- HCW 4.

The problem of being too pre-occupied with schoolwork is common during exam time. They cannot neglect their exam; thus they usually attend to it first. There is a need for special bookings of learners during exams with the education sectors and health facilities to enable learners not to get distracted on their treatment, neither their examinations'. - HCW 5.

4.3.15. Sub theme 12: Lack of knowledge and skills

Although lack of knowledge and skills is not a major barrier identified by most participants, some health care workers pointed out that their shortcomings can become a barrier for Adolescents to fully adhere to treatment. For example, HCW 1 stated that '*The lack of knowledge and skills can also be a barrier because there has not been refresher training on disclosure and adherence counseling conducted in recent years. HCW 2 'Lack of knowledge and skills I would say yes as I feel we are not well equipped*

with adequate information on the Adolescents' Friendly Health services implementation'. This means that it can create gaps in service provision resulting in ALHIV not getting the required services they are entitled to under their unique circumstances.

4.4. THEME 2: Adherence Promotion Initiatives

The best way to resolve any issue or phenomenon is to have a plan of what needs to be done. By making reference to Gifford (2003) who reported that although adolescents issues are often viewed as sensitive in the academic world, it is of utmost importance for more research studies to be conducted on the impact of HIV on them and explore how they are coping, investigate the relevance and effectiveness of HIV programs aimed at improving adherence, design ways to identify and assist the vulnerable ones and keep monitoring the outcomes of interventions to ensure that interventions are responsive to the identified unique needs.

Gifford (2003) Further recommends for confidentiality to be ensured at all health facilities; preferably by having a private space or room whereby adolescents can freely express their problems and be counseled in return. A multi-disciplinary teams experienced in HIV management, adherence support and monitoring mechanisms should be in place at all health facilities rendering services to ALHIV as it is one of the important predicators of adherence to medications (Adolescent guideline, 2019).

What's more, Biadgilign & Reda (2012) advice that Interventions to improve adherence can be initiated by adopting systems that delivers good quality, health care and social support for adolescents as a matter of urgency. Thus, Health care workers are urged to develop adherence monitoring tool that will be monitored closely with the patient's clinical outcomes. According to UNICEF (2021) Prioritization of particular growing needs of adolescents is vital in achieving the global aim of ending AIDS epidemic by 2030 as it was discovered that an intensified focus on adolescents' need can result in improved treatment outcomes.

Moreover, WHO (2011), advises that disclosure should be done incrementally to accommodate cognitive skills and emotional maturity of children as it can promote

good treatment adherence. The Adolescent guideline (2019) recommends that health care workers should screen patients with poor treatment adherence especially adolescents for depression as an effort to support treatment adherence. In addition, it is specified that it should include assessing symptoms such as irritability, tiredness, anger, lack of energy, sleeping issues, unhappiness amongst others

In light of this, health care workers who took part in the study made sound recommendations on how best Adolescents living with HIV can be supported in terms of adherence promotion and taking into account the common barrier affecting them. The following were summarised from the narratives:

Table 6: Recommendations from Health Workers

Level	**Recommended adherence promotion initiatives**
Health facility (clinic)	• Donation of time reminders such as box pill counts for 7 days basis, watches with set alarms etc. • Strengthen regular health education on the importance of adherence and involvement of Caregivers for support at home. • Continue to facilitate Teen club meetings and activities • Thorough assessment of individual cases especially the ones of concern and be referred to Social workers for further management. • Provision of adolescent health friendly services • A playground is needed as they learn a lot through play. • Possible soup kitchens since some are from very far with poor socio-economic backgrounds. • Conduct group counselling first before they are issued with their medications. • Integration of services to avoid having a clinic/site designated for HIV services only.

Household level (Home)	• Parental care and support • Social assessment and the provision of psycho-social support services. • Health education is needed with Caregivers. • Caregivers need to report behavioural problems affecting treatment adherence at the health facility for interventions to be initiated. • Caregivers to always respond positively upon the request of the HCWs to present at the clinic to resolve identified barriers to treatment.
Community at large	• Conduct awareness raising meetings with the general public to educate them on the importance of adherence, unique needs, addressing stigma and discrimination. • Mobilization with community leaders on adolescents needs. • Community members to start giving information/reporting cases of concern from their community. Community engagement with the clinic is lacking.

Table 2: Adherence promotion interventions from the perspectives of Health Care Workers

From the above-mentioned recommendations to improve adherence amongst Adolescents living with HIV, it is worth noting that most of the recommendations if not all are doable and that it only require the planning on how to go about it. Also, it is clear from the findings that much alone cannot only be done at the clinic level without the involvement of the Caregivers at home as well as community at large. Based on these recommendations the researcher made her own recommendations which were included in the next chapter.

4.5. THEME 3: Attitudes and Behaviours of ALHIV towards Treatment Adherence

In general, according to Mihalyi (2021) adolescents experience psychological, social and physical aspects of maturation that can influence their attitudes and behaviours. Additionally, sometimes adolescents have unclear roles about their lives and often experience ambiguous feelings in this regard making it difficult for them to behave differently. Mihalyi (2021) thus advise for a thorough behavioural assessment to be conducted in order to understand the contexts of their behaviours and to be able to help them holistically prior to drawing conclusions that might be misleading. Also supporting the behavioural analysis is Ikeakanam (2020) whose study revealed that some of the ALHIV are battling with mental health issues which mean that no matter the level of support and education that is rendered to them, they are more likely to have poor adherence as they do not purely get the message and sometimes they forget.

It is clear from this study that the attitudes of Adolescent living with HIV differ towards treatment adherence as they are unique though they have one thing in common; that of taking treatment. It is further discovered that Adolescent's attitude towards treatment adherence is a key component in adherence promotion as it can either positively or negatively affects the treatment outcomes. This is what some of the Health care workers shared on the attitudes of ALHIV towards treatment adherence.

'*The ones with HVL (high viral load) are not serious sometimes because they are being counseled several times but they seem not to improve/change their issues of concerns even when they are able to do. Also, some of them feel that they are doing a favor to the HCWs when they take their medications accordingly but in the end they lack the understanding on the importance of taking treatment, some fail to answer simple questions'- HCW 1.*

'The attitudes and behaviors of ALHIV differ as they are challenged with different barriers and with different social circumstances. You find those who do not want to take the treatment simply because they lack interests to continue taking medications. We also find the ones that are not yet fully disclosed and when it is done, they are often in denial especially when disclosed late. Some they do not take because they forget or some feel when they adhere, it is a favor they are doing to the HCWs and even to their Caregivers' – HCW 2.

'Most of them understand why they are taking treatment. It is just a matter of them being adolescents in general. Some they are not aware that the consequences of poor treatment adherence can be very devastating and that they do not take it serious, rubbing it off that they are still doing well beside them not taking treatment' – HCW 3
The behavior highlighted is that of a typical adolescent that sometimes they fail to take things seriously as it supposed to. The behavior is also portraying that they are more into emotions and thus they need a caring and supportive environment to enable them to thrive in various areas of their life including their medications.

4.6. THEME 4: Level of Understanding on the Importance of Taking Medications

The level of understanding on the importance of taking medications has been described differently by Health Care workers. Some feel that most of the ALHIV fully understand the importance of taking medications as majority has been fully disclosed of their status. it is further viewed that it is circumstances they find themselves in that is playing a major role with adherence. Health care workers had this to say on the level of understanding of ALHIV specifically known with poor treatment adherence:

Some understand why they are taking medications but some I would say they are still in denial, ignorance, shameful of the treatment which in return makes it difficult for them to acquire a deeper understanding on the treatment they are taking. Some they understand but now they pretend like they do not know especially when being attended by new staffs that in most cases do not know their social circumstances'- HCW 1.

From experience, I realised that most of them with history of poor adherence do not understand. This is either due to disclosure that was rushed through and that in most cases HCWs assumes that they understand which is always not the case without clearly checking whether the child fully understand or not. In most cases when ALHIV are asked why they are taking medications they often say yes but it is their reasoning that indicates to us that they do not understand -' HCW 2.
Concluding on the level of understanding, is HCW 4 who highlighted that *'I think our ALHIV also lack understanding that although the medications is putting them in*

uncomfortable situations sometimes, it just has to be taken for their well-being. We are doing our level best to ensure that they understand why they are taking the medications but Adolescents sometimes simply choose not to take treatment'.

The level of understanding is deemed moderately with some health care workers being of the opinion that the understanding is there; only that adherence to treatment is influenced by diverse social challenges. The level of understanding is also said to be due to the extra information sharing at school and at home.

4.7. THEME 5: HCWs Perception on Barriers

According to Beima-Sofie, Brandt, Hamunime et al (2017), HIV infected adolescents were found to have unique social and psychological issues that often negatively affect their adherence to treatment and consequently leads to poor health outcomes. Majority of Health care workers shared the same sentiments; highlighting that barriers affecting treatment amongst ALHIV are categorized as social and emotional and mainly lies with adolescents themselves as well as their parental support at home.

It is further identified that boys falls patients of poor treatment adherence than girls and also more adolescents in general as compared to adults. Literature has it that Adolescent's girls are especially more affected by the epidemic as compared to male counterparts with reasons driven by physical, cultural and structural barriers of HIV prevention (UNICEF, 2021). This goes with participants who highlighted more girls are affected than boys. Additionally, others felt it is just a 50/50 situations of adherence be it boys with girls or adolescents with adults. Health care workers had this to say: '*More boys are prone to poor adherence as compared to girls. Reason being that boy's role in the society differs from that of girls. For example, most of the household chores for the boys are conducted outside the house such as looking after livestock whilst for the girls it is more household-based'- HCW 5.*

'More girls have adherence problems than boys according to our records for adherence counseling sessions. Also, majority are girls on treatment than boys. when it comes to adults in comparison with the adolescents, adults have poor adherence depending on their social circumstances such as forgetting to take medications due to substance abuse, multiple partners amongst other factors'- HCW 6

'When it comes to Adolescents adherence as compared to adults, I have learned that the adherence amongst adolescents is poor as compared to adults who are taking the same treatment. Additionally, I have learned that this gap is due to the fact that Adolescents depend on their Caregivers for supervision and support. When they are no longer Adolescents, I have noted that their adherence improves. Again when I look at the adherence of smaller children below 15, their adherence is very good. As of Adolescents, somehow they are being neglected as the caregivers leaves the responsibility of taking their medications solely to them with the perceptions that they are all grown and that they can take care of their own affairs. Also, with regard to boys and girls, I have come to discover that the adherence among boys is poor as compared to girls. I have come to learn that in most cases boys do not take things serious as compared to girls (ignorance)' HCW 2.

Moreover, Health care workers indicated that at times they are confronted with situations whereby they are unable to detect exactly where the barriers are. '*Sometimes we do not really know where the problem is and when you call the Caregiver, most of them report that it is the ALHIV who is a problem and that everything is fine at home. Sometimes when we try to find out from the child, they always report that the problem lays with their Caretakers', claims HCW3.*

4.8. Conclusion

In conclusion, the barriers affecting treatment adherence emerged as discussed. This will make it easier for the planning of efforts to address the phenomenon as indicated under adherence promotion initiatives. The study revealed that some of the ALHIV find it difficult to see the future consequences that are brought upon by their present actions. That they do not visualize what is likely to happen in their future that is linked to their current situation of poor treatment adherence. The study supported the notion that when dealing with Adolescents living with HIV with poor adherence, the focus should really be on supporting them rather than reprehension as it came out clearly that majority are faced with diverse barriers impeding their treatment adherence. With the findings of the study, it is also clear that the heterogeneity of the adolescents; that although they fall in one category in terms of their age and the treatment they are taking, their situations totally differs and that they are unique in their own ways. It then

implies that heterogeneity of adolescents needs to be recognized and form part of their treatment and management.

CHAPTER 5: CONCLUSION AND RECOMMENDATIONS

5. Conclusion and Recommendations

5.1. Introduction

After data is analysed, the process does not end there. The researcher is required to draw meaningful conclusions that emerged from the study and make future recommendations thereof. Thus, this chapter present the outcomes, conclusions and recommendations drawn from the study. The aim is to test whether the proposed study objectives were attained.

5.2. Identifying details of participants

5.2.1. Adolescents

There was an equal representation of gender with 50% males and 50% female's adolescents living with HIV (ALHIV) taking part in the study. Majority of them are school drop-outs. All participants have been on antiretroviral therapy since their childhood. Most of them are orphans (6/10) and living with non-biological parents including Grandparents and Aunts.

5.2.2. Health care workers

All health care workers (three Nurses and three Health assistants) are involved in treatment and care for ALHIV with a minimum of two (2) years working experience. They were selected from sampled health facilities.

5.3. Research objectives

Overall, the study sought to explore and discuss perceived barriers to ART treatment adherence amongst adolescents aged 15-19 and recommends for need-based interventions to promote adherence. Below were the objectives of the study and a discussion on its achievement:

5.3.1. Objective 1: To explore perceived barriers and investigate social challenges contributing to poor treatment adherence among ALHIV.

Literature review on barriers to ART treatment was explored and as part of the data gathering, participants shared their personal experiences on barriers affecting treatment adherence. It is clear from the Ecological system perspective that the barriers

to treatment adherence lies within various societal systems that Adolescents interacts with. Majority of the Adolescents indicated that the major barrier to treatment adherence is associated with poor parental care at home. This sentiment was also acknowledged by the Health Care Workers. Most of the Adolescents are challenged with insufficient food at home; often take medications on an empty stomach. Unavailability of transport money to go collect medications from the health facility was also cited as one of the barrier to treatment adherence; not only missing their follow-up review but also failing to have stock of medications to take at home. In contrast, it was also identified that the problem of poor treatment adherence merely lies with the Adolescents themselves as some simply skip to take their medications due to lack of interest, forgetfulness, stress and failing to take medications on the allocated time slot due to various social activities with their peers such as soccer (boys).

It is surprising to note that there is still stigma and discrimination experienced by people living with HIV. This then makes it difficult for Adolescents to adopt a culture of taking their medications freely especially in the presence of strangers. In addition, it is worrisome to learn that majority of Adolescents finds it difficult to disclose HIV status to their intimate partners that they have a tendency of hiding their medications and eventually skip taking them. The study also brought to light that this population is challenged with social stressors associated with unresolved grief of biological parents and extended family members who served as their treatment supporters in the past and that they were not counselled for grief.

Additional barriers that emerged from the study is that some Adolescents do not take medications on time as they do not have access to accessories such as a cell phone or watch to confirm the time for taking medications with some relying on the sun as an alternative. Medication side effects associated with nausea, dizziness and generalised body weakness was also identified. This result in resistant behaviour as a way to avoid the discomfort experienced after taking medications.

5.3.2. Objective 2: To identify available support system for ALHIV in order to address barriers to treatment adherence

The study acknowledged that ALHIV face diverse barriers that obstruct their treatment adherence. Against this background, they shared their recommendations on how best they feel they can be supported in order to improve adherence to treatment, taking into account their unique needs and social circumstances. Their experience is grounded within the 'Ubuntu' perspective of '*nothing for us, without us*'. In addition, these are some of the adherence promotion initiatives identified from the study from Adolescent's point of view. This is giving the impression that these are workable solutions to the phenomenon of poor adherence because it is how best adolescents view they should be supported to enable them to fully adhere to treatment. In a way, these strategies can be viewed as the involvement of ALHIV in decision making.

- **Provision of psycho-social support services**

  The need for continuous emotional support during follow-up was raised and interventions to be extended at household level to allow for social circumstances assessment. Psycho-social support services to include the provision and referral for food aid for those identified in need as it negatively affects treatment adherence when medications is taken on an empty stomach. The provision of psycho-social support services is viewed as a way of instilling hope to the hopeless ones.

- **Teen club/peer support**

  The facilitation of teen club meetings is necessary. Adolescents feel at peace when they mingle with other peers in a supportive environment and discuss issues pertaining to their treatment. This view point was aligned with an African proverb '*a problem shared is a problem solved*'. Peer support gives them courage; that they are not the only ones and in the process boosting their self-confidence which is vital in the promotion of adherence.

- **Regular provision of health education and Adolescents health friendly services at respective health facilities**

  Adolescents made a recommendation for the HCWs to always ensure a safe environment that promotes confidentiality of their discussions and treatment at all times in order to protect them. Furthermore, they suggested that health education should be given one on one rather than always in a group setting to ensure privacy. Also, it was emphasized that individual circumstances require specific interventions. ALHIV wishes to be treated in a friendly and non-judgmental manner by all health care workers at all times.

- **Parental involvement**

  Because majority of ALHIV expressed concern over poor parental care, it is then suggested that Caregivers should be informed by the HCWs of how the treatment is going (issues of concern) and how best they Caregivers can offer support at home. Supervision and monitoring of medication intake is needed at home. Caregivers urged to be honest with their adolescents and give factual information on why they are taking the treatment, support them instead of scaring them that they are going to die if they do not take their treatment.

- **Community engagement**

  Emphasis is placed on raising awareness on the needs of adolescents living with HIV as well as implementing interventions directed toward addressing stigma and discrimination against people living with HIV.

5.3.3. To examine ALHIV attitudes and behaviors towards antiretroviral treatment adherence

Attitudes and behaviors have a major impact on adherence, be it in a negative or positive way. This study revealed that some ALHIV simply decide not take their medications as a personal choice. Some believe that the medications are not helping them but rather a waste of their precious time; that they are doing well even when they omit taking medications. It was further discovered that some ALHIV feels irritated during adherence counseling sessions, some feel burdened and are tired of taking medications every day, some shocked upon being informed that they are required to take medications for life.

However, other ALHIV reported a positive attitude and behavior in the sense that they have come to terms with living with HIV and that their only issue of concern is being faced with diverse social challenges that affects their treatment adherence. Moreover, it was concluded that, the resistant behavior among ALHIV to take medications is embedded in various psycho-social aspects and this call for holistic analysis in addressing the problem.

5.3.4. To establish ALHIV level of understanding on why they are taking antiretroviral treatment

Majority (90%) expressed gratitude that they are alive and healthy because of the medications they are taking. In other words, they understand why they are taking medications and therefore acknowledged the importance of taking treatment although they admit that on some occasions, they fall off the wagon due to various barriers. It was further noted that the level of understanding differs among individuals; that some adolescents are younger in age but their level of understanding is sky-scraping and vice-versa.

In addition, it was learned that majority of ALHIV are well informed that the medications are taken in order to suppress the virus in the body. Conversely, there are still those who do not know the specific reasons as to why they are taking medications although they were fully disclosed. Concern was expressed over the manner in which health education is conducted by health care workers; that sometimes adequate information is not shared in a friendly and conducive manner.

5.3.5. To explore health care worker's perceptions on barriers to ART adherence amongst ALHIV

It came to light that sometimes the focus of health care workers (HCWs) is mainly on emphasizing the implications of non-adherence rather than on exploring the drivers of non- adherence which in return may worsen the situation. HCWs admitted that ALHIV are challenged with diverse barriers mainly ranging from personal to family related barriers. It was further learned that ALHIV become more vulnerable due to poor parental care at home as treatment success rate is associated with the level of parental care at home. Poor parental care is linked with dysfunctional family dynamics such as substance abuse, family violence, etc.

In addition, it was reported that often adolescents lie to the HCWs that they are taking treatment accordingly when in reality it is not the case. HCWs are aware that some ALHIV lack monitoring and supervision by their Caregivers and that most of them are not staying with biological parents but rather extended family members and non-relatives. It is surprising to learn that efforts by the health care workers to involve the Caregivers in the promotion of adherence are not always successful as some of the

caregivers fails to turn up at the health facility as requested with worse scenario of some insulting the Health Care Workers in return.

Moreover, some Caregivers are reported to deliberately delay the process of disclosure to their ALHIV with fear that they may accidentally disclose their own status. This is said to be an additional barrier to treatment. Concern was expressed over peer pressure as ALHIV try to fit in with peers in social affairs. In addition, issues of stigma and discrimination are happening at hostels and camping at schools that school-going ALHIV sometimes stop taking their medications with fear of being seen by peers.

5.4. Discussion

Treatment adherence amongst Adolescents has been one of the health issues of concern facing the district. Thus far and according to the researcher's knowledge, this is the first qualitative study to explore barriers to ART adherence amongst the key population of adolescents living with HIV in the rural setting within Omuthiya district particularly from a perspective of social welfare and ecological system theory holistically analyses systems involved in a certain human behaviour.

On the other hand, there has been a study conducted elsewhere such as in South Africa and other parts of the country (Namibia) such as in Khomas region whereby the same research problem was studied with a different population (inmates). There was also a study conducted in Onandjokwe on the same topic. Both these studies added value to this study as they both has served as baseline studies to this specific study. The researcher believes that the findings of this study are essential as it contributes to the knowledge base of barriers affecting treatment adherence specifically in Omuthiya district where the study was conducted. The study is also imperative that the findings can be compared to other findings on the same topic in different geographical locations and be able to draw discrepancies and similarities with future studies.

With regard to the barriers affecting treatment adherence, it is worth noting that deep analysis of factors was conducted with affected Adolescents as well as in a way confirming with the Health Care Workers as key informants as they know their circumstances well through their experiences. In other words, the prevailing barriers such as patient related and family could easily be identified from both perspectives of

Adolescents themselves and the Health Care Workers. For that reason, it added value to the validity of the findings.

The study findings from the viewpoints of both participants (Health care workers and Adolescents themselves) acknowledged the importance of health education, parental involvement and provision of friendly health services as one of the adherence promotion initiatives. Additionally, the findings will be of assistance to the ART District Coordinating Committee in planning for the adherence promotion initiatives and programs as it will take into account the evidence based identified barriers and specific adherence promotion initiatives thereof from the participants who has or are experiencing the problem. Nationally, findings from this study may facilitate to inform health policies to steadfastness the structural and social barriers to ART adherence among ALHIV.

Some participants (Adolescents) testified that they are living in vulnerable social conditions dominated by diverse social challenges such as poor parental control, poverty, stigma and discrimination, stress etc. Also some felt that staying with non-biological Caregivers and moving between different caretakers (house to house) disrupt their treatment adherence in the process as they are challenged with adjustment issues; being forced to start over again trying to adapt in a new environment they find themselves in with its presenting challenges. Consequently, this they said make them patients of poor adherence not necessarily by choice but rather by default as in most cases they do not have control and mandate to change their unfavourably social conditions at home such as food as they mostly rely on the support of Caregivers. Moreover, it is clear from the study findings that the need for psycho-social aspects should be prioritized as part of ensuring that comprehensive service delivery is rendered to this special population namely ALHIV.

With regard to trainings of HCWs to provide Adolescents health friendly services, majority indicated that they pose basic trainings on Adolescents care and that they are able to support them where they are able to. However, it was noted and then recommended that continuous refresher trainings are crucial to keep up with emerging trends and needs of Adolescents living with HIV. Also, it came to light that apart from addressing adherence problems with ALHIV in exclusion of their Caregivers, it is less

likely not to yield fruitful outcomes of improved adherence as the problem requires holistic interventions. This argument is also supported by the ecological system theory that recommends for a holistic approach of relevant systems within an environment of which an individual interacts with. A similar study by Eliphas, (2017) at Onandjokwe hospital in northern Namibia found that "factors contributing to poor ART adherence among adolescents are patient and family related, socio-economic, and related to substance abuse, stigma and discrimination, health care and health systems, as well as the environment and weather." Eliphas (2017) study findings are closely related to this study which confirms this study's findings. The only difference is that he finds weather as a significant factor in hindering the adherence by ALHIV while this study did not find weather as a significant factor. In Malawi, Kim et.al. (2017) finds that "violence in the home or alcohol use as well as poor treatment self-efficacy were associated with worse adherence." The northern part of Namibia had less incidences of violence in homes however this study agrees with Kim et.al. (2017) that alcohol is a significant factor in non-adherence.

5.5. Recommendations

The following recommendations were made.

5.5.1. Recommendation for practice

- Multi-sectored interventions including parental involvement in the adherence promotion initiatives. This will be achieved through the formulation of policy by the Ministry of Health and Social Services. With the involvement of parents in the initiative this will ensure the initiative is successful at local level (Around Omuthiya) as compared to at national level alone.
- There is also a need for early identification and interventions for ALHIV in need of psycho-social support services by Health Care Workers especially at the first presentation of an HIV case as well as robust home based care program which ensure that all patients' ART adherence is monitored.
- It is further recommended that all health facilities should ensure the functionality of teen clubs for peer support. This is done through collaboration with the Ministry of Education to ensure that peer educators are selected from selected schools around Omuthiya district and trained on the importance of ART adherence to influence their peers.

- The study also recommends that the Omuthiya District ART committee should incorporate the identified barriers in planning adherence promotion initiatives when they formulate policies. Such barriers such as alcohol and drug abuse are some of the most important factors to combat.

5.5.2. Recommendation for education and training

- Refresher training on disclosure, adolescent's health friendly services and adherence counselling is needed for Health Care Workers. This will help them to understand the new trends in ART Adherence which keeps them updated with the ever changing narrative of HIV/AIDS and the fight against it.
- Continuous health education during follow-up visits for ALHIV. This helps to monitor adherence especially among the ALHIV around the Omuthiya district area.
- There is need for parental education programs to enhance interaction among community members to share the burden as well as encourage them to monitor their adolescent children. This is also strengthened by holding regular Community meetings for awareness raisings especially addressing stigma and discrimination

5.5.3. Recommendation for policy makers

- The Ministry of Health and Social Services to incorporate findings of recent health related researches in guidelines reviews. For example, in revising National ART guideline, National guideline of Adolescents living with HIV in Namibia.
- It is further recommended that a multi-sectored team be set up and a policy guideline to help them on how to tackle the multifaceted problem brought about by non-adherence.
- This study also recommends to policy makers especially to Omuthiya District Health Officers to work closely with other non-governmental organisations dealing with HIV/AIDS matters to help health workers and peer educators in ensuring adherence among ALHIV. Also looking at what other regional health centres around the country and other countries are doing will be a helpful benchmark in combating the ART non-adherence problem among ALHIV in Omuthiya.

5.5.4. Recommendation for future studies

This study is significant as a baseline study for future research with Adolescents living with HIV especially in rural settings. A similar study should be conducted in other part of the country to explore barriers affecting ART treatment adherence amongst the same population or to do a comparison between adolescents and adults. A study to evaluate the importance of parental care in the promotion of treatment adherence amongst adolescent is needed.

5.6. Summary

It is clear from the research findings that the concept of poor adherence amongst adolescents is encircled by diverse social challenges such as patient and family related barriers that call for multi-sectored approaches to address the problem and improve adherence in this key population. The conclusions drawn from the study were presented in this chapter and recommendations given.

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Appendices

ETHICAL CLEARANCE CERTIFICATE

Ethical Clearance Reference Number: FEHS/618 / 2021   Date: 1 September 2021

This Ethical Clearance Certificate is issued by the University of Namibia Research Ethics Committee (UREC) in accordance with the University of Namibia's Research Ethics Policy and Guidelines. Ethical approval is given in respect of undertakings contained in the Research Project outlined below. This Certificate is issued on the recommendations of the ethical evaluation done by the Faculty/Centre/Campus Research & Publications Committee sitting with the Postgraduate Studies Committee.

Title of Project: An Exploratory Study Of Perceived Barriers To Antiretroviral Treatment Adherence Amongst Adolescents In Omuthiya District

Student: ESTER NEFUNGO

Student Number: 200645714

Supervisor(s): *Dr. Ndumba Jonah Kamwanyah*

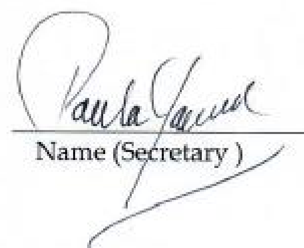
FACULTY OF EDUCATION AND HUMAN SCIENCES

Take note of the following:

1. Any significant changes in the conditions or undertakings outlined in the approved Proposal must be communicated to the DEC. An application to make amendments may be necessary.
2. Any breaches of ethical undertakings or practices that have an impact on ethical conduct of the research must be reported to the DEC
3. The Principal Researcher must report issues of ethical compliance to the DEC (through the Chairperson of the Faculty/Centre/Campus Research & Publications Committee) at the end of the Project or as may be requested by DEC
4. The DEC retains the right to:
   1. Withdraw or amend this Ethical Clearance if any unethical practices (as outlined in the Research Ethics Policy) have been detected or suspected,
   2. Request for an ethical compliance report at any point during the course of the research.

HREC-H wishes you the best in your research.

Name (Chairperson)



Name (Secretary)

REPUBLIC OF NAMIBIA

MINISTRY OF HEALTH AND SOCIAL SERVICES

Ministerial Building
Harvey Street
Private Bag 13198, Windhoek

OFFICE OF THE EXECUTIVE DIRECTOR

Tel: No: 061 -203 2507
Fax No: 061-222 558
Andreas.Shipanga@mhss.gov.na

Ref: 17/3/3/EN
Enquiries: Mr. A. Shipanga

Date: 22 October 2021

Ms. Ester Nefungo
Ministry of Health and Services Social
Omuthiya District Hospital
Namibia

Dear Ms. Nefungo

Re: An exploratory study of perceived barriers to antiretroviral therapy adherence amongst older adolescents in Omuthiya District.

1. Reference is made to your application to conduct the above-mentioned study.
2. The proposal has been evaluated and found to have merit.
3. **Kindly be informed that permission to conduct the study has been granted under the following conditions:**
   - 3.1 The data to be collected must only be used for academic purpose;
   - 3.2 No other data should be collected other than the data stated in the proposal;
   - 3.3 Stipulated ethical considerations in the protocol related to the protection of Human Subjects should be observed and adhered to, any violation thereof will lead to termination of the study at any stage;
   - 3.4 A quarterly report to be submitted to the Ministry's Research Unit;
   - 3.5 Preliminary findings to be submitted upon completion of the study;
   - 3.6 Final report to be submitted upon completion of the study;
   - 3.7 Separate permission should be sought from the Ministry for the publication of the findings.
4. All the cost implications that will result from this study will be the responsibility of the applicant and **not** of the MoHSS.

Yours sincerely,

BEN NANGOMBE
EXECUTIVE DIRECTOR

All official correspondence must be addressed to the Executive Director.

(UREC) Annex 5C: Informed Parental Consent for Qualitative Studies

INFORMED PARENTAL CONSENT FORM

Informed Consent for parents of older adolescents aged 15-19 years participating in the research titled "An exploratory study of perceived barriers to antiretroviral treatment adherence amongst adolescents in Omuthiya district"

Name of Principal Investigator:	Ms. Ester Nefungo
Name of Sponsor:	N/A

This Informed Consent Form has two parts:

- **Information Sheet (this section, to share information about the study with you)**
- **Certificate of Consent (for signatures if you choose to participate)**

You will be given a copy of the full Informed Consent Form.

<u>PART I: INFORMATION SHEET</u>

Introduction

My name is Ester Nefungo working for the Ministry of Health and Social services at Omuthiya District Hospital. I am pursuing a Master degree in social work at the University of Namibia. I am conducting this research study as an effort to support and promote treatment adherence among adolescents living with HIV in Omuthiya District. As part of the study, I will engage selected older adolescent (aged 15-19) in one on one in-depth interview. Whenever researchers study children, it is ethical that parents and guardians are consulted and asked to grant permission. Thus, you are kindly invited to grant your child permission to take part in this research project. You are free to consult anyone you feel comfortable talking with about this research study and that you can take time to reflect on whether you want your child to participate or not. Should you agree, the next step will be to ask your child for their agreement as well. Both of you have to agree independently before I can begin. This consent form may contain words that you do not understand. Please ask me to stop as we go through the information and I will take time to explain. If you have questions later, you are free to ask them of me.

Purpose of the Research

The aim of this study is to explore and identify perceived barriers to ART treatment adherence among adolescents in Omuthiya district and recommends for possible need based interventions to promote adherence. Although it has been noted with concern that most of the adolescents have history of poor treatment adherence, there has not been a single qualitative study to explore this behavioral pattern and assess whether the interventions in place are responsive to adolescents diverse needs. It is then imperative that older adolescents are engaged in one on one interview (in favor of their developmental stage which stipulate that they might be shy to express themselves among peers) to enable them to share freely and openly their knowledge and understanding so that we can find amicable ways of supporting them with their treatment adherence.

Type of Research Intervention

As indicated under the introduction, this research will involve your child's participation in an in-depth interview that will last about thirty minutes.

Participant Selection

The study focus is on exploring barriers to treatment adherence. It is therefore paramount that adolescents with history of poor adherence are considered to take part in the study to enable them to share their experiences and make sound recommendations on how to best address the barriers. Moreover the study strictly chooses adolescents in Omuthiya district catchment area only.

Voluntary Participation

The participation in the study is voluntary. As a guardian and or as adolescents, you have the right to decide not to participate in the study. Your child will still receive the same services as usual even when you choose or they decide not to participate. I am fully aware that it might not be an easy decision for adolescents and their guardians to make especially when the research includes sensitive topics such as HIV treatment adherence. You can ask as many questions as you like and I will take time to answer them. You do not have to decide today. You can think about it and tell me what you decide later.

Procedures

The in-depth interview is planned to take place at the health facility where the selected adolescent is receiving treatment. The exact date of the group discussion will be communicated after the informed consent is obtained and it will be on the treatment follow-up date at the health facility (clinic).

The following applies to interviews:
If your child does not wish to answer any of the questions during the interview, she may say so and the interviewer will move on to the next question. The interview will take place at the clinic where the child is receiving treatment. No one else but the interviewer will be present unless your child asks for someone else to be there. The interview session will be tape recorded and treated as confidential. The recordings will be destroyed after completion of data analysis.

Duration

The interview will take around 30 minutes. The discussions will be guided by the interview guide and there is no other questionnaire that participants are entitled to complete on their own.

Risks

Participants might experience discomfort in sharing their personal experiences since HIV treatment adherence is a sensitive topic. However, as a guardian be assured that your child will not be forced to answer any question if he/she does not wish to do so, and that is also fine. He/she does not have to give us any reason for not responding to any of the question, or for refusing to take part in the interview.

Benefits

There will be no immediate and direct benefit to your child or to you as a parent, but your child's participation will contribute to efforts of improving treatment adherence needs amongst our adolescents in the district. The research findings will also contribute to planning of the national adherence promotion programs for adolescents.

Reimbursements

To avoid extra costs and expenses (such as travelling) associated with the study, the interview will be scheduled on the child's follow-up date at the health facility to avoid additional costs since your child will not be provided with any payment for taking part in the study.

Confidentiality

Little is done on qualitative studies at the health facilities and district at large. Thus this study may be viewed as something out of the ordinary in our respective communities. This means that it will draw much attention out of curiosity, that you as a guardian and your child will be asked questions by other community members. In address this, the gathered data will not be shared for the purpose not in line with the research objectives and it will be kept confidential. Information about your child that will be collected from the research will be put away and no-one but the researchers will be able to see it. Any information about your child will have a number on it instead of his/her name. Only the researchers will know what his/her number is and will store the information in a lockable cabinet until completion of data analysis.

Sharing the Results

At the end of the study, research findings will be published in order for the interested audiences to learn from the study and if possible to use it as baseline study for future research in the same discipline. Confidentiality will be ensured as the participants personal details will not be attached to the findings.

Right to Refuse or Withdraw

As a guardian, you may choose not to have your child participate in this study and your child does not have to take part in this research if she/he does not wish to do so. Moreover, choosing to participate or not will not affect either your own or your child's future treatment at the health facility in any way. You and your child will still have all the benefits that would otherwise be available at the facility. Your child may stop participating in the discussion at any time that she/he wishes without either of you losing any of your rights to treatment.

Who to Contact

If you have any questions or concerns, you can ask them now or later. If you wish to ask questions later, you may contact me at social services Omuthiya District hospital office or alternatively telephonic on 0814030440 or email ester.nefungo@gmail.com.

This research has been reviewed and approved by the relevant Ethics Review Committee at the University of Namibia, which is a committee whose task it is to make sure that research participants are protected from harm. The committee reports to the University's Centre for Research Services. If you wish to contact this Centre, please call +264 61 206 4673 or send an e-mail to research@unam.na.

You can ask me any questions about any part of the research study if you wish to. Do you have any questions?

PART II: CERTIFICATE OF CONSENT

I have been asked to give consent for my child to participate in this research study which will involve her in participating in one focused group discussions with his/her peers.

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have been asked have been answered to my satisfaction. I consent voluntarily for my child to be a participant in this study

…………………………………………………

…………………………………

Name of Parent/Guardian (print) Signature of Parent/Guardian

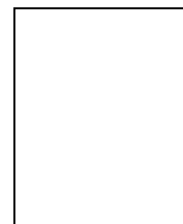
………………………………

Date (day/month/year)

If illiterate

[*A literate witness must sign. (If possible, this person should be selected by the participant and should have no connection to the research team.) Participants who are illiterate should include their thumb print as well.*]

I have witnessed the accurate reading of the consent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.



…………………………………………………

Name of Witness (print)

Thumb print of Participant

…………………………………

Signature of Witness

………………………………

Date (day/month/year)

Statement by the Researcher/Person taking Consent

I have accurately read out the information sheet to the parent of the potential participant, and to the best of my ability made sure that the participant understands that the following will be done:

1. In-depth interview

I confirm that the parent was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this ICF has been provided to the participant.

…………………………………………………. …………………………………

Name of Researcher Signature

………………………………

Date (day/month/year)

If Assisted by an Interpreter: Statement by Interpreter

I have accurately interpreted the information sheet to the parent of the potential participant in …………………………………….. (insert name of target language), and to the best of my ability made sure that the they understand that the following will be done:

1. In-depth interview

I confirm that the parent was given an opportunity to ask questions about the study, and all the questions asked by the parent have been interpreted correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

I declare that I will not divulge any information that I interpret during this research intervention to a third party outside this study.

…………………………………………………. …………………………………

Name of Interpreter (print) Signature

………………………………

Date (day/month/year)

UREC Annex 5C: Informed Parental Consent for Qualitative Studies

INFORMED PARENTAL CONSENT FORM

Epitikilo/ezimino lyomutekuli gokanona taka lumbu nombuto yo HIV/AIDS okuza poomvula 15-19 opo ka kuthe ombinga momapekapeko gena sha *'nomashongo ga taalela epango lyaanona taya lumbu nombuto yo HIV/AIDS yeli poomvula 15-19 moshitopolwa shopaundjolowele Omuthiya'* nelalakano olyo ku hwepo paleka noku yambidha aanona mbaka opo ya tsikile noku dhiginina omiti dhawo.

Omupekapeki:	Ms. Ester Nefungo
Edhina Lyomuyambidhi:	N/A

Epitikilo/eziminino ndika olina iitopolwa iyali:

• Omauyelele (oshitoplolwa shika, okugandja omauyelele shina sha nomapekapeko ngaka)

• Onzapo yezimino (Yina eshaino uuna wa zimina okaana koye kakuthe ombinga)

Oto pewa okopi yeziminino ndika.

OSHITOPOLWA I: OMAUYELELE

Efalemo

Edhina lyandje o Ester Nefungo handi longele uuministeli wuundjolowele nonkalonawa moshipangelo sha Omuthiya. Otandi ilongele ondondo yopombanda monkalonawa moshiputudhilo UNAM. Otandi ningi omapekapeko ngaka nelalakano olyoku hwepo paleka noku yambidhidha aanona taa lumbu nombuto yo HIV/AIDs yoomvula 15-19 opo ya tsikile noku dhiginina omiti dhawo. Onga oshitipolwa shomapekapeko ngaka, onda tothamo aanona yoomvula dhika opo ndiye nayo moonkundathana. Aluhe omapekapeko ga guma uunona, oshuuthwa opo aatekuli yaanona mboka ya tothwamo ya tseyithilwe yo ya gandje ezimino. Nomolwashi nee, oto indilwa nesimaneko enene opo u gandje ezimino opo omunona goye a kuthe ombinga. owa manguluka okupula omauyelele ga gwedhwa po kuyalwe manga inoo ninga etokolo opo okanona koye ka kuthe ombinga. Uuna wa ninga etokolo Okanona

koye ka kuthe ombinga, onkatu ya landulako okupula wo okanona ngele otaka zimine nga ka kuthe ombinga. Amuhe omwa pumbwa okuninga omatokolo mwa manguluka, omanga inaandi tameka. Ombapila ndjika ohashi peya mukale muna iitya kuuyuvite. notandi indile ne wu pule mpa kuuvite sho tandi tsikile nokukupa uuyelele ngaye ndiku fatulile. Nongele ouna omapulo galwe, owa manguluka oku pula ndje.

Elalakano lyomapekapeko

Elalakano oku konakona omashongo ga taalela epango lyaanona taa lumbu nombuto yo HIV/AIDS yeli poomvula 15-19 moshitopolwa shopaundjolowele mOmuthiya nelalakano olyoku hwepo paleka noku yambidhidha aanona mbaka opo ya tsikile noku dhiginina omiti dhawo. Okwa ndhidhilikwa nolukeno kutya yamwe yomaanona yoomvula 15-19 oyena eitulemo mepango lyawo lya nkundipala. Molwa onkalo ndjika, inapu ningwa natango omapekapeko ku konakonwe kutya uunkundi ouli naana peni opo shitu kwathele moku hwepo paleka onkalo, koku talike wo ngele oprograma dhili le po oku nkondopaleka aanona yiitule mepango lyawo otadhi kwathele nga shili. Opo ne pwazi etokolo opo ku ningwe omapekapeko tuuve maanona yo yene kutya onkalo ndjika oyeyi talako ngiini pauyene itaashi ningilwa mokati kayakwawo shaashi yamwe itaa vulu oku manguluka ya popye nawa molwa omatompelo giili nogiili nonkee ne twa tokola opo kehe gumwe ayiwe naye moonkundathana oye awike opo ku talike kutya otaa yambidhidhwa nomikalo dhini po.

Oludhi lomapekapeko (type of Research Intervention)

Ngaashi sha hololwa metetekelo, omapekapeko ngaka oga kwatelamo ekuthombinga lyaanona ta lumbu nombuto yo HIV/AIDS moka wo omumwoye a tothwa mo opo a kuthe ombinga moonkundathana dhomuule ndhoka tadhi kwata uulethimbo wetatawili (30 minutes).

Ehogololo lyaakuthimbinga

Omapekapeko ngaka ogena sha noku konaakona muule omashongo taga nkundipaleke eitulemo mepango ga taalela aanona yepipi 15-19 mboka taa lumbu nombuto yo HIV/AIDS. Onkene osha simana nee kutothwemo aanona mbono yakonekwa yena eitulemo lyankundipala opo ya gandje omauyelele shinasha noonkalo dhawo opo shi kwathele okutulapo omilandu dhoka tadhi kwathele wo ooyakwawo yeli nenge taaka adhika komashongo ngaashi yoo. Omapekapeko ngaaka otaga ningilwa owala aanona yuukwatya wa tumbulwa moshitopolwa shuundjolowele Omuthiya.

Ekuthombinga itali thiminikilwa (Voluntary Participation)

Ekuthombinga momapekapeko ngaka itali thiminikilwa nando. Ongomuvali/omutekuli gokanona ka tothwamo ouna uuthemba woku tinda/ waa gandje epitikilo komunona goye opo ka kuthe ombinga. Shika otashiti nee, Okanona koye otaka tsikile nokumona omayakulo ngashi hakega mono shito uuna a kutha nenge inaa kutha ombinga. Ondina ontseyo kutya kashishi oshipu kaatekuli naanona yamwe okuninga etokolo ndika uunene tuu shashi oonkundatha otadhi tala onkalo yopaumwene yina sha neitulemo mepango. Manguluka upule mpa inoo yelelwa nawa notandi kutha ethimbo opo ndiku fatulile nawa. Natango owa manguluka ukeshi ipule muule washo opo u ninge etokolo lyomondjila ngweye togalukile ndje netokolo lyoye.

Omilandu (Procedures)

Oonkundathana otadhi ningilwa poklinika mpoka omunona ha mono omayakulo konima sha omukuluntu a gandja epitikilo. Shika otashi ningwa nee mesiku lyoka omunona tiile omiti dhe koklinika opo kaa shi gandje okugalukila koshipangelo mesiku limwe kaalina sha nepango lye.

Shika oshina sha noonkundathana:
Ngele Okanona koye oka tokola kaa yamukule omapulo gamwe po moonkundathana, shika itashi imbi nande osha, oonkundathana otadhi tsikile nepulo lya landulako. Oonkundathana otadhi ningilwa poklinika mokanduda kehungomwenyo. Kapuna we gumwe takala po moonkundathana kakale komupekapeki nokanona, shila uuna ngele omunona oye a hogolola akale po naangu a hala. Oonkundathana otadhi ndhindhikwa newi (recording) nuuyelele mbuka otau kalekwa megameno sigo wa dhindwa nawa notawu ka dhimwa po thiluthilu uuna omishangwa (report) yapwa

Ethimbo

Oonkundathana otadhi kwata etatathimbo (30 minutes) nota dhi kwatelwa komeho komapulo geli po (interview guide). Kapuna we omapulo galwe taga ka pulwa nenge aanona ya tegelelika yaka shange.

Omaupyakadhi (Risks)

Aakuthimbinga ashipeya ya kale inaa ya manguluka moku gandja omauyelele shina sha noonkalo dhawo dhopaumwene molwasho eitulemo mepango onkalo tayi gandja omwahwilili (sensitive) ku yamwe. Ashike onga omuvali koneka kutya Okanona koye

ita ka kondjithilwa nande opo a yamukule epulo inaa manguluka okuli yamukula sho shika kashina nande uupyakadhi washa ye ina tegelelika agandje omatompelo gasha.

Uuwanawa (Benefits)

Kapuna nande (There will be no immediate and direct benefit) shimwe tashi gandjwa kokanona nenge Komutekuli konima yekuthombinga momapekapeko ngaka ashike uuyelele owa pumbiwa opo ku ningwe omalunduluko momayakulo noonkambadhala dhoku yambidhidha aanona opo ya dhiginine epango lyawo ngaashi shuuthwa no nande yeli ya taalelwa komashongo ogendji gi ili nogi ili.

Oofuto (Reimbursements)

Opo ku keelelwe oondando dha gwedhwa po ngaashi dhiiyenditho okuya koclinic, shina sha nomapekapeko ngaka, oonkundathana otadhi ningwa mesiku lyokwiila omiti poklinika yawo shaashi kapuna nande ofuto yasha.

Egameno lyuuyelele (confidentiality)

Omapekapeko goludhi nga nduka oga pumba ashike oga pumbiwa. Oko kutya ne, otashi vulika nga ga talikeko ga penga kuyamwe shaashi ye wete inaaga pumbiwa go tageeta nee omapulapulo ogendji komutekuli/komunona kaakwashigwana uuna yeshi mono/uvu. Opo nee ku keelelwe ayihe mbika, omauyelele taga gongelwa itaga pitithwa nande nomalalakano kageena sha nomapekapeko ngaka no taga kala geli megameno. Omauyelele kombinga yokaana koye otaga kala gena onomola peha lyedhina lye. omupekapeki oye owala takala eshi kutya onomola oya kalela po lye, nuuna ayihe yapwa uuyelele mbuka otawu tuulwa po.

Egandjo lyiizemo (Sharing the Results)

Uuna omapekapeko ngaka gapwa, iizemo yolopota otayi shangwa opo mboka yena ohokwe yiilonge mosha yo yamwe ya longithe uuyelele oku tungila ko shina sha nomapekapeko goludhi nga nduka monakuyiwa. Uuyelele wa gandjwa kaakuthimbinga owa gamenwa shaashi kapuna nando uuyelele wawo wopaumwene tau ka shangwa molopota.

Uuthemba wokutinda (Right to Refuse or Withdraw)

Onga Omutekuli gokanona ka tothwa mo, ouna uuthemba woku tinda waa gandje epitikilo opo Okanona koye ka kuthe ombinga. Natango, Okanona koye okena wo

uuthemba opo ka ninge etokolo lyako mokukutha ombinga nenge ka hulile ondjilakati. Shika kashianasha nande nomayakulo gepango lyokanona nenege Omutekuli.

Uuyelele wa gwedhwa po

Uuna wuna omapulo nenge omalimbililo, owa manguluka oku pula ndje paife nenge nale. Uuna wa pumbwa oku pula ndje nale, oto vulu oku ninga etwatathano nombelewa yandje yonkalonawa moshipangelo shaOmuthiya nenge pangodhi konomola yandje 0818710733 nenge ko email ester.nefungo@gmail.com.

Omapekapeko ngaka oga konakonwa nokupewa epitikilo okuza kuungundu konakoni wuna sha nomapekapeko (Ethics Review Committee) koshiputudhilo shopombanda sha University of Namibia, hoka kena oshinakugwanithwa sho ku gamena aakuthimbinga yomapekapeko komaningonayi. Uuna wa hala oku ninga ekwatathano nokangundu haka dhenga ko +264 61 206 4673 nenge u tume etumwalalaka ko e-mail research@unam.na.

Natango, manguluka wu pule epulo kehe una shina sha nomapekapeko ngaka. Ouna epulo?

OSHITIOPLWA II: ONZAPO YEPITIKILO

Onda pulwa ndi gandje epitikilo opo Okanona kandje ka kuthe ombinga moonkundathana dhomuule momapekapeko ngaka.

Onda leshelwa omauyelele agehe. Ondali nda mono nompito yokupula omapulo no gali ga yamukulwa nawa. Otandi gandja nda manguluka epitikilo kokanona kandje opo ka kuthe ombinga ngaashi naye a pitike a kuthe ombinga.

…………………………………………………….

…………………………………

Edhina lyomutekuli (print) Eshaino lyomutekuli

Edhina lyokanona (print) Eshaino Lyokanona

………………………………

....

Esiku ....

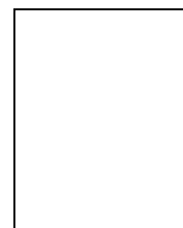
Uuna keshi okushanga nokulesha (If illiterate)

[Omukalelipo eshi okushanga nokulesha nashaineko. (Uuna tashi shiwa, omuntu nguka na hogololwe komukuthimbinga ye ina kala ena ekwatathano nomupekapeki. Uuna omukuthimbinga keeshi oukulesha nokushanga, nastambe nonyala ye.

Ondili ombangi kutya omukuthimbinga okwa fatulilwa nawa, nokwa pula nawa omapulo nota ndi koleke kutya ye mwene okwa gandja epitikilo amangauluka.

…………………………………………………….

Edhina lyombangi (print)



Estambo lyomukuthimbinga

…………………………………

Eshaino lyombangi

……………………………

Esiku

Statement by the Researcher (iitya yomupekapeki)

Onda lesha uuyelele wa yela shina sha nekuthombinga momapekapeko ngaka komutekuli gokanona nonda kala noshinakugwanithwa opo ndi kwashili paleke kutya okwa yelelelwa nawa komukuthimbinga kutya ota kundathanwa naye oonkundathana dhomuule shina sha nomashongo ga taalela eitulemo mepango lye.

Otandi koleke kutya Omutekuli okwali a pewa ompito yoku pula omapulo kombinga yomapekapeko nomapulo ga pulwa komukuthimbinga oga yamukulwa mondjila. Otandi kwashili paleke natango kutya Omutekuli ina kondjithwa opo a gandje epitikilo nokwali eshi ningi memanguluko nokomayiuvo ge.

Okopi yepitikilo ndika oya gandjwa wo Komukuthimbinga.

…………………………………………………….

…………………………………

Edhina lyomupekapeki Eshaino

………………………………

Esiku

Uuna ekwatho lyomutoloki lya pumbiwa(Statement by Interpreter)

Otandi kwashili paleke kutya onda toloka mondjila uuyelele wokombinga yomapekapeko komutekuli gokanona taka kutha ombinga melaka.................................. nonda kwashili paleke kutya ayehe oyuuvako kombinga yoonkundathana dhomuule.

Otandi kwashilipaleke woo kutya omutekuli okwali a pewa ompito yokupula omapulo kombinga yomapekapeko ngaka no gali ga yamukulwa mondjila. Natango, otandi kwashilipaleke kutya okanona inaka kondjithwa opo ka pitike ka kuthe ombinga, ihe okweshi ningi memanguluko.

Otandi gana wo kutya itandi gandja nande uuyelele nda toloka palwe kaashili momulandu gomapekapeko ngaka.

………………………………………………….   ……………………………………

Edhina lyomutoloki (print)   Eshaino

………………………………

Esiku ....

Interview guide: Older ALHIV (15-19 years) Oshiwambo version

Komukuthimbinga,

1. Edhina lyandje o Ester Nefungo (student number 200645714). Ondili omwiilongi moshiputudhilo shopombanda (UNAM) tandi ilongele onkatu yopombanda (Master) monkalonawa yopantu. Otandi ningi omapekapeko genasha nomashongo ga taalela epango ly aanona taa lumbu nombuto yo HIV/AIDS yeli poomvula 15-19 moshitopolwa shopaundjolowele Omuthiya nelalakano olyoku hwepopaleka nokuyambidha aanona mbaka opo ya tsikile noku dhiginina omiti dhawo.

   .

2. Owa hogololwa opo u kuthe ombinga momapekapeko oshoka ouli mongundu yaamboka yuukwatya wa pumbiwa. Otandi ku indile nduno nesimaneko enene opo u manguluke mekuthombinga ndika.

3. Omapekapeko tandi ningi oga pewa epitikilo koshikandjo shomapekapeko moshiputudhilo shopombanda (UNAM) osho wo okuza kuuministeli wuundjolowele moshilongo. Nandi ku kwashilipaleke woo mwaambi:
   a. Ito thiminikwa wu kuthe ombinga ngele ito shi pitika.
   b. Oto vulu ku kala ino tsikila nekuthombinga ethimbo kehe uuna omaiyuvo goye guuvite ngaaka. Kapuna nande oshilanduli oshiwinayi mwaashika.
   c. Ekuthombinga lyoye olili meholamo, Kapena ngu ta tseya uuyelele wagandja kakele komupekapeki. Otashi ti ne, nonando tandi keku pula uuyelele unasha nonkalo yoye, inandi pitikwa nande nande opo ndi gandje uuyelele mbuka kuyalwe yo yeku tseye kutya ongweye weu gandja. nuuna tandi ka shanga kombinga yiizemo yomapekapeko, inashi pitikwa okutumbula omadhina nenge omauyelele taga dhimbululitha aakuthimbinga.
   d. Oonkundathana dhetu otadhi ndhidhilikwa nomauyelele agehe otaga kalekwa megameno, uuna ashike pamwe aakuluntu yandje okuziilila koshiputudhilo taye keg a pula opo ya koleke shat aye ke shi pumbwa. Uuna omauyelele gomapekapeko ga dhindolwa, nena uuyelele otau dhimwapo momukalo gwa gamenwa noguna esimaneko.
4. Ngele ouna omapulo ga gwedhwa po shina sha noonkundathana ndhika, nenge kuuviteko nande, manguluka u pule ndje notandi ku fatulile nawa nenyanyu.
5. Uuna wa pumbwa uuyelele wa gwedhwapo shinasha nomapekapeko ngaka tandi ningi, manguluka u pule, notandi kupe uuyelele oundji wa gwedhwapo.
6. Oonkundathana dhetu otandhi kwata uulethimbo wuli lwopominute omilongo ndatu.
7. Oto vulu okumonandje konomola yandje yongodhi ko 0818710733 nenge ko e-mail ester.nefungo@gmail.com.
8. Uuna wa pumbwa oku ninga ekwatathano noshikandjo shomapekapeko koshiputudhilo shopombanda sha UNAM, nenge una egwedhelepo nenge ekemo lina sha nomapekapeko

	ngaka nenge kombinga yandje, manguluka u dhenge ko (+ 264 61) 206 4673, nenge u tumine ko e-mail to research@unam.na. Nuuna toshi ningi, gandja uuyelele wa yela.
9.	Ondeku pandula unene kohokwe yoye opo u kuthe ombinga momapekapeko ngaka. Tangi!

Omulandu goonkundathana: Aanona yeli poomvula 15-19 noya tseyithilwa kutya omolwashike haya nu omiti

Esiku: **Etameko thimbo:** **Ehulilo thimbo:**

Uukwatya womukuthimbinga

Ocode yomukuthimbinga (AD A,B,C)	
Oomvula:	
Uukwashikekookantu:	
Ondondo yelongo:	
Oomvula eli kepango:	
Edhina lyo clinic:	

Elalakano 1: oku totha mo omayimbo osho wo oku konakona omashongo gopankalathano tageeta enkundipalo meitulemo lyepango maanona yoomvula 15-19.

Omapulo:

1. Tothamo omayimbo nenge omashongo gopankalathano wa koneke kutya otaga yi moshipala nenge tage kwiimbi opo wiitule mo mepango lyoye ngaashi shuuthwa?

Omapulapulo gomuule koonkalo:

- Yopaumwene (oku dhimbwa, oshinyenu, uudhano, kaapuna ohokwe yokunwa omiti, einekelo lyopauntu, ino tseyithilwa nawa kutya omolwashike honu omiti)
- Oonkalo dhomomagumbo (uuteku wankundipala, uupyakadhi oku taamba omaso gaapopepi, oonkalo dhopaliko mwakwatelwa iikulya niiyemo)
- Omashundulo nokatongo (omikalo omiwinayi tadhi shindula notadhi tongola mboka taa lumbu nombuto ngaashi okuyiithana omadhina osho wo omaitaalo (beliefs) ga puka)
- Oonkalo dhopaunamiti (uupyakadhi taweetwa komiti ngashi onkungo)

- o Dhomayakululo koklinika (ethimbo ele momikweyo, omangwandjagulo kaayakulo, ontseyo nuunongo wankudipala, omayakulo goopalela oonkalo dhawo)
- o Oonkalo dhokooskola nenge palongo (elulilo lyiinyangadhalwa yoskola, einekelo maalongi naanaskola)

2. Oho kwashilipaleke ngiini kutya owanwa omiti kehe esiku pethimbo nongaashi shuuthwa?
3. Fatulula ngele owa manguluka nga oku popya kombinga yo HIV naapopepi yoye waana nande uumbanda wokuningwa okatongo nenge okuulwa omalaka omawinayi molwasho to lumbu nombuto yo HIV. Yambidhidha eyamukulo lyoye.
4. Membwalangandjo, ouwete kutya oonkalo nenge omashongo geni taageta aanona yaagundjuka taa lumbu nombuto yo HIV/AIDS opo ya kale yankundipala meitulomo lyoku dhiginina epango lyayo?
5. Kombinga yomikalo dhaa yakuli yetu yopaundjolowele poklinic ototi ko ngiini kombinga yomayakulo hatu mono oku ziilila kuyo genasha nepango lyetu lyo HIV? Uunkundi uni wakoneke tawuyi moshipala eitulemo mepango lyoye?

Elalakano 2: oku tothamo omikaloyakulo (support systems) tadhi vulu okuyambidhidha aanona yoomvula 15-19 opo yawape oku kandulapo omashongo ngono ga taalela eitulemo mepango lyawo. ***(Omomikalo dhini tamu vulu okuyambidhidhwa)***

1. Oto thaneke shike sha pumbwa okuningwa poklinika, kegumbo nomomudhingoloko goye shono tashi kwathele opo wu kale twiitulamo noto dhiginine epango ngaashi shuuthwa? (omayakulo goludhi luni ga pumbiwa ga kale po)?
2. Totha mo kutya eyambidhidho lini po to pumbwa paumwene opo wu kwathelwe wiitulemo nuudhiginini mepango lyoye?

Elalakano 3: oku konakona omikalo dhaanona taa lumbu no HIV/AIDS ngele tashi ya keitulemo lyayo lyepango.

1. Oho kala wuuvite ngiini ngele tashiya kokunwa omiti esiku kehe onkalamwenyo yoye ayihe nomolwashike?

2. Ohashi kuuvitha ngiini nomolwashike ngele to nu omiti dhoye puna aantu yokomagumbo nenge aantu mboka inaa ya tseya kutya oto lumbu nombuto yo HIV/AIDS?

Elalakano 4: oku tala ondondo yeuveko lyaanona taa lumbu nombuto yo HIV/AIDS kutya omolwashike haanu omiti dhepango.

1. Pauveko lyoye, hokolola muule ngele osha simana/pumbiwa tuu opo aanona taalumbu nombuto yo HIV/AIDs ya nwe omiti dhawo esiku kehe ngaashi ya lombwelwa

koshipangelo nomolwashike? osha simana nga okunwa omiti nonande kuna uuwehame washa nomolwashike?

2. Pauveko lyoye, oshike tashi vulu oku holoka monkalamwenyo yomunona ta lumbu no HIV/AIDs ngele ita dhiginine epango lye?

3. Okunwa omiti esiku kehe sigo aluhe otashi lulile yamwe. Oho ningi ngiini uuna wa adhika kombepo ndjino wuuvite wafa inoo hala okunwa omiti dhoye esiku lyoka?

Pehulilo, ouna po shilwe wa hala okushi popya/ okupula? Omathaneko gasha nenge oma gwedhelepo?

Tangi unene sho wali wa kutha ombinga!

INFORMED CONSENT FORM FOR HEALTH CARE WORKERS

Informed Consent of health care workers participating in the research study titled **“**An exploratory study of perceived barriers to antiretroviral treatment adherence amongst older adolescents in Omuthiya district”

Name of Principal Investigator:	Ms. Ester Nefungo
Name of Sponsor:	N/A

This Informed Consent Form has two parts:

- **Information Sheet (this section, to share information about the study with you)**
- **Certificate of Consent (for signatures if you choose to participate)**

You will be given a copy of the full Informed Consent Form.

PART I: INFORMATION SHEET

Introduction

My name is Ester Nefungo working for the Ministry of Health and Social services at Omuthiya District Hospital. I am pursuing a Master degree in social work at the University of Namibia. I am conducting this research study as an effort to support and promote treatment adherence among older adolescents living with HIV in Omuthiya District. You are kindly invited to take part in this research project as a key informant. You are free to consult anyone you feel comfortable talking with about this research study and that you can take time to reflect on whether you want to participate or not. This consent form may contain words that you do not understand. Please ask me to

stop as we go through the information and I will take time to explain. If you have questions later, you are free to ask them of me.

Purpose of the Research

The aim of this study is to explore and identify perceived barriers to ART treatment adherence among older adolescents in Omuthiya district and recommends for possible need based interventions to promote adherence. Although it has been noted with concern that most of the older adolescents have been reported with history of poor treatment adherence, there has not been a single qualitative study to explore this behavioral pattern and assess whether the interventions in place are responsive to adolescents diverse needs. It is then crucial that health care workers rendering treatment and support to adolescents are engaged in key informant interviews to share their practice experience so that we can find amicable ways of supporting adolescents with their treatment adherence.

Type of Research Intervention

As indicated under the introduction, this research will involve key informant interviews with health care workers working with adolescents living with HIV at ART department. It will last about twenty minutes.

Participant Selection

The study focus is on exploring barriers to treatment adherence. It is therefore vital that health care workers involved in the treatment and support of older adolescents living with HIV are considered to take part in the study as key informants to enable them to share their practice experiences and make sound recommendations on how to best address the barriers.

Voluntary Participation

The participation in the study is voluntary. As an eligible health care worker, you have the right to decide not to participate in the study. This will not affect your work in any way. I am fully aware that it might not be an easy decision to make especially when the research includes sensitive topic such as HIV treatment adherence. You can ask as many questions as you like and I will take time to answer them. You do not have to decide today. You can think about it and tell me what you decide later.

Procedures

The key informant interview is planned to take place at the health facility where the staff is working and in a way that it will not interrupt service delivery. The researcher and the health care worker will agree on a suitable time for interview that is scheduled to last for 20 minutes.

The following applies to key informant interviews:
The interview guide will be used. If you do not wish to answer any of the questions during the interview, you may say so and the interviewer will move on to the next question. The interview will take place at the ART clinic. No one else but the interviewer will be present during the interview. The interview session will be tape recorded and treated as confidential. The recordings will be destroyed after completion of data analysis.

Duration

The key informant interview will take about 20 minutes. There is no other questionnaire that you are entitled to complete on your own.

Risks

You might experience discomfort in sharing your personal experiences since HIV treatment adherence is a sensitive topic. You will not be forced to answer any question if you do not wish to do so, and that is also fine. You are not expected to give reasons for not responding to any of the question, or for refusing to take part in the interview.

Benefits

There will be no immediate and direct benefit to you as a health care worker. However, your participation will contribute to efforts geared towards improving treatment adherence needs among adolescents in the district and country at large.

Reimbursements

You will not be provided with any payment for taking part in the study.

Confidentiality

The gathered data will not be shared for the purpose not in line with the research objectives and it will be kept confidential. Any information about participants will have a number on it instead of real names. Tape recordings will be kept safely and will be destroyed after completion of data analysis.

Sharing the Results

At the end of the study, research findings will be published in order for the interested audiences to learn from the study and if possible to use it as baseline study for future research in the same discipline. Confidentiality will be ensured as the participants personal details will not be attached to the findings.

Right to Refuse or Withdraw

You may choose not to take part in this research if you do not wish to do so. Moreover, choosing to participate or not will not affect your work in any way.

Who to Contact

If you have any questions or concerns, you can ask them now or later. If you wish to ask questions later, you may contact me at social services Omuthiya District hospital office or alternatively telephonic on 0814030440 or at email ester.nefungo@gmail.com.

This research has been reviewed and approved by the relevant Ethics Review Committee at the University of Namibia, which is a committee whose task it is to make sure that research participants are protected from harm. The committee reports to the University's Centre for Research Services. If you wish to contact this Centre, please call +264 61 206 4673 or send an e-mail to research@unam.na.

You can ask me any questions about any part of the research study if you wish to. Do you have any questions?

PART II: CERTIFICATE OF CONSENT

I have been asked to give my consent to participate in this research study which will involve me in participating in key informant interview as a health care worker.

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have been asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study

…………………………………………………. ………………………………….

Name of Participant (print) Signature of Participant

……………………………….

Date (day/month/year)