THE ASSOCIATION BETWEEN DISCLOSURE AND ADHERENCE TO ANTIRETROVIRAL THERAPY AMONG ADOLESCENTS LIVING WITH HIV IN WINDHOEK, KHOMAS REGION, NAMIBIA

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ABSTRACT

The study was conducted in Windhoek, Khomas region, Namibia, focusing on adolescents living with HIV aged 10-19 who had been receiving antiretroviral therapy (ART) care for at least six months between 2010 and 2021. It also included healthcare workers who had worked in the ART department for at least six months during the data collection period. The primary objective was to assess the association between disclosure (the process of revealing one's HIV-positive status) and adherence to ART among adolescents living with HIV. A mixed-method approach with an explanatory sequential design was employed. The quantitative component used an unmatched case-control design with a 1:1 ratio, while the qualitative component utilized an exploratory design to complement the quantitative analysis. The study participants included 20 healthcare workers and 37 adolescents living with HIV who were on ART care. Findings revealed that among adolescents with good adherence (≥90%), 76% had been fully disclosed about their HIV-positive status, while 20% were partially disclosed. In contrast, among adolescents with poor adherence (<90%), 92% had not been disclosed about their HIV-positive status. Some adolescents who were fully disclosed learned about their status accidentally. Caregivers of the adolescents and healthcare workers were the key informants in disclosure and adherence aspect. The study recommends strengthening disclosure programs through enhanced efforts by the Ministry of Health and Social Services. This includes training healthcare providers involved in the disclosure process, educating parents/caregivers or guardians about the disclosure process and the skills required to conduct it at home, ensuring equitable distribution of disclosure tools and equipment among health facilities, and implementing standardized disclosure processes through Standard Operating Procedures (SOPs) and guidelines consistently across all health facilities nationwide. Future research should explore factors that enable adolescents to accept their HIV-positive status with reduced distress and examine their experiences during and after disclosure sessions, including their psychosocial support needs. In summary, this study aimed to understand the relationship between disclosure and adherence to ART among adolescents living with HIV in Namibia and provided recommendations to improve the disclosure process and support for these adolescents.

Key words:
Adolescents, Adherence, disclosure, Anti-retro viral therapy (ART), Health care workers.

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LIST OF ABBREVIATIONS AND/OR ACRONYMS

AIDS	Acquired Immuno-Deficiency Syndrome
ALWHIV	Adolescents Living With HIV
ART	Antiretroviral Therapy
ARVs	Antiretrovirals
CD4	Cluster of Differentiation 4 Cells
DAPP-TCE	Development Aid from People to People- Total Control of Epidemic
EDT	Electronic Dispensing Tool
QePMS	Quantum Electronic Patient Monitoring System
HAs	Health Assistants
HCWs	Health Care Workers
HIV	Human Immuno-Deficiency Virus
HREC-H	Human Research Ethics Committee – Health
IIT	Interrupted in treatment
I-TECH	International Training and Education Centre for Health
MoHSS	Ministry of Health and Social Services
PCBs	Patient Care Booklets
PLHIV	People Living With HIV
PMTCT	Prevention of Mother to Child Transmission of HIV
SPSS	Statistical Package for Social Sciences
TB	Tuberculosis
UNAIDS	The Joint United Nations Programme on HIV/AIDS
WHO	World Health Organisation
M&E	Monitoring and Evaluation

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DEDICATION

I dedicate this thesis to Dr. Penehafo Angula, my research mentor and initial supervisor, who greatly assisted in the initiation of the research topic and study focus. Sadly, she departed from us on November 14, 2022. Dr Angula was not merely a guide or mentor, but a beacon of wisdom, inspiration, and unwavering support throughout the initial phase of my research journey. Her sudden departure left an irreplaceable void, and my heart mourns the loss of such an exceptional individual.

Her dedication to knowledge, relentless pursuit of excellence, and passion for research shaped the person I am today. Her guidance, patience, and belief in my abilities pushed me to surpass my limits and strive for greatness. The countless hours we spent discussing ideas, analysing data, and refining methodologies are etched in my memory, serving as a constant reminder of her invaluable contributions to my intellectual growth. Her commitment to fostering a nurturing academic environment was truly remarkable.

My dedication also extends to my daughter Sumaila Siboleka, who made me stronger, better, and more fulfilled than I could have imagined, giving me all the reasons to work hard on this research. May this work inspire her in any academic endeavours she might embark on in the future.

DECLARATION

I, Martha Kachana Manvwali, hereby declare that this study about THE ASSOCIATION BETWEEN DISCLOSURE AND ADHERENCE TO ANTIRETROVIRAL THERAPY AMONG ADOLESCENTS LIVING WITH HIV IN WINDHOEK, KHOMAS REGION, NAMIBIA, 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.

I, Martha Kachana Manvwali, grant the University of Namibia the right to reproduce this thesis in whole or in part, in any manner or format, which the University of Namibia may deem it.

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STUDENT SIGNATURE	DATE

CHAPTER 1: INTRODUCTION OF THE STUDY

1.1 Introduction

The chapter offers an overview of the study, and focuses on the research hypothesis, research purpose and objectives, significance of the study. Definition of key concepts and the demarcation of the field of study, as well as the research design, methods, limitations, delimitations, tools, scope, and ethical considerations in place are highlighted. The chapter gives the structure of the thesis and a summary that outlines the key issues discussed under each of the subsections.

1.2 Overview of adherence to treatment and disclosure of Human Immuno deficiency Virus (HIV) status.

Adherence to treatment is the degree to which a patient follows a treatment regimen, mostly used to describe medication or drug compliance, it requires that the prescription be obtained promptly, and the drug be taken as prescribed in terms of dose, dosing interval, duration of treatment, and any additional special instructions[1]. In the ART management context of Namibia, adherence to treatment is described as the clients' achievement of ≥90% adherence rate of which only 2 to 4 doses were missed in the prescribed period, while non-adherence is achieving an adherence rate of < 90%, of which ≥5 doses were missed in the prescribed period of treatment for all client on ART (adolescents and adults[2]. Disclosure of HIV status to adolescents is the act of telling them that they are living with the HIV, disclosure is not always voluntary or safe, as some health care services require people Living with HIV (PLHIV) to be disclosed to or disclose to others before certain activities pertaining to their health care are done or offered.[3]

People infected with HIV need to have a broader understanding about their status, to have accepted their status and take responsibility for their own health to prolong their lives[4]. The study places a significant emphasis on assessing whether an adolescent's knowledge of their

HIV-positive status influences their adherence to HIV treatment. This is a critical question, as it addresses the relationship between disclosure and treatment adherence, considering the unique challenges faced by adolescents in understanding and managing their HIV status[5]. Additionally, factors such as adolescents' level of maturity and cognitive development can impact their ability to understand their HIV status fully[6].

The disclosure program was successfully implemented in the ART services in Namibia in 2010, and several Health Care Workers (HCWs) have been trained in conducting the process. Before 2010, there were no mechanisms in place in Namibia to inform adolescent clients on ART care of their HIV positive status, which led to HCWs) report experiences of high levels of stress due to their own unpreparedness for talking with adolescent clients about adherence, their HIV status, and caregiver resistance to HIV disclosure. In response, the Namibian Ministry of Health, and Social Services (MoHSS), in collaboration with the International Training and Education Centre for Health (I-TECH), developed and implemented an empirically grounded and theoretically informed 32–37 child disclosure intervention to reduce barriers to and provide support for HCWs and caregivers in the disclosure process, by developing a disclosure tool and curriculum to capacitate and guide HCWs on carrying out the disclosure process[7].

1.3 Background of the Study

Improved access to HIV testing and ART has reduced the number of deaths among adolescents, However, the adolescent population has not made progress in adherence to ART and achieving viral suppression which has resulted in poor health outcome[8]. Globally; 250 000 adolescents aged 10–19 years were newly infected with HIV in 2015, and 41,000 lost their lives in the same year. Diagnosis of HIV infection and taking ART with good adherence are the principal means of suppressing viral load and maintaining a healthy condition[8]. Adherence to ART is a great challenge among adolescents that even after initiating ART, adolescents do not know their HIV status and the actual reasons for taking medicines daily, and such knowledge gaps are critical barriers to ART adherence[4]. In many cases, after adolescents learn their HIV positive status, they commonly improve adherence to ART, which could contribute to delayed disease progression and death[4]. Adolescents and young adults represent over 40% of new HIV infections globally, where ART coverage among adolescents is 74% among girls and 86% among boys[9].

There are challenges that adolescents face during their period of transition from childhood to adulthood[9], they go through behavioural, physical, social changes which enhances their preferences of independence to decide whether to take their ART medicines[9]. Adolescence is sometimes characterised by high-risk sexual behaviour and lack of engagement with health care services that can affect adherence to antiretroviral therapy[9]. The Ministry of Health and Social Services (MoHSS) therefore solemnly promised to put more efforts in the improvement of HIV care and management among children and adolescents[10].

Namibia adopted the World Health Organisation (WHO) definition of adolescents which is 10-19 years old with further classification as younger adolescents (10-14 years old) and older adolescents (15-19 years old)[10]. Adolescence is a time of major transition when young people develop many habits, different behaviour patterns, many of them engage in risky behaviour, develop unhealthful habits that may contribute to poor health in future, a range of health issues can be identified and addressed in ways that can affect not only their function but also the quality of their adult life[6]. It is important to disclose HIV status to adolescents living with HIV (ALWHIV) so that they fully understand and engage in their health care to improve their adherence to treatment and health[11].

Adherence is a crucial factor in achieving best outcomes across diseases' states including HIV/AIDS[12]. The willingness of the adolescents to access health care services can improve after disclosure of HIV status, as their understanding of HIV/AIDS is boosted[11]. While learning about one's own HIV positive status is clearly an emotional and pivotal point in an adolescent's life, fulfilling the right of the adolescents to know their health status is one of the common reasons for disclosure which can translate their health into better[11].

1.4 Problem Statement

Adolescents have been described as the ‘fulcrum’ and the ‘centre of the epidemic’, with 42% of new HIV infections occurring in this age group in 2010 and have been frequently recognised as a vulnerable group to becoming infected and to be marginalised from healthcare provisions[4]. Acquired Immuno-Deficiency Syndrome (AIDS)-related mortality among adolescents world-wide has increased by 50% during 2014 and 2021, according to the joint United Nations Programme on HIV/AIDS (UNAIDS) estimates[13]. The recent data collected from Sub-Saharan Africa shows that only 10% of young men and 15% of young women (15-24 years) are aware of their HIV status. It is also reported that children and adolescents who are aware of their HIV status score higher in quality-of-life assessments and have improved medicine adherence, however adolescents who do not know or understand the reason for taking the prescribed medicines, tend to have a compromised cooperation[14].

The MoHSS in collaboration with International Training and Education Centre for Health (I-TECH), conducted research on paediatric HIV disclosure in 2017, where the adolescents who were screened and included in the study showed that only 11% knew their HIV status, which was found to be extremely low[7]. ALHIV were infected mostly through vertically before the Prevention of Mother to Child Transmission (PMTCT) programme was implemented in Namibia[14]. There was improvement in HIV treatment where infants who were infected with HIV survived to the adolescent age, but later at the adolescent stage, they developed poor adherence habits to care and treatment, poor retention to care after they have interrupted their treatment, which resulted in poor health and well-being[10]. It is within this background that this study intended to analyse the association between disclosure of HIV disclosure and adherence to ART among adolescents.

1.5 Purpose of the Study

This study's purpose was to assess and examine the association between disclosure and adherence to antiretroviral therapy among ALHIV aged 10-19 in Windhoek, Khomas region, Namibia, to compare adherence levels between adolescents who have been informed of their HIV-positive status and those who have not, and intended to answer the question of whether knowledge of an adolescent's HIV-positive status influences their adherence to ART.

1.6 Objectives of the Study

- To assess the level of adherence among adolescents on ART treatment in Windhoek, Khomas region, Namibia.
- To examine the status of HIV/AIDS disclosure to adolescents on ART treatment in Windhoek, Khomas region, Namibia
- To compare the adherence level by HIV discourse among adolescents who are aware of their HIV status to those who are unaware of their HIV status.

1.7 Hypothesis

Null: There is no significant difference in HIV treatment adherence levels and HIV disclosure status among the adolescents in Windhoek district, Khomas region.

Alternative: There is significant difference in HIV treatment adherence levels and HIV disclosure status among the adolescents in Windhoek district, Khomas region.

1.8 Significance of the Study

The result of the study serves to contribute to the understanding of the importance of HIV positive status awareness to adolescents by health care workers, stakeholders, and policymakers. It may help in capacitating HCWs in systematic steps and approaches to achieve full disclosure of HIV positive status to the adolescent clients without hindering their treatment but enhance good adherence and understanding to their treatment. This study is highly significant to the public health sector, offering valuable insights for stakeholders and policymakers into the challenges faced by adolescents, caregivers, and healthcare workers during the disclosure process. These insights can inform the development of standard operating procedures, guidelines, and policies that address these challenges. Furthermore, the study's findings provide valuable information on adolescent HIV disclosure and adherence, which can benefit future researchers exploring this or related topics, aiding in their literature reviews.

1.9 Limitations of the Study

Two biases might have limited the conclusions of this study: the chicken-and-egg dilemma and survivorship bias.

The chicken-and-egg dilemma refers to situations where it is unclear which of two events should be considered the cause and which the effect. In this study, there might have been ambiguity regarding the cause-and-effect relationship between adherence and disclosure. It is unclear whether good or poor adherence was caused by full disclosure or non-disclosure, or whether adolescents' disclosure status (full or non-disclosure) was determined after assessing their adherence levels. To address this bias, the researcher ensured that the interview questions were specific and detailed to determine the cause and effect of disclosure and adherence from each participant. Additionally, they verified the sequence of events using the pharmacy Electronic Dispensing Tool (EDT) and the Quantum Electronic Patient Monitoring System (QePMS) to identify which was captured first.

Survivorship bias occurs when a dataset only considers existing observations and ignores those that no longer exist. In this study, this bias might have been present because investigations were conducted only on active ART adolescents who were up to date with their clinical follow-ups, rather than on those who had interrupted their treatment. "Surviving" or "existing" observations may have been active in care because they were more resilient to the outcomes of disclosure, while others who ceased to be active may have been affected by the same disclosure outcomes.[16]. The researcher identified and excluded deceased, transferred out to health facilities outside Windhoek, and interrupted-in-treatment adolescent ART clients as part of the study's exclusion criteria. Data collection was conducted using pre-existing medical records, but some records had limited data quality as certain variables were missing. To address this, adolescent PCBs (Patient Care Booklets) with incomplete records were excluded from the study. The status of patients can change over time (e.g., patients who were active could become IIT after 28 days of missing a scheduled appointment). However, this was a minor issue and did not affect the sample size, as only active adolescent clients were included in the study.

Obtaining consent from guardians of minor adolescents for interviews was a lengthy process, and many guardians were hesitant to allow participation due to fears of accidentally disclosing the HIV-positive status to the adolescents. To mitigate this, the researcher reassured the participants and provided detailed information to the guardians to ensure they understood the study. Guardians were given ample time to decide without pressure. As a result, only three out of 20 participants from the non-disclosed adolescents' population did not take part in the interviews for the following reasons: guardians refused to give consent, guardians indicated their children were too young for interviews, or caregivers declined participation because the child was not adhering to medication and the interview might have worsened the situation.

The data collection period exceeded the proposed timeframe of 10 weeks due to delays caused by guardians and some healthcare workers postponing interview appointments. This delay affected the analysis and completion of the study report. Consequently, the researcher obtained an extension for the study from the regional director for Khomas, under whose supervision the health facilities operate.

1.10 Delimitations of the Study

The research was delimited to HIV positive adolescents of the age 10-19 years' old who have been on Antiretroviral therapy for less than 6 months, adolescents who were transferred out of the health facilities where sampling of participants was. The study was also delimited to the health care workers that have worked for not more than 6 months in the ART department of the state health facilities in Windhoek district, Khomas region, Location was another delimitation factor as the facilities in the study sample did not include the three state clinics that lie on the outskirts of Windhoek, namely Baumgartsbrun, Groot Aub and Dordabis clinics, due to distance with a very micro number of clients accessing ART services at the facilities.

1.11 Chapter Summary

This introductory chapter presented the background for the study. It provided brief description of the terms adherence to ART and Disclosure to HIV, the rates of disclosure the world, sub-Saharan and in the Namibian contexts. In this first chapter, the background of the study, problem statement, purpose, objectives, significance of the study, limitations and delimitations of the study were presented. The next chapter focuses on the literature review.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

The aim of conducting a systematic search for literature, was to find out what information is known about the research topic[17]. Furthermore, it helped to supply in-depth knowledge that the researcher needs to study about the selected problem[17]. This study's literature review focused on the benefits and challenges of different adherence levels to ART and HIV status disclosure in adolescents. Prior studies that include concepts and prominence of adherence and disclosure were explored. Types of HIV positive status disclosures are highlighted, as well as the barriers in achieving successful disclosure. The literature review highlights approach to achieve successful full disclosure of HIV status to adolescents on ART. The literature search utilized The University of Namibia (UNAM) library, which supplied researcher with related articles and journals. Google Scholar and PubMed were Computerized databases used. Keywords/search words used included "HIV disclosure," "adherence to ART," "HIV in adolescents," some related terms such as "awareness of HIV status" and "HIV treatment" were used. Seach words also included those classified under population groups e.g. adolescent, and those classified under outcome variables e.g. association and adherence level were also used. The Inclusion criteria of literature for the study, looked at relevance, alignment with study scope, and credibility from reputable institutions like WHO, UNAIDS, I-TECH, and MOHSS. Historical studies showing the development of disclosure programs in Africa, particularly Namibia, were included, as well as the literature that was accessible with full text, to avoid incomplete information. Ethical standards in research were also a key inclusion criterion, literature that described this aspect as required were considered. Literature that had non-peer-reviewed sources, such as opinion pieces and non-academic blogs was excluded.

2.2 Context of HIV/AIDS In Namibia

Namibia's major public health and development challenges are mostly influenced by the HIV epidemic, and approximately 200 000 are adults, of which 120 000 are women, with reported deaths of 5000 per year[18]. Reports further show that Namibia has an antenatal HIV prevalence of nearly 18% 30 and over 10,000 children have initiated ART, with scale-up of access to ART[7]. In general, HIV disease progresses faster in children and adolescents than in adults, the reason why good adherence to ART is important to help prevent HIV drug resistance and improve viral suppression, especially among children and adolescents[19].

The approach to disclose HIV positive status is prominent in adolescent ART, assessing how adolescents find out about their HIV positive status helps to decide their belief towards their treatment, which will help decide the level of adherence[20]. The findings of a study done in Tanzania on modality of primary HIV disclosure and association to mental health, stigma, and ART adherence, found that 80% of the adolescents found out about their HIV status on their own without any preparation or enrolment in the ART disclosure programme[21]. Depressive and emotional/behavioural symptoms, internal stigma, incomplete adherence was significantly more in adolescents who found out their HIV status on their own[20].

Other findings from the research study done by Tjituka, in Namibia, on the effect of HIV disclosure and non-disclosure on psychosocial well-being, adherence and treatment outcomes in 2018; one of the pilot sites for HIV status disclosure program was Katutura State Hospital[19]. The study revealed that Katutura State Hospital have enrolled 754 adolescents on ART in 2012 and only 459 out of them were disclosed to their HIV positive status[19]. Another research conducted in Namibia on paediatric HIV disclosure in 2017 by the Ministry of Health and Social Services with I-TECH, had 1466 adolescents screened for inclusion, 314 satisfied inclusion criteria. The results showed that only 34 (11%) knew their HIV status, during the period of assessment, there was a documented full disclosure of 120 (43%) adolescents[14].

The average time to full disclosure was approximately 2.5 years, which concluded that an urgent development of interventions to help health care workers with the challenging and crucial process of HIV disclosure to adolescents and children was needed[14]. The full disclosure of 43% was achieved in adolescents on ART, but still shows a knowledge gap of HIV status among adolescents[14]. The first target in the UNAIDS HIV/AIDS management targets is 90% of the people infected with HIV to be aware of their HIV status, which in this case, 43% full disclosure among adolescents achieved thus far, was still below the target[13,14]. Therefore, efforts and improvements need to be made to achieve successful disclosure among HIV positive adolescents on ART.

2.3 The child/adolescent disclosure intervention conceptual model in Namibia

The Namibia child/adolescent disclosure intervention conceptual model describes how the disclosure intervention process is carried out at the health facilities. First and foremost, the health care workers must have knowledge, skill and possess a good level of comfort in conducting the disclosure process, while care givers should possess characteristics that will enable them to work closely with the heath care workers to achieve successful disclosure outcomes[7]. Care givers should have accepted the HIV positive status of the adolescent, have a maintained level of anxiety about disclosure, they should be confident in the child’s readiness for disclosure and have a maintained fear of child’s reaction during and after the disclosure process[7]. Self-efficacy in the health care workers focuses on offering disclosure and counselling, while that of the care giver focuses on supporting the child/adolescent’s disclosure experience[7]. The age and maturity of the child/adolescent or paediatric client is assessed, after then enrolment in partial disclosure is done, where partial knowledge is imparted on adherence. After this stage is successfully covered, full knowledge of HIV positive status and reasons for adherence is acquired by the child/adolescent[7]. Expectations of boosted self-efficacy, hopefulness and adherence that will result in good health outcomes and maximise growth and potential is worked on through strengthened counselling and support by health care workers and care givers[7].

2.4 Importance of Adherence

Adherence is regarded as a principal factor in achieving best outcomes across the diseases' states[22]. In HIV treatment, poor adherence has the potential to affect outcomes on multiple levels[22]. Adherence to treatment reduces the development of resistance to medication, it improves clinical state of well-being of patients by boosting the functionality of their immune system, for medication to work as intended, they need to be taken as prescribed In ART clinical practice[23]. Adherence to treatment is described as the clients' achievement of ≥90% adherence rate of which only 2 to 4 doses were missed in the prescribed period, while non-adherence is achieving an adherence rate of < 90%, of which ≥5 doses were missed in the prescribed period of treatment[2].

Misconceptions about treatment goals and risks e.g., that ARVs make people fat and the stomach becomes big," embarrassment and shame, particularly around the stigmatisation of PLHIV are among the common reasons why patients might not adhere to treatment[24]. Treatment fatigue was mentioned in Van Wyk's study on challenges to HIV treatment adherence amongst adolescents in a low socio-economic setting in Cape Town; as a profoundly significant barrier to adherence by all participants in the study: feelings of taking pills every day is challenging for many adolescents, as they get bored and always ask if they will ever stop taking these pills; reasons why many adolescents do not like them, which is another compromise to adherence[25]. Participants in Van Wyk' study found the treatment routine associated with ART extremely rigid and were frustrated by the fact that there was no apparent leniency allowed, as they are expected to take the pills same time daily, this has resulted in many missing them[25]. This outlines the importance of the healthcare system to develop strategies that will enhance adherence among adolescent clients/patients.

2.5 Benefits of Disclosure

Disclosing HIV positive status to adolescents could generate complex feelings, commonly, they are strongly distressed when they are informed about their HIV positive status, while some get a feeling of relief, Acceptance of HIV positive status would not be an easy process[3]. Adolescents have the right to be given correct information about their HIV positive status, and the purpose of taking medicine and having regular check-ups at the hospital when their level of understanding is ready enough to process the news[3]. Health care workers believe that adolescents should be told about their status as soon as possible to motivate them in taking full responsibility for their health[20].

2.5.1 Benefits to the care givers

Disclosure relieves the stress and anxiety among caregivers that goes with deception and secrecy and develops a trustful relationship and a more open communication with the child, cooperation from the child is improved, easier access to other services and support for the child is made easy[3].

2.5.2 Benefits to the adolescents

Disruptive behaviours that might hinder adherence to medication and clinical outcomes may improve[21]. the functioning of the child socially, academically, may as well improve, willingness of the child to access health care services can greatly be enhanced as the child's understanding is boosted[20].

2.5.3 Benefits to the health care worker

Interaction with the adolescent may improve, openness relationship between the HCW and the child is more likely to improve[14]. The health care worker can then give correct information on health care issues and HIV/AIDS without using deceptive words to avoid revealing HIV positive status accidentally to the adolescent[3]. The adolescent's freedom to ask questions to the health care worker and discussing more about the disease to fill in knowledge gaps is enhanced[3].

2.6 Types of HIV Disclosure

There are two classifications of disclosure, which is non-disclosure and Full disclosure, under which there are five subtypes in each class [7,9]. Non-disclosure comprises of complete non-disclosure, partial disclosure, and deception[13,14], while full disclosure can occur in different approaches, namely accidental or through the disclosure program in health care facilities [7,9]. Detailed definitions are described below:

A ***Complete Non-Disclosure***: In this pattern, no information about the disease or why the children take their medicines is given to the child, all the questions are either ignored or general information is given in response to those questions[3]. It supplies no added insight of health[3]. For example, "we are going to the hospital so that doctor can check your health." This is also challenging because when the child begins to be rebellious when it is time to go to the doctor or drink their medicines, the caregiver might use force to make the child take the medicines[7].

Partial Disclosure: This is when an insight of information about HIV is supplied but HIV is not mentioned, meaning the information is partially true, which includes information that will help the child take the medication to reduce symptoms and other health disorders[3]. For example, telling the child "when you take the medicines well, you will have many soldiers to keep you well, you must remember taking your medicines at the right time to keep the *bad guy* that attacks your body *soldiers* in your body to sleep", In this statement Cluster of Differentiation 4 (CD4) cells are referred to as soldiers, while HIV is referred to as the bad guy, the statement is truly an encouragement to the child to take their medicines because if they don't, the bad guy will wake up, in this type of disclosure, the truth on who the bad guy is, not revealed[7]. Adolescents with partial disclosure are in the initial 4 chapters of the disclosure toolkit in the programme that do not reveal who the bad guy is[7].

Full Disclosure: Unlike in partial disclosure, the truth of the terms ``Bad guy,' "soldiers" and "medicines" is known[3]. The bad guy being HIV, the soldiers being CD4 cells and the medicines being antiretroviral medicine[3]. Full disclosure is the last step or exit step of the disclosure programme and is the most challenging and critical phase in adolescents' disclosure[3,7]. Health care workers and the caregiver must be ready to tell the truth to the child/adolescent, and for full disclosure to take place, the child/adolescent must have gone through partial disclosure, because a foundation of the understanding of why they take their medicines is a requirement by MoHSS toolkit[11].

***Deception*:** The information given to the child about why they take their medicines is not true, instead of the caregiver saying they drink the medicines because they are HIV positive, they focus on other health conditions, for example telling them they have Anaemia[3]. Some caregivers may mention that there's something in the adolescents' stomach that they don't want to grow because it will make them very sick[9]. This is not much safe as it is against the ethical notion of truthfulness, it might potentially create false understanding of the disease by the adolescent, the adolescent may find out about the truth accidentally, and will start blaming themselves by asking: e.g., "what did I do to God", "why me", "what did I do to deserve this" …they will not trust or believe their caregivers or health care workers in much severe situations, and this might hinder their adherence to treatment[8,11].

***Accidental Disclosure*:** Telling the child or adolescent about their HIV positive status without preparing them, bringing them to know their HIV positive status by accident[3]. It is usually done unintentionally, for example when the adolescent overhears the caregivers or health care workers discussing the adolescents' HIV positive status[14]. Accidental disclosure requires the health care worker to act on at least partial disclosure of an HIV status to the adolescent, a readiness assessment and discussion with the parents or caregivers should be undertaken as soon as feasible as possible[14].

2.7 Process and steps in Successful HIV Status Disclosure to Adolescents

In the Namibian disclosure program, enrolment into the disclosure program begins at the ages from of 5 to 8 years old, while full disclosure is to be done from 9 to 14 years old[14]. Baseline and updated information to what the adolescent knows about his or her health care is gathered, the health care workers then ascertain the relationship of the caregiver to the adolescent, which helps to support adolescents during the entire disclosure process[14]. After successful full disclosure is done to the adolescent, they are linked to support groups e.g., Teen clubs and youth groups, that involve activities that are geared towards adolescent education and coping with long-term treatment[7,11,14].

A disclosure cartoon book called “why I take my medicines' is an intervention tool that was developed to help as a guide in HIV disclosure to children and adolescents in Namibia[7,11]. The book was intended for use by health care workers who have been trained on its use and has five chapters which function as systematic steps to follow in the disclosure programme, the health care workers includes Registered/Enrolled nurses, Medical Doctors, Pharmacists, health assistants, community health care workers, Namibia adolescent treatment supporters, HIV nurse/clinical mentors and HIV program managers, social workers, psychologists, paediatricians and child welfare officers, that have received MoHSS training in Paediatric HIV disclosure[7,11]. Before the health care workers read this book with the adolescent, they must show it to the caregivers and get their permission, health care workers and caregivers can decide together how far to go with the chapters, before they start reading[11,14].

The disclosure intervention tool describes the disclosure process as follows: chapter one introduces the adolescents to parts of their bodies called body soldiers, that help keep them from getting sick, and help them get better faster when they get sick, it draws their attention to the need of consistency in taking treatment as it helps their bodies produce many soldiers and how this will keep them healthy to grow up and live to achieve their dreams[7]. Chapter two points out the importance of treatment by informing them about the bad guy that attacks their body soldiers that becomes powerful and unstoppable if they do not take their special medicines[7]. Chapter three informs the adolescent of the importance of adherence by educating them on ensuring that they all the time need to remember to take their medicines on time, pack them along if they are travelling, so that medicine blanket covers the bad guy and avoids him from waking up[7].

The consequences of not taking treatment are then highlighted in chapter 4, where it states that if the adolescent forgets to take their medicines the bad guy will wake up to attack the body soldiers because the medicine blanket will no longer be there, and the adolescent will end up very sick[7]. Chapter five outlines the process of full disclosure and begins with the word STOP! to caution health care workers about its sensitivity. Health care workers and care givers must be sure that the adolescent is ready for full disclosure. The body soldiers are revealed as CD4 cells, the bad guy is revealed as HIV, and the special medicines are revealed as ARVs[7]. Discussions and counselling emphasize more on strengthened post full disclosure to the adolescents at their ART follow-up visits to ensure their psychosocial wellbeing is stable and assess adherence changes to treatment and manage further[7].

The five chapters in the disclosure intervention tool kit ensures a systematic and successful process to inform adolescents about their HIV positive status, but may influence adherence in two different ways, where the adolescent might continue to be adherent to treatment, since they understand the reasons of treatment or they will end up having poor adherence due to the emotional breakdown of having the deadly virus in their bodies, hence the importance of strengthened post full disclosure counselling[7,25,26].

2.8 Barriers to Successful HIV Status Disclosure to Adolescents

Transition to adulthood is a difficult period for adolescents even for those without HIV, they experience physical, cognitive changes and maturation, these changes in their bodies affect their emotions and behaviours[6]. HIV adds to the burden and might lead to them defaulting in taking their medicines[1]. Opportunities exist to affect adolescents and in emerging young adults' prognosis, through their own understanding and ownership of the disease process, depending on the resilience and the support system that the adolescent has, knowing his/her HIV status can be remarkably valuable or potentially devastating[25].

2.8.1 School Factors

Communication with schoolteachers and negative teacher attitudes are some factors found to play a deterring role in caregivers ensuring access to regular clinic visits by their children[25]. Adolescents often express conflicted feelings between school commitments and the need to attend clinic appointments and become difficult with non-disclosed adolescents as they question or rebel the prominence of clinic visits, which to them are seen as conflicting their school schedules[25]. The need of caregivers to communicate adolescents attending regular clinic visits to teachers and adolescents themselves, pose a significant barrier to attending regular clinic follow-ups as they fear unintended disclosure which may potentially lead to stigma and discrimination of their children by teachers or learners[1,25]. Frequent absenteeism may lead to unintended disclosure of the HIV positive status to the adolescent and teachers, many caregivers have indicated school as an obstacle to enrolment of their children in the disclosure program[1,25]. It is well documented that if adolescents have been disclosed to their HIV positive status in a more organised and professional way through the disclosure program in health, they are more likely to seek help in the form of knowledge and resources to help them cope with a HIV diagnosis and to access and remain in HIV care, further recommendations were that educators should be sensitised to be competent in HIV management – to handle HIV disclosure of learners with sensitivity and understanding[1].

2.8.2 Health care system Barriers

Health care workers reported to experience high stress levels due to their unpreparedness of interacting with HIV positive adolescents about their HIV status, adherence, and the resistance of caregivers to disclosure[7]. This is one challenging activity in adolescents ART care, health care workers do not know the background of the living conditions or family set up of the children, it becomes challenging to figure out the best way to approach them and contributes to slow achievement of successful disclosure[7]. The most common challenge experienced by People Living with HIV (PLHIV) in Namibia is fear to transit HIV, followed by limited support for disclosure, and limited information on disclosure[14]. Caregivers raised fears that the flow of patients at many health facilities may lead to unintended disclosure of their adolescents' HIV positive status, because the area in which they waited in the clinic gave a clear indication of the services patients are coming for, in many situations, caregivers would rather not turn up for their children's clinical visits, they wish to stay home, to avoid the consequences of the child/adolescent knowing about their HIV status[26]. In previous studies, parents were reluctant to disclose HIV positive status to their adolescent children, due to fears of losing reputation and being blamed by them for transmitting HIV to them[26]. Most caregivers do not disclose HIV positive status of their children to them due to so much underlying fears they have; social rejection and isolation of their children from them and the world, they fear parenteral sense of guilt by blaming themselves that if it were not for them, their children would be HIV negative, they worry that the child will not keep the diagnosis to themselves and might spread the situation to friends and family[26]. They also fear that it might affect the psycho-social well-being of their child, especially with the existing stigma on HIV world-wide, furthermore, they indicated that the child 'self-esteem might be lost, the child might get into depression, where they’ll have wishes of turning back time and change the events of the past, and the elevated feelings of unworthiness among other people may influence suicidal thoughts among HIV adolescents[21,26].

2.9 Chapter Summary

The researcher analysed the current literature specifically on HIV disclosure and ART adherence, which extended to the exploration of the importance and benefits of HIV disclosure and adherence to ART among adolescents. Various barriers related to HIV disclosure, adherence to ART were illustrated and described. This highlights the significance that this study has in contributing to the understanding of the current disclosure processes in Namibia, and its influence of ART adherence among adolescents, to health care workers and policy makers, to be able to make informed decisions on ART care strategies and SOPs, guidelines content that will address these areas, which will as well contribute to the identification of possible interventions to improve levels of adherence and disclosure approaches for the adolescent ART clients in health care. The next chapter focuses on research methodology.

CHAPTER 3: RESEARCH METHODOLOGY

3.1 Introduction

This chapter covers the techniques that were used by the researcher to structure the study, to gather, and analyse information relevant to the research hypothesis. The researcher describes the research methods that were applied during the study systematically. Methods includes defining study population, sample selection, determining sample size, process of data collection and data analysis. Listing of independent and dependent variables is as well be covered in this chapter.

3.2 Research Design

This study used a mixed method approach, with an explanatory sequential design to assess the association between disclosure and adherence to antiretroviral therapy among ALHIV aged 10-19 in Windhoek, Khomas region, Namibia. The quantitative part was an unmatched case-control study using client care data related to HIV disclosure status and adherence outcomes which were collected and captured on the Electronic Dispensing Tool (EDT), the Quantum Electronic Patient Monitoring System (EPMS) and Patient Care Booklets (PCBs), which capture all HIV treatment information and monitoring data. The study used a case-control ratio of 1:1 to ensure equal representation from all the groups for comparison. The collection and analysis of quantitative data was supplemented by a qualitative exploratory design, to support the quantitative analyses. The qualitative approach helped to explain and interpret the quantitative results about disclosure and adherence to HIV treatment. The qualitative approach was collected data through key informants from both health care workers and adolescents. The independent variable in this study is disclosure, which is classified as the cause, while the dependent variable is adherence, classified as the effect.

3.3 Study Population

Quantitative: The quantitative part of the study target population consisted of Patient care booklets for adolescents between 10 and 19 years who were registered to receive ART at all government health facilities that offer ART services in Windhoek district from January 2015 to January 2016 and who were on ART for at least 6 months which are according to the MOHSS and I-TECH were estimated at about 130 active adolescent patients, and those that new their HIV positive status were 11% [7,14] constituted the target study population. The period of 2010 is referenced to the year in which the paediatric disclosure program was implemented in Namibia[11].

Qualitative: The population under the qualitative part were the key informants who were the HIV positive adolescents enrolled in HIV care and the health care workers (Registered/Enrolled nurses, Medical Doctors, Pharmacists, health assistants, community health care workers, Namibia adolescent treatment supporters, HIV nurse/clinical mentors and HIV program managers, social workers, psychologists, paediatricians and child welfare officers) that have received MoHSS training in Paediatric HIV disclosure and are working at the ART sites of the health facilities. Hence, the conduction of interviews for health care workers at 7 facilities within Windhoek district.

3.4 Inclusion Criteria

Quantitative: This study focused on adolescents aged 10-19 years old in 2022 who were enrolled in ART care between 2010 and 2020, a period when disclosure was implemented in Namibia. The adolescents who were currently active on ART and had documented treatment records in QePMS, PCBs, and/or the EDT within state health facilities in Windhoek district were included. The study included HIV-positive adolescents in state/public health facilities, as these facilities had accessible data and provided more comprehensive records compared to private health facilities. Adolescents with full disclosure dates were included as cases, while those enrolled in disclosure without full disclosure dates were considered controls.

Qualitative: This study included health care workers who were offering HIV care services to the adolescent population for at least 6 months and more because they have a reached a stage of viral suppression and have diverse information to give pertaining to their health care. The latter were the key informants in supplying in-depth and detailed information about disclosure and adherence through their observations and experience, they so far have in ART management.

3.5 Exclusion Criteria

The study excluded HIV-positive adolescents aged 10-19 who had been on ART for at least six months but had incomplete patient records (e.g., incorrectly filled, missing data, or no records) to avoid inconsistencies that could lead to erroneous conclusions. Additionally, face-to-face interviews were not conducted with HIV-positive adolescents in this age group who had interrupted their treatment (IIT) or were seeking ART services as in-transit patients outside the Windhoek district due to the difficulty and extended time required to locate these clients. Health care workers offering HIV services to adolescents in the ART department for less than six months were also excluded, as they would lack extensive experience and information over time.

3.6. Study Setting

All state and public healthcare facilities in the Windhoek district of the Khomas region were included in the study, except for one referral hospital where ART services were discontinued, and clients were redistributed to other facilities. The selected facilities provide ART services to patients. The clinics on the outskirts of Windhoek were excluded due to their lack of paediatric and adolescent clients, as well as the logistical and financial challenges of conducting interviews with clients residing on nearby farms. The study was conducted across 7 facilities, comprising of one hospital, two health centres, and four primary clinics.

3.7 Sample and Sampling Method

Quantitative: The researcher obtained a sampling frame from the MoHSS QePMS, of all active adolescents who were aged 10 – 19 years during the enrolment period (2010-2021) where the study sample was drawn. To determine the number of participants to who were interviewed for the study, a formula was used to determine the sample size from the study population stated above, at 95% confidence interval, with the ratio control of 1. A simple random sampling method for cases and controls was used at facility level to select the study participants. The simple random sampling method reduces the chance of sampling error, thereby ensuring equal chance of participation[27]. The study population consisted of 65 cases and 65 controls, for each group's total sample was multiplied with the proportion of active patients for each facility to determine and increase the fairness and representation of all facilities. The sample size for this study was **40** participants. The researcher used the obtained sampling frame from the ministry of health and assigned them unique numbers from 1 to 130. The researcher used a Microsoft excel to generate a random number table using [=RAND ()] formula. This allowed the selection of 40 participants using the table, corresponding to the number of the sampling frame. Participants who were already selected and assigned a number were omitted. The study used an unmatched cases control by employing Fleiss with continuity correction equation in Epi info version 7.2.5.0 to estimate the sample size. The Epi info computation is illustrated below.

The cases in this study were the active HIV positive adolescents on ART who were fully disclosed of their HIV status, and the controls were the HIV positive adolescents on ART who were not disclosed of their HIV status.

Qualitative: A non-probability purposive sampling technique was used by recruiting health care workers (Nurses, Doctors, Health Assistants, Pharmacists) that have worked in the ART department for at least 6 months and more. The latter was the key informant in supplying in-depth and detailed information about disclosure and adherence through their observations and experience. A multistage sampling method was employed on the adolescents, selecting a calculated sample of both disclosed and non-disclosed adolescents from the quantitative data, to be interviewees in the study. This sampling approach was chosen due to the small population of 130 active adolescents in the Windhoek District during the data collection period.

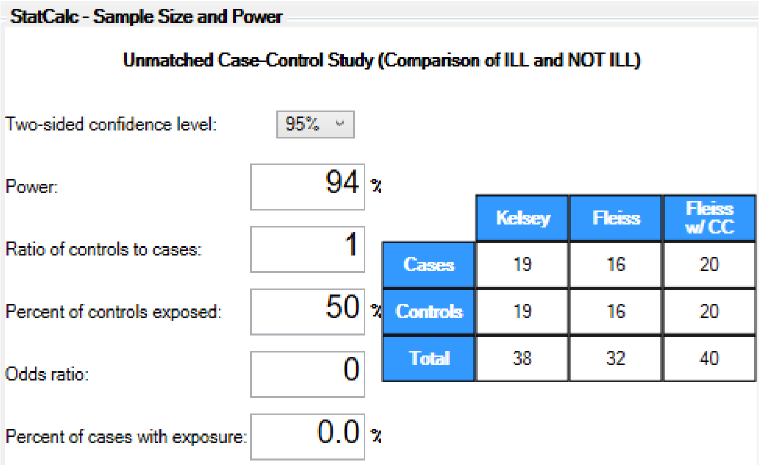

Table 1. Sample table

Health Facility	Population-Total number of active HIV positive adolescents on ART per facility	Sample size per facility
Donkerhoek Clinic	6	1
Hakahana Clinic	7	3
Katutura Health Centre	9	4
Katutura Intermediate Hospital	67	21
Khomasdal Health Centre	17	4
Maxuilili Clinic	20	6
Robert Mugabe Clinic	4	1
Windhoek District	Total population=130	Total sample size=40

3.8 Research Instruments

In addition to the data acquired from three MoHSS data sources, additional information on adolescent participants was collected with interview questionnaires which was developed based on the literature to assess the association between HIV disclosure and adherence for adolescent patients. The questionnaire consisted of structured, semi-structured and unstructured questions to get in-depth information from the participants. Section one of the questionnaire consisted of the variables on demographic features that are not part of electronic systems such as marital status, education attainment and occupation. Section B filled the gap of extracted data from the PCB, EDT and Quantum EPMS system for adolescents which cover data which includes, clinical and treatment outcomes in terms of adherence levels and status of HIV disclosure. Semi-structured interview guides were developed for qualitative data collection, to allow the researcher to ask specific questions and probe. Semi-structured interviews also allowed participants to open up, as both closed ended and open-ended questions were included. The questionnaires were in English at the basic level. The participants explained everything that they did not understand to ensure quality of the data. In addition, if need arose the researcher could have identified a translator for languages that participants would be comfortable using other than English.

3.9 Measures of Validity and reliability and to avoid bias.

To ensure validity and reliability, the researcher employed data triangulation by cross-verifying information from multiple sources, including PCBS, QePMS patient records, and pharmacy EDT systems. Investigator triangulation was also utilized, involving a statistician in data analysis and interpretation to minimize individual biases. Standardized tools were used for data collection: questionnaires for each healthcare worker and adolescent in the qualitative approach, and a checklist with standard variables to maintain consistency throughout the data collection process. Simple random sampling was employed to avoid bias. During interviews, guiding questions were avoided, and probing techniques were used instead.

3.10. Data Collection

3.10.1 Recruitment of participants

After securing research approval, ethical clearance, a permission letter from the university, and permission from the Ministry of Health and Social Services (MoHSS), the researcher began data collection. For the quantitative phase, participants were recruited from the QePMS list, considering that multistage sampling method was employed on the adolescents, where the calculated sample of both disclosed and non-disclosed adolescents from the quantitative data, to be interviewees in the study. This sampling approach was chosen due to the small population of 130 active adolescents in the Khomas region during the data collection period. Caregivers were contacted by phone, informed about the study, and briefed on the involvement of their adolescents. Appointments were scheduled based on the caregivers' availability, considering the adolescents follow-up date for ART care. Consent was obtained from both the caregiver and the adolescent participant before proceeding.

3.10.2 Data collection process

To interview 40 adolescents and 20 healthcare workers, the researcher required a 12-week period, averaging at least three interviews per week. Depending on participants' schedules and availability, interviews were conducted at the respective health facilities where clients received care, ensuring a conducive, comfortable environment that maintained confidentiality and privacy. Face-to-face interviews were used to administer questionnaires, as adolescents might not fully understand the medical language used in the study. This technique allowed participants to provide their own responses without assistance, preventing accidental disclosure and preserving privacy. Additionally, this method was chosen for its simplicity, cost-effectiveness, and time efficiency compared to other methods. Interviews were recorded using a voice recorder.

3.11 Quantitative Data Analysis

The data analysis process started with data verification for completeness from QePMS and EDT, the data where then linked based on the client's unique ART number, de-identified then transferred into Statistical Package for Social Science (SPSS) version 22 for analysis. Quantitative data analysis started with analysing frequency tables and graphs on the following variables such as: age, gender, and type of health facility of the findings in interviews of HIV positive adolescents. These descriptive statistics were formatted using Microsoft Excel 365, since it gives a change for better enhanced graphics and allows easy alteration of charts when necessary.

3.12 Qualitative Data Analysis

The research utilized audio recordings and notes during face-to-face interactions with adolescents and healthcare workers. Qualitative data analysis began with transcribing the audio recordings into text using Microsoft Word. Overarching themes were identified manually from the participants' responses. The themes were reviewed and refined to ensure they accurately represented the data, which involved combining, splitting, and discarding themes as necessary. Different coloured highlighters were used to organize and distinguish the themes systematically, ensuring clarity and avoiding mix-ups.

3.13 Research Ethics

Ethical principles of respect for research participants, prevention of harm and ensuring good and fairness to research participants was observed in the study[17]. Codes of ethical research applied to protect the rights of the research participants[17]. The researcher has the right to search for truth in the most rigorous way, but never at the expense of the rights of individuals and communities[27].

The following principles were adhered to as per University of Namibia ethics guideline:

Respect

In this study, approval of the research from the University of Namibia was granted, following the Ethical clearance certificate from the University's Decentralised Ethical committee of Oshakati Campus, together with the permission letter from the University. Permission was granted from the Ministry of Health and Social Services: Office of the Executive director, the regional director for Khomas directorate MoHSS and from the medial superintendent of intermediate hospital Katutura, to interview and review documents and records of the HIV positive adolescents on ART and the health care workers working at the ART sites. Permission granted by the Ministry of Health and Social Services was presented to the health facility managers and obtained their permission to conduct the data collection. A written informed consent form was given to health care workers and adolescents who were 18 years and above or guardians of the minor adolescents (<18 years old), who took part in the study.

Autonomy

was applied where all participants were provided with the option or liberty to have full control of what happens to them, they were given an opportunity to indicate how they would want to be addressed by the researcher, as a way of respecting and complying to their cultural beliefs and sexual orientation. There are participants that preferred to not have eye contact with the researcher as it was not culturally acceptable to them, and this was highly respected and followed by the researcher.

Confidentiality and Privacy

This was maintained by using an anonymity strategy of distributing codes to participants, such as: 422-1022-01 for adolescents, 422 being the facility code, 1122 representing month and year of interview, and 01 being the sequential number of participants interviewed. Among HCWs 1, 2, 3…; thus, no names of participants were written on the transcripts, checklists. The 9 facilities were coded according to this order: Health Centres: HC, Clinics: C, Hospital: HP.

No maleficence

No harm or discomfort in any form was endured by all participants: Participants for the study were not patients, but clients in ART care, so they were not in any physical illness that could compromise their health function during the interview, should there have been any participant who was not in a good state of health, the researcher would have differed the interview session in agreement with the participant.

Beneficence

The welfare of participants was prioritised, this was applied before any consent giving by participants and caregiver to researcher was done. The researcher explained the research study and its aim for the participant and care giver to understand that the study focused on the awareness of HIV positive status and based on adolescents' experiences, which might have an impact on their emotional and psychological function. Participants were assured of their rights that they may withdraw from the study interview if they felt uncomfortable in any way. They were encouraged not to answer questions that may upset them or that they felt not to answer due to discomfort or any other reasons. The researcher ensured that the language used were that of the participant's choice. For participants that came for both interview and clinical appointment, were taken to the consultation room first before interview and did not have to wait in ques.

Justice

Fair selection of study participants was assured, participants had equal treatment, with no form of discrimination of race, level of education, employment status, religion, age, sex etc.

Participants were selected for reasons directly related to the research problem, not because they were readily available. Participants' rights to fair selection and treatment were followed.

3.14. Chapter Summary

This chapter focused on the methodological aspects of the study, detailing the research design, population, inclusion and exclusion criteria, sampling, data collection procedure, data analysis of qualitative and quantitative data, and research ethics. Validity and reliability of the study were described. The next chapter will present the research results.

CHAPTER 4: RESULTS

4.1 Introduction

This chapter presents the data collected, results of statistical analysis done and interpretation of findings that are presented in tables and graphs. This chapter is further divided into subdivisions into three main sections as per research objectives. This section: 4.1 introduces the chapter, Section 4.2 provides qualitative and quantitative results of participants, both adolescents and health care workers.

4.2 Results

4.2.1 Quantitative analyses for adolescent participants.

This section outlines the demographic data of adolescents, which is segregated and displayed in the following categories: Age, sex, educational level and qualifications, occupation, primary care giver, and clinical information that comprise of disclosure status, regimen line, duration in ART care, adherence level by ART duration, viral load status by adherence and adherence level by disclosure. The detailed information on the characters of the adolescents is well outline in Appendix K.

4.2.1.1 Adolescent Demographic Information

Table 2: Disclosure status by facilities for ALHIV enrolled in health facilities in Windhoek, Khomas Region, Namibia, 2010-2021 (n=37)

Health facility (identified in codes)	Disclosure Status (in quantum EPMS)				
	Disclosure		Not disclosure		Total
	Frequency	Percent	Frequency	Percent	
C 1	1	100.0%	0	0.0%	1
C 2	0	0.0%	4	100.0%	4
HC 1	0	0.0%	2	100.0%	2
HP 1	18	85.7%	3	14.3%	21
HC 1	0	0.0%	5	100.0%	5
C 3	0	0.0%	3	100.0%	3
C 4	1	100.0%	0	0.0%	1
Total	20	54.1%	17	45.9%	37

Table 2 shows the distribution of the adolescent participants among the health care facilities by disclosure status in Windhoek, Khomas region. Overall, 54% (n=20) of the participants who participated in the study were disclosed while 46% (n=17) of the participants were not disclosed of their HIV status.

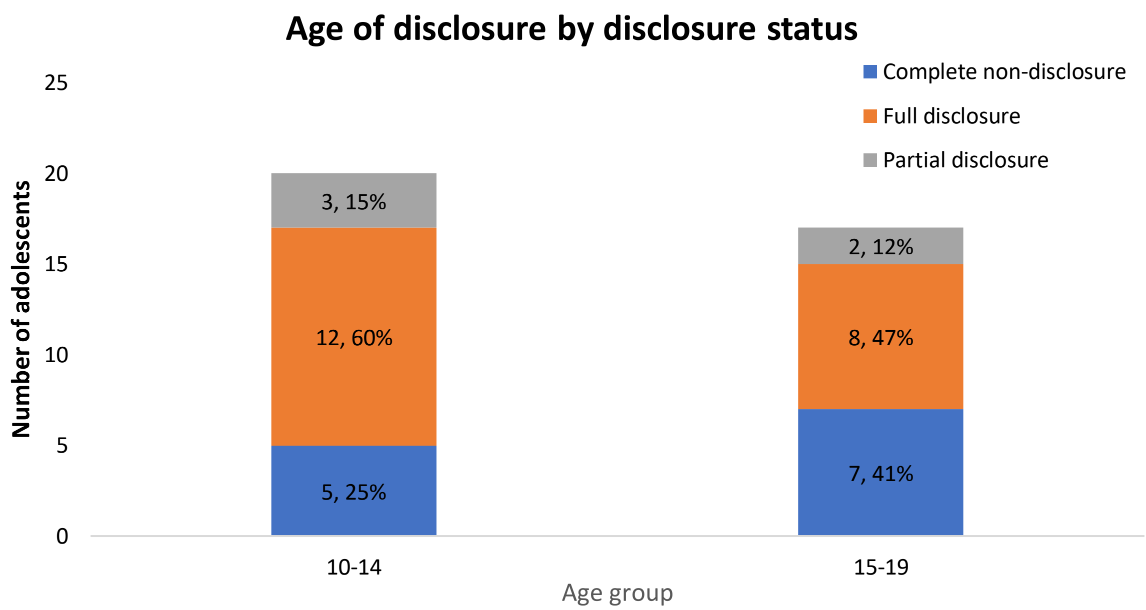

Figure 1. Age and disclosure status of ALHIV enrolled in health facilities in Windhoek, Khomas Region, Namibia, 2010-2021 (n=37)

Fig 1 illustrates that many adolescents living with HIV were mostly disclosed within the age group of 10-14. The first case of AIDS in Namibia reported in 1986; Namibia's epidemic has since matured with a changing profile of children and adolescents in need of HIV care[14,28]. The number of newly infected children and adolescents increased from 500 in 1990 to a peak of 3600 in 2002, when PMTCT was introduced, the decline to <378 by 2020 was observed[18]. This illustration displays that the disclosure program interventions are carried out at the earliest ages for better and improved outcomes in desired health care status.

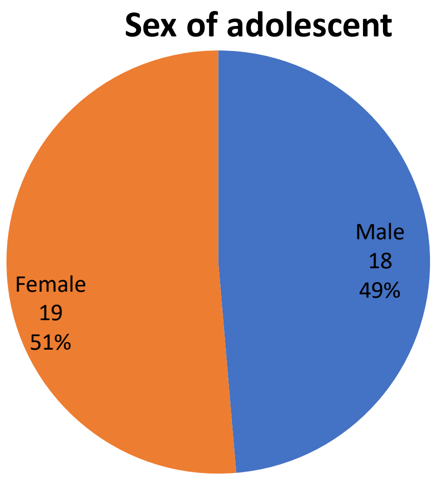

Figure 2: Sex of ALHIV enrolled in health facilities in Windhoek, Khomas Region, Namibia, 2010-2021 (n=37)

It is depicted in figure 2 above that about 49% (18) males and 19 (51%) females' adolescents that participated in the study. This figure does not represent any significant output between male and female adolescent populations, it just visualises the sex distribution among the adolescents that took part in the study.

4.2.1.2 Adolescent clinical information

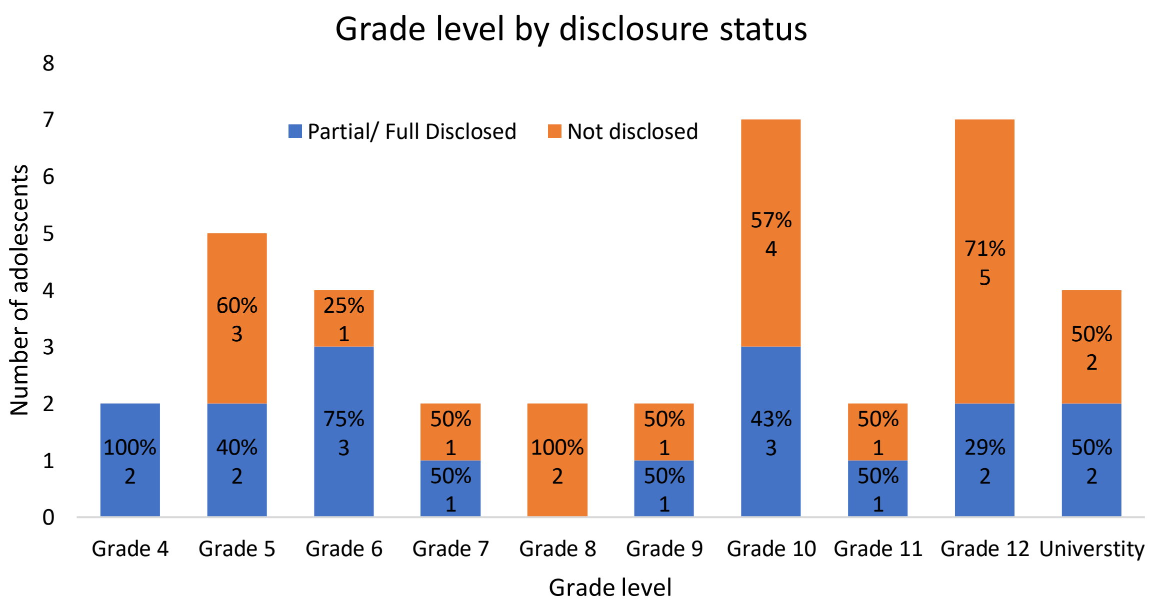

Figure 3: Current education level for ALHIV enrolled in health facilities in Windhoek, Khomas Region, Namibia, 2010-2021 (n=37)

Fig 3 illustrates the current educational level of adolescents who took part in the study. Despite the HIV/AIDS disclosure status and level of adherence of the adolescent participants, they all go to school, this attributes to the care and support they receive from their caregivers and health care workers. Going to school improves understanding, and enhances health seeking behaviours of adolescents, which may empower them to make healthy life choices that may greatly contribute to the reduction of HIV transmission in this age group.

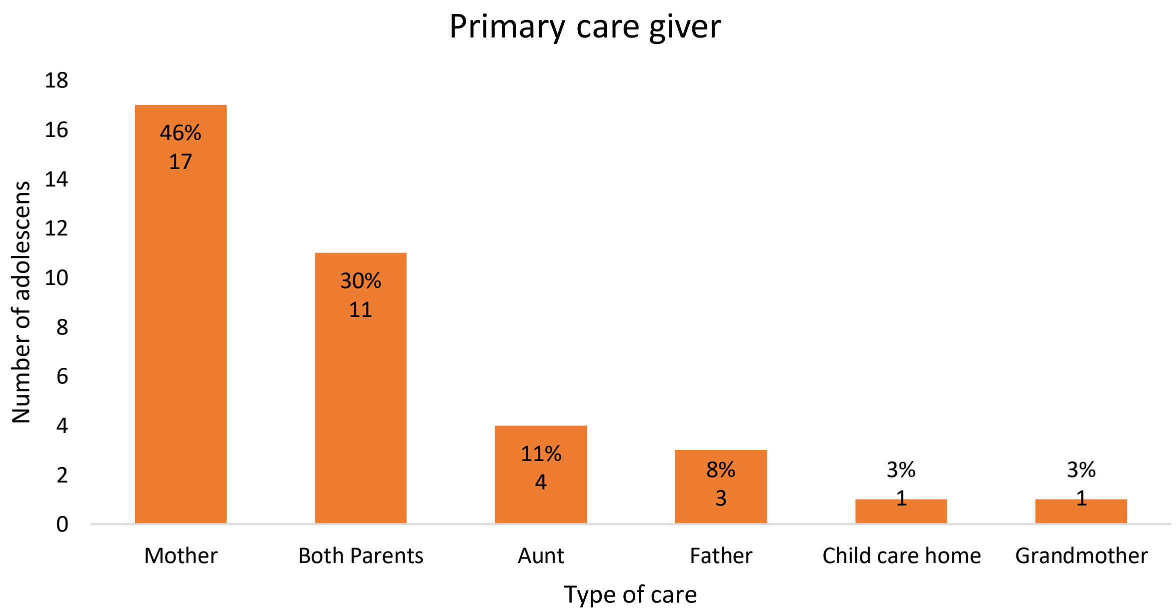

Figure 4: Primary caregivers for ALHIV enrolled in health facilities in Windhoek, Khomas Region, Namibia, 2010-2021 (n=37).

Fig 4 illustrates the type of caregivers for the ART adolescent participants in the study. The type of caregiver to the adolescent, plays a very important role in their ART journey, the caregiver ensures a safe and secure environment, and provides access to necessities, some caregivers might not pay much attention to the well-being of the adolescent in terms of ART care, which might complicate the health of this adolescent[29]. Type of caregiver was one of the major barriers to ART adherence in the study on the challenges to HIV treatment adherence amongst adolescents in a low socio-economic setting as many adolescents under care of non-biological caregivers experienced negative household dynamics where there were ill-treated or given no support ART treatment[29].

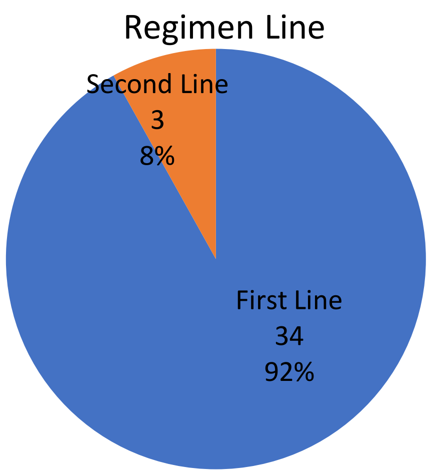

Figure 5: Regimen line for ALHIV enrolled in health facilities in Windhoek, Khomas Region, Namibia, 2010-2021 (n=37)

Fig 5 shows the regimen lines adolescent participants are on. 95% on the first line regimen is an indication of the effectiveness of ART among adolescents. 5% on the 2nd line might be due to other factors that might need to be explored in other studies causing treatment failure among adolescents.

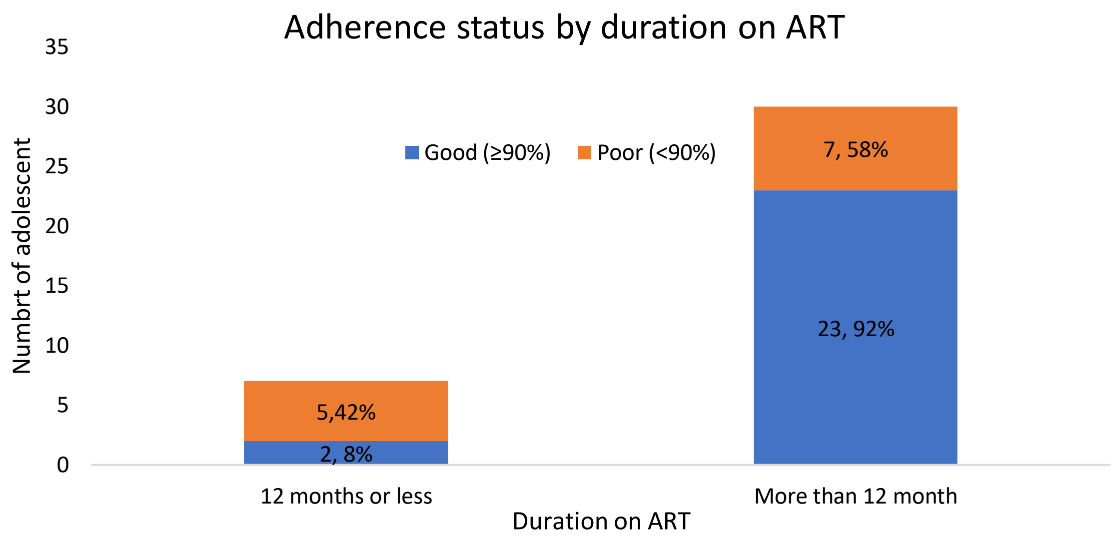

Figure 6: adherence by duration on ART for ALHIV enrolled in health facilities in Windhoek, Khomas Region, Namibia, 2010-2021 (n=37)

It is shown in figure 6 that 42% (n=5) of the adolescent participants who were on treatment for 12 months or less have poor adherence, while 92% (n=23) of the adolescents who were on ART for 12 months or more were reported to have a good adherence. We can conclude based on the study findings that, the longer an HIV positive adolescent is on ART, the more adherence improves over time.

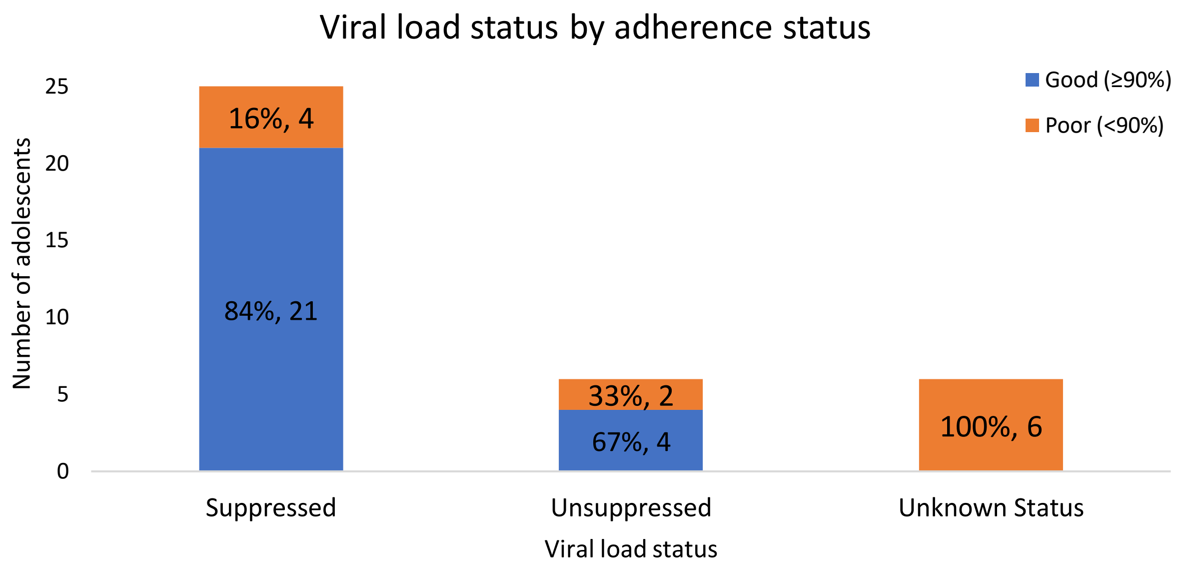

Figure 7: Adherence by viral load status on ART for ALHIV enrolled in health facilities in Windhoek, Khomas Region, Namibia, 2010-2021 (n=37)

It is illustrated in the figure 7 above that 84% (n=21) of the adolescent patients who are virally suppressed (VL: TND/<40 copies per ml or <20 copies per ml), are seen to have a good adherence, while only 16% (n=4) among them, had a poor adherence. It is also shown that 67% (n=4) of the participants who are not suppressed (VL ≥1000 copies per ml) have a good adherence while, 67% (n=4) of the participants with good adherence and the other 33% (n=2) of the adolescent participants both had unknown VL status.

Table 3 Disclosure status by duration on ART for ALHIV enrolled in health facilities in Windhoek, Khomas Region, Namibia, 2010-2021 (n=37)

Disclosure status	Duration on ART in months				
	12 months or less		More than 12 months		Total
	Frequency	Percent	Frequency	Percent	
Complete non-disclosure	4	33.3%	8	66.7%	12
Full disclosure	1	5.0%	19	95.0%	20
Partial disclosure	2	40.0%	3	60.0%	5
Total	7	18.9%	30	81.1%	37

Table 3 above illustrates the disclosure status by period on ART, it is indicated that about 67% (n=8) of the adolescents who have been on ART for over 12 months are not disclosed of their HIV status, 95% (n=19) are fully disclosed and about 50% (n=3) of the adolescents in the same age group are partially disclosed. We can agree based on the study findings that, by 12 months on ART care, most adolescents get to know their HIV status then. This highlights the efforts that the health care workers are putting in the disclosure program, with how they can manage within their capacity.

4.2.1.3 Adherence level by HIV/AIDS status disclosure

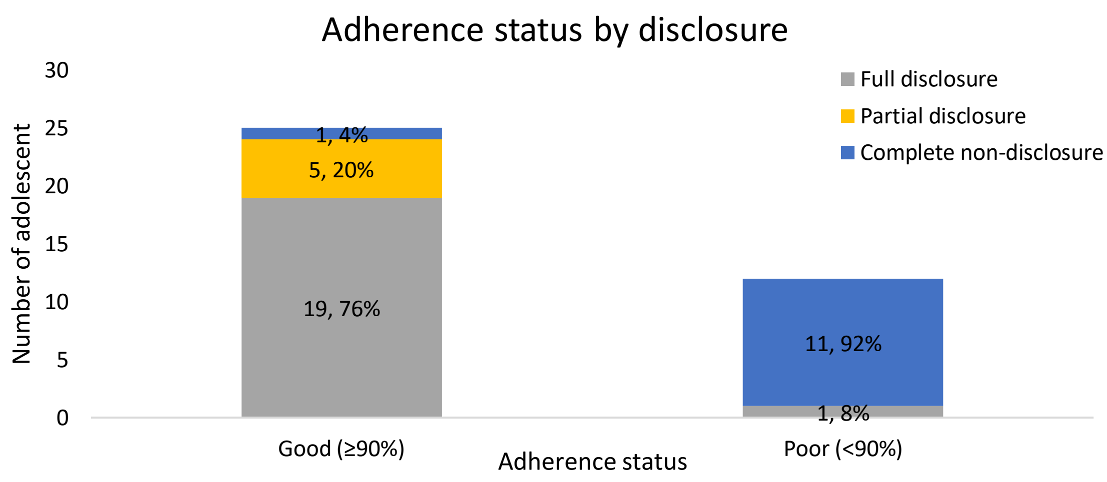

Figure 8: adherence by disclosure status on ART for ALHIV enrolled in health facilities in Windhoek, Khomas Region, Namibia, 2010-2021 (n=37)

Figure 8 shows that 76% (n=19) of the adolescents with a good adherence were fully disclosed of their HIV positive status, and 20% (n=5) other adolescents were partially disclosed (≥90). Nonetheless there about 92% (n=11) of the adolescents with poor adherence (<90%) were completely not disclosed of their HIV status. This illustration highlights the prominence of disclosure in achieving good adherence, it is through knowledge and understanding that adolescent clients will be capacitated to take responsibility for their own health.

Table 4 Odd Ratio for ALHIV enrolled in health facilities in Windhoek, Khomas Region, Namibia, 2010-2021 (n=37)

Variable	Case (disclosed)	Control (non-disclosed)	Odds Ratio	P-value
Sex				
Male	7 (35%)	10 (59%)	0.377	0.330
Female	13 (65%)	7 (41%)		
Age				
10-14	12 (60%)	8 (47%)	1.688	0.517
15-19	8 (40%)	9 (53%)		
Adherence status				
Good (≥90%)	19 (95%)	6 (35%)	34.833	<0.0001*
Poor (<90%)	1 (5%)	11 (65%)		
Duration on ART				
<12 months	1 (5%)	4 (40%)	0.079	0.033*
1 year or more	19 (95%)	13 (60%)		

**p-value less than 5% significance level*

Table 4 shows the odds ratios of disclosure status by sex, age, adherence status and duration on ART. It is clearly illustrated in the table that the odd of sex are lower among cases (disclosed adolescents) than the odds of sex among controls (non-disclosed adolescents) (0.377). The odds of age are 1.688 greater among cases (disclosed adolescents) than odds among non-disclosed adolescents. It is further illustrated that the odds of adherence are 34.833 greater among cases (disclosed adolescents) than the odds in controls (non-disclosed adolescents), while the odds of duration on ART is less (0.079) among cases (disclosed adolescents) than the odds of duration among controls (non-disclosed adolescents). The p-value highlights that sex and age are not statistically, significantly associated with disclosure, since they have a p-value greater than 0.05 significant level, while adherence status and duration on ART have a statistical significance with disclosure status since their p-value is less than 0.05. conclude that there is an association between HIV disclosure and ART adherence among adolescents enrolled on ART between 2010-2021.

4.2.2 Qualitative analysis for adolescent participants

In the study, 37 adolescents out of 40 sampled took part in the interviews. The findings were analysed, and key points of interest are presented verbatim. To protect the participants' identities, pseudonyms were assigned using a 9-digit code. The first three digits represent the facility code, the next four digits indicate the month and year of commencement of ART medication, and the last two digits are a sequential number. This coding method effectively distinguishes adolescents from healthcare worker participants. Four themes were identified from the study findings and are listed in Table 4.2.2.1, with further details provided below.

4.2.2.1 Themes (Adolescent participants)

Theme no	**Theme**	**Sub theme**
Theme 1:	Importance of taking ART medicines	**Subtheme 1.1**. Taking medicines prevents severe sickness or illness
		Subtheme 1.2. Taking Medicine to Keep the 'Bad Guy' Dormant
Theme 2	The Hidden Reality of Medication Intake	
Theme 3	Burden of ART medication	
Theme 4	The Journey of Learning HIV Positive Status	

1. Importance of taking ART medicines

The responses from both non-disclosed and fully disclosed adolescents highlighted their understanding of their understanding of the importance of taking ART medicines.

1.1. Taking medicines prevents severe sickness and prolonging life.

Adolescents who were fully disclosed explicitly mentioned taking medication because they have HIV. They were aware of their HIV-positive status. Many of them understood that the medication's primary purpose was to prevent the HIV virus from getting worse. They recognized that HIV has no cure, and the medication helps suppress the viral load. Fully disclosed adolescents also mentioned that taking ARVs helps prolong their lives and prevents

HIV from progressing to AIDS. Some adolescents mentioned that the medication boosts their immune system, making them less susceptible to co-infections like Tuberculosis, cancer, severe skin infections, and other diseases associated with AIDS. These responses indicate that fully disclosed adolescents had a clearer understanding of the purpose and importance of taking antiretroviral medication. They recognized the role of medication in managing HIV and safeguarding their health.

Participants 419-1122-02 said: "*If we don't drink, we might get sicker and then later the medicines won't be able to work on our body*."

Participant 134-1122-05 said: "*It's important to take this medication so that the virus can be suppressed and so that I can live a long and healthy life."*

Participant 134-1122-06 said: "*it's important because it's used to prolong your life. If you don't take it means you are giving time for the virus to takeover and make you sick*."

Participant 134-1122-07 said: *"It's very, very important because if I don't take this medication, we are talking about my life. I won't have that life I want to live if I'm not taking the medication, So I'm basically taking this medication so that I can prolong my life and live healthy"*

Participant t134-1122-10 said*: "hmm ok, ok the... HIV is a bad guy, so when I don't drink, it wakes up and attacks my body, then get sick and die."*

Participant 217-1122-12 said*: "I know about HIV/AIDS and also know that if i don't take the medicine, I will get very sick and die."*

Participant 134-1122-13 said*: "it suppresses the virus for it to not multiply, then I can live healthy."*

Participant 421-1122-16 said*: "If I don't drink my medicine, HIV will become AIDS and I'll be very sick with diseases like TB, Cancer, then I'll die, shuuuu!"*

Participant 128-1122-18 said*: "It's very important so that I remain healthy and don't get diseases that will make me very sick and lead me to having AIDS, which is a guaranteed death sentence."*

Participant 134-1122-20 said*: "So that the HIV can remain low and not kill the army in my body that is protecting me from AIDS."*

Participant 122-1122-21 said*: "To prolong my life as healthy person"*

Participant 134-1122-22 *said: "very much important, HIV/AIDS has no cure, so these ARVs kind of like deactivates the virus so that it doesn't multiply, because if it does, it overpowers the immune system then opportunistic infections like TB, Cancer and other skin problems starts to show, eventually leading to death."*

Participant 134-1122-23 said*: "so that HIV does not wake up to attack my body and then I don't get sick."*

1.2 Taking Medicine to Keep the 'Bad Guy' Dormant

The non-disclosed adolescents mentioned taking medication for the "bad guy" in their bodies not to wake up and for the "soldiers" in their body to remain strong. This metaphorical language suggests a simplified, age-appropriate way of explaining the importance of treatment to them. Participants said:

"I am drinking because the medicine will keep the bad guy in my body sleeping" (Participant 421-0123-24)

Participant 218-0123-32 said*:* "*I have a bad guy in my body, so that he must not wake up to attack me."*

Other participants did not only mention the Importance of for taking medicines only, but also mentioned the consequences of not taking them:

Participant 128-0123-33 said*, "I drink because I have a cell called the bad guy in my blood system, so I drink my pills so that the cell must not wake up, because it will attack my soldiers in my body, then my immune system will be weak"*

Participant 218-0123-32 said*: "Because if I don't drink the bad guy will be very strong and wake up, then it will kill the soldiers in my body, then I'll be thin and die."*

Participant 110-0123-34 said*: so that the bad guy doesn't wake up to attack my body then I get sick"*

2. The Hidden Reality of Medication Intake

Among non-disclosed adolescents, some were misled about the reasons for taking their medication, believing it was for a completely different purpose rather than knowing it was ART medication. Participants said:

"If I don't take pills, the thing in my stomach will grow, and then I will get sick." (Participant 420-0123-25)

Participant 134-0123-28 said*: "My mother just said that I should drink they are multivitamins to keep my immune system strong."*

Participant 128-0123-29 said*: "Because I have low white blood cells in my blood so I have to take, so that my immune system can get these cells to help me fight infections or diseases."*

Participant 134-0123-30 said: *"so I don't get TB again like my doctor says."*

Participant 115-0123-37 *said: "so that I can have all the vitamins needed for growth and development."*

One participant had no idea why they were taking the medication and displayed visible frustration during the interview. The session was calmly concluded, and the participant was promptly referred to a healthcare worker for immediate psychosocial support.

Participant 134-0123-27 said*: I don't know, I have to drink every day, I'm tired.!"*

Overall, the varying levels of disclosure among adolescents influenced their understanding of medication. Fully disclosed adolescents had a more accurate and comprehensive understanding of why they were taking medication, whereas non-disclosed adolescents often used simpler, metaphorical explanations or had misconceptions about their treatment. These findings underscore the importance of effective and age-appropriate disclosure processes in HIV care for adolescents, ensuring they have a clear understanding of their treatment and its benefits.

3. Burden of ART medication

The burden of daily medication was a common concern. Adolescents expressed difficulty in swallowing the large ARV tablets daily, they mentioned how this situation was an additional burden on their daily lives, as they had to ensure that even when they go out or with friends, they always had to carry their medicines. Many of the adolescents dwelled upon being tired and exhausted to take ARV. With proper disclosure programs we could confirm that it enhances adolescents to focus more on the importance and benefits of medication rather than its disadvantages. Participants said:

Participant 419-1122-02: *"It isn't nice to see other people not drinking the tablets, while I'm drinking, that's the only one thing. So yes, it isn't nice."*

Participant 419-1122-03: *"Hmm…I got used to the medicine now, but it also it becomes tiring for a young person, knowing that its part of your routine now every day until you die. It is not easy especially when I started, but at some point, I was just like, I really need to take them, because even if I don't feel sick, the virus will slowly multiply and affect me."*

Participant 419-1122-04*: "It's overwhelming at times, but if you put your mind to it, you understand why you're drinking your medication, then it's it becomes easier with time and especially if you have a proper support system."*

Participant 134-1122-05*: "Sometimes you have highs and lows so. It's not easy to take medicine daily, but as time goes by, you just get used to it because it's for a good cause."*

Participant 134-1122-06*: "The fact that I must drink every day is just too much work and the tablet is also too big."*

Participant 134-1122-08*: "Oh. Honestly, I feel like it's very annoying because like you have to like drink pills every day, since it's daily one needs to be more focused every."*

Participant 128-1122-09*: "OK, it used to bother me like when I used to take it two times a day, but now it doesn't bother me because I only have to take one time and it's just one tablet and I only take it like in the evening, so it doesn't really bother me."*

Some participants were still struggling with taking the medicine daily, several challenges and concerns were raised, below were some sentiments of participants pertaining to taking the medicine.

Participant 217-1122-12 said*: "It's difficult! I never think in my mind that I can be HIV positive, now to swallow that big tablet every day it's not nice."*

Participant 422-1122-14 said*: "I'm not saying it's not important, I mean it's just not necessary according to me. Okay, I know it's important because it will keep the virus low, it's just disturbing drinking medicine while I don't feel sick."*

Participant 228-1122-15 said*: "I don't want to drink anymore because me I am fine; I am not having a sick."*

Participant 134-0123-28 said*: "sometimes I want to rest for some days and not drink, but my mother gets angry at me, I don't feel nice when she's angry at me."*

Participant 128-0123-29 said*: "it is sooo disturbing, like sooo much work, I have to set an alarm on my phone, have to maintain the same time for drinking, its tiring"*

Participant 134-0123-30 said: "It's just inconveniencing especially if I have to go out with friends, I must remember to carry it and drink, its handful."

The opinions and feelings expressed by the adolescents about taking ARV medication highlight the complex emotional and psychological aspects associated with HIV diagnosis and treatment adherence. While some adolescents expressed negative feelings, others, despite their negativity, understood the importance of maintaining their medication regimen.

4. The Journey of Learning HIV Positive Status

Adolescents, particularly those who experienced accidental disclosure of their HIV-positive status, developed negative or mixed feelings upon learning about their status. Some were shocked and had difficulty accepting the diagnosis, as they never expected to be HIV-positive. adolescents who were not fully disclosed did not see the need or importance of taking ARVs. They did not feel sick and did not understand that the medication was meant to stabilize HIV. This lack of awareness led to a sense that taking medication was unnecessary**.**

Participant 419-1122-02 said*: "First I was wondering why I was drinking medicine every day and then I asked my aunt which I live with. Then she said she'll tell me when I'm older. Then when I was in grade 7, she told me that it's because I have a virus. It was very shocking."*

Participant 419-1122-03 said*:* "*Well, I was basically, I was born with HIV, and then when I was growing up. I used to come to the hospital with my mom and all that. So, one day I asked my mom why I'm taking the medicine, she said it was for me to healthy. So, the time for me to be told came, my mother told me at home, which was not quite easy, I didn't understand how I got HIV but the counsellor at the hospital helped me by telling me how mothers can pass it on to the child but also how to accept reality and live positively, and all that."*

Participant 134-1122-05 said*: "I was at school and there was a blood donation happening, So I went to the blood donation area. I personally didn't want to donate, I just did it so that I can also get cookies they were giving when interview is done. They took my blood and said they* *will call me in 1 week time. So, they called my mom we went to their offices, so when we went there, that's when they told my mom that they test before they take the blood, so they found that my blood was HIV positive. We went back home that's when I also found out that my mom is also positive because I didn't know. But yes, I understood"*

Participant 134-1122-06 said*: "I used to wonder why I'm going to hospital all the time and getting medicine to drink every day, I asked my sister and my grandmother. They were saying I have a liver disease. Okay that was fine, when I was in grade 7, when I went to the hospital, I took my file and I read, then I just saw that everything is corresponding with the topic of HIV/AIDS in life skills, then I saw that they were trying to escape from the truth, because I was like wow! what is this then? So, I have HIV? I'm just like, OK. They were coming to me to explain, then I told them to let me consult myself since they were trying to escape from reality., But everything is okay no, I accepted."*

Participant 134-1122-07 said*: "I didn't use to go to the hospital with my mom a lot, it was only occasionally, so this other day we came with my mom because the doctor said next time I should come with my mom because I used to come alone. and then they told me with the counsellor, that: "you're taking your medication because you are HIV positive". I went mute, I cried. I didn't talk with my mom that day, she bought me ice cream just to calm me down. When I went home, I'm like, Okay I accept, it's okay."*

Participant 134-1122-13*: "The nurse at the hospital told me, there was also other nurses, and counsellors, they used to read for me this book that has pictures of the soldiers in the body…. I'm tired to drink medicine, but I'm used to it now, because I want to reach my career while I'm healthy."*

Participant 421-1122-16 said*: "when my parents told me, I was surprised that me and my parents we have HIV, I thought it was just for other people in other countries, but I accepted because both my parents are like me, so I didn't feel alone."*

Participant 128-1122-18 said: *"When my mom told me I am positive, i thought it was a joke first, coz I was not involved in sex that time, then they told me at the hospital that I was born with it, I got angry at my mom for a moment, but when the nurse told me that, my mom can't explain how she got it, and how she never wanted this for me, I felt bad then I forgave her. She is the best mom ever."*

Participant134-1122-22 said *: "I was told here at the hospital, there was a nurse that told me that I was born with the virus, she told me that it doesn't change anything with my life, it just requires me to be responsible for my health, she also told me that I shouldn't be mad at my mother, but work with her and support her."*

Some participants were still struggling to cope, to accept their HIV positive status and to accept life -long treatment, below are the verbatim that were captured:

Participant 217-1122-12 said: "My mother was talking on the phone to ask my aunty to take me for the doctor at the hospital, I don't know what my aunt answered, then my mom said " IF there was no AIDS in the world my son and I would be very free" I was very shocked and I was angry at her for giving me HIV, while me I didn't do anything wrong…. But Is okay, it's just that me I don't want to go to the hospital, she's the one whose getting for me, me I go only when they are going to take the blood, the clinic is full, my friends might see me also."

Participant 422-1122-14 said*: "To be honest nee? Me I wanted to stop taking these ARV, so sometimes I'll not go to go the clinic, that time I just knew that I'm taking vitamins, so that I don't get sick, I must grow healthy. So, my aunt told me at home that I'm HIV positive so I must not stop going to the clinic."* The participant was asked whether they now fully understand and have accepted their situation, and they responded: "*I think not fully, but ja I get most of the things now"*

These sentiments illustrate the emotional challenges faced by adolescents living with HIV. The process of disclosure and education about HIV and its treatment plays a crucial role in shaping their perceptions and attitudes toward medication. Adequate support, counselling, and information are essential in helping these adolescents cope with their diagnosis and understand the importance of adherence to ARV medication for their long-term health and well-being. It also underscores the importance of a holistic approach to HIV care, addressing not only the physical aspects of the disease but also the emotional and psychological needs of adolescents living with HIV.

4.2.3 Health Care workers' Quantitative Data

This section outlines the demographic data of health care workers, which is segregated and displayed in the following categories: Age, marital status, educational level and qualifications, occupation, and years of experience in the ART health care department. This highlights the characteristics of the health care worker participants for this study. Appendix M, illustrates the characteristics of health care workers more clearer in a single table.

4.2.3.1 Health care workers' Demographic Data

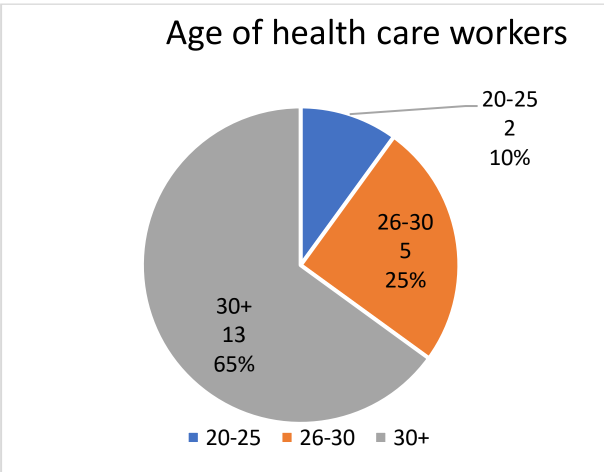

Figure 9: Age of health care workers

Fig 9 shows that there 65% (n=13) of the HCWs are aged 30 years and above, followed by 25% (n=5) who are aged 26 to 30 years old and then 10% (2) of the HCWs who are aged 20 to 25 years old.

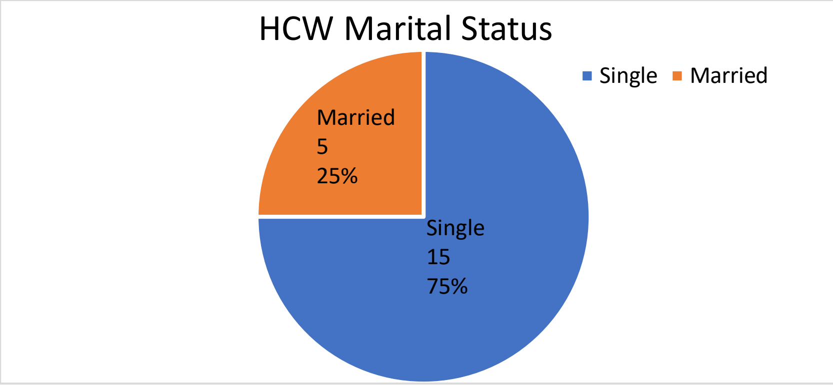

Figure 10: Marital status of health care workers

Fig 10 indicates that about 75% (n=15) of the HCWs who participated in the study are single, while the other 25% (n=5) of the participants are married.

Table 5. Level of education for health care worker in Windhoek, Khomas Region, Namibia, (n=20)

Highest Qualification	Frequency	Percent%
Certificate	5	25.0
Diploma	4	20.0
Bachelor's Degree	2	10.0
Honors Degree	6	30.0
Post Graduate Diploma	1	5.0
Master's Degree	2	10.0
Total	20	100.0

Table 5 shows that most of the HCWs have an honours degree 30% (n=6), followed by 25% (n=5) of the HCWs who possess a certificate and then 20% (n=4) of the HCWs with a diploma as their highest qualification. Educational level of the health care workers might define their ability to give required adherence counselling to improve adherence among adolescents. Level of education can as well determine the quality of disclosure services rendered by the health care workers to adolescents, this also allows the disclosure program to Identify training needs for the specific health care workers that might lack some educational skills.

Table 3: Occupation	Frequency	Percent%
Nurse	11	55.0
Health assistant	5	25.0
Doctor	2	10.0
HIV Nurse Mentor	1	5.0
Senior Health Program officer	1	5.0
Total	20	100.0

Table 6. Occupation for health care worker in Windhoek, Khomas Region, Namibia, (n=20)

It is shown in the table above that about 55% (n=11) of the HCWs who participated in the study are nurses, followed by 25% (n=5) of health assistants and then 10% (n=2) of the HCWs who doctors were. This illustration indicates the distribution of health care skills among the participants, which are essential to the disclosure program.

Table 7. Years of experience in ART services for health care worker in Windhoek, Khomas Region, Namibia, (n=20)

Table 4: Years of experience in ART services	Frequency	Percent%
6 months - <5 years	9	45.0
5-<10 years	10	50.0
11+ years	1	5.0
Total	20	100.0

Table 4 shows that about 45% (n=9) of the HCWs have six months to 5 years ART experience, 50% (n=10) have 5 to 10 years of experience and then about 5% (n=1) of the HCWs who have 11 years or more in ART services experience. This defines the quality of the output of the health service delivery among health care workers. This figure indicates that 50% of health care workers have been in the ART division for 5 to 10 years. Showing the experience in ART these health care workers have, which will benefit the disclosure program.

4.2.4 Qualitative analyses for Health care workers.

4.2.4.1 Themes (Health care workers participants)

In this study 20 health care workers were interviewed of which below were their responses under themes:

Theme no	**Theme**
Theme 1:	Variations in adherence among partially and fully disclosed adolescents **Subtheme 1.1 Improved adherence post disclosure** **Subtheme 1.2 Resistance to treatment**
Theme 2	Implementation challenges of disclosure program **Subtheme 2.1** Lack of training **Subtheme 2.2** workload

Theme 3	Family and Caregiver Involvement in ART care
Theme 4	The need of strengthened Disclosure Program

1. Variations in adherence among partially and fully disclosed adolescents

The healthcare workers who participated in the study provided valuable insights into the relationship between HIV status disclosure and treatment adherence. They observed that adolescents who are aware of their HIV-positive status tend to adhere better to their treatment. This is because they understand the importance of taking medication to prevent the virus from multiplying and causing further health issues. Conversely, those unaware of their status often have poor adherence because they do not fully understand the reasons for taking the treatment, especially when they are not visibly ill.

1.1 Improved adherence post disclosure

Below were the verbatim from the healthcare workers relating to this subtheme:

"For the period I have worked here at ART clinic, I have seen that our children who knows that they are taking treatment for HIV adhere well, they even come for their follow-ups alone without their parents." (HCW-1022-03)

"What I have seen with my kids at this clinic is that the ones who were told they are HIV positive, start adhering after some time, first they are heartbroken after they are told, they don't eat, they just cry and refuse to take medicine, but after some time they come around and take their medicine well." (HCW-1022-04)

"All I can say on that point is that we must just inform these kids about their situation, many of them become serious with medicine after they know the reason why they drink medicine, it will just make life easier for us health workers to give them care when they know." (HCW-1022-05)

"When they know they are positive they take medicine well, we also try our best as nurses to give them full support and attention." (HCW-1122-09)

Some responds from health care workers highlighted that despite good adherence after disclosure of HIV positive status to adolescents, they still go through some emotional challenges, where they try to adapt to the news. They further indicate how they continue supporting the adolescents to remain on care. Below were some of these responses:

"They do adhere well, those ones who got to know that they have HIV, but you know for every developing adolescent there are a few challenges here and then to make them drink medicine, but they do take the medicine well." (HCW-1022-07)

"At the end of the day these little creatures are only human, they have feelings too, with all they are learning at school and to be told that they are HIV positive, is life changing, but I have observed 5 of them that we did disclosure here at our clinic, they even improved, because I think they understood better coz we continued counselling them at every visit."(HCW-1022-09)

"No health workers wants to see a child go through that trauma, these kids cry too much after being told, they ask us questions like why them? How possible, oooh? Its really not easy, but eventually they come around, they just need that support, we have them here who are doing much better now, after we told them its ARVs they are taking." (HCW-1022-12)

"*Its not easy ma'am, its really not, one of the kids refused to go home with her mother after we told her her status, I had to go with her to my house, coz she's been in my care since she was 4 years old, and now she's 14 years old, she is my ka best friend, I spoke to her at home, and she really understood, these kids ask too many questions, for as long as you give them answers they will comply."* (HCW-1122-13)

1.2. Resistance to treatment

Healthcare workers have expressed difficulty in managing adolescents in ART care. They highlighted several issues, such as adolescents' resistance to treatment, their failure to attend follow-up appointments on time, and their lack of honesty. Parents and caregivers have reported similar challenges to the healthcare workers. Below are some verbatim accounts of these issues.

"Sometimes I feel like running away from this profession you know… But I understand that these kids are undergoing grief, they miss their dates to come to the clinic, when we call their parents, they also don't have answers, these kids dodge" (HCW-1122-09)

"Adolescent stage is one difficult one to deal with, some of them don't even take their medicine at all, they pack them aside, there's a mother who came here with a full plastic bag of medicines she found stuffed in her child's bag of clothes, she tried asking her child but the child walked away, when we asked her here at the clinic, she told us to mind our business we are not her parents, can you imagen?, but it's our job we just deal with what comes." (HCW-1122-15)

"I have one ka boy in my care here, he knows very well that he has HIV, and understands the consequences of not taking his treatment, for every visit we counsel him, but this boy is never honest, he'll tell us excuses that he didn't come for follow-up because they had activities at school, sometimes he'd say his parents didn't give him taxi money to come, obviously we always call their parents in these cases, but we find out its not true."(HCW-1122-16)

"*One day these kids will beat us, some of them are out of control, even their parents can't put them in line, they are the ones with high viral load even, they are always against what we tell them, it's like we are disturbing their peace, it's tough really."* (HCW-1122-17)

"*We have 2 small kids in our care, very smart kids, they were always threatening us that they will stop taking treatment because they don't feel sick, they even say they'll report us to the court of law because we are not respecting their rights to refuse, luckily their parents are always there with us, and always convinces them, we have also managed to enrol them in disclosure, because we really won't keep up, they are too smart and are starting to question."* (HCW-1022-11)

One of the health care workers pointed out the challenges faced with adolescents that do not know their HIV positive status, they see no use of taking medicine because they feel okay, Participant HCW-0922-01 said:

"When they don't know their HIV status is difficult to convince them to take medicines every day, or to make sure they come for follow-up every month, sometimes you run out of ideas to keep them on board. In other cases when you tell them their status, they get so upset and now starts to have poor adherence, its really challenging but we try our best."

Another health worker said:

"The ones at this clinic that don't take medicine well, its those ones that don't know they have the virus, that's why we try hard for them to know, because it helps reduce their rebellious behaviour." (HCW-1122-20)

2. Implementation challenges of disclosure program

Health care workers highlighted some challenges in performing the processes of the disclosure program in their health facilities, due to system related issues that will be discussed in the following subthemes.

2.1. Lack of training

Health care workers raised lack of training on disclosure as one of the challenges for a successful disclosure program. Below are their verbatim:

"I feel unprepared to handle disclosure because we haven't received proper training on how to approach this sensitive topic with adolescents, I have been working here for a year now, but no training was given, but I try to learn from others though." (HCW-1022-02)

"I find it challenging to provide correct disclosure honestly, I know I have been in this department for long, but there was no guidance on the process or orientation when I came, but I'm learning a bit now, because we have mentors helping us and showing us." (HCW-1022-03)

"I still struggle with knowing the right time for disclosure for a child, maybe because I didn't receive a formal training, but for now I really feel it's just safe for the parents of these children to just do the disclosure themselves." (HCW-1022-04)

"This issue of not training us will bring us problems one day, because all of us do this disclosure any how we all feel is okay, we are not doing the same thing, yes the disclosure books are, but we still need to know how to use them correctly, like myself really, how do i address the emotional reactions that can arise during disclosure from the child?." (HCW-1022-05)

"Me sometimes when it comes to answering difficult questions from adolescents like why they are taking those pills, I really get lost, but I call a colleague of mine who knows well, they must just train all of us." (HCW-1022-06)

"I feel like us health workers who did not receive full training cause more harm than good during the process, we might be reading from the disclosure book, but our understanding might be different, then we confuse the poor kids." (HCW-1122-09)

2.2. Workload

A significant challenge mentioned by healthcare workers is the heavy workload. Due to a shortage of staff, the continuity of the disclosure program is often disrupted. With only a few healthcare workers responsible for a large number of patients, there is limited time to follow the correct procedures step by step. Below are some verbatim accounts reflecting these sentiments.

"I am the only ART nurse here, many times when I'm even on leave, they either still call me or they close the ART clinic, I feel overwhelmed really, I do everything at the clinic, then there is also disclosure itself that takes a lot of time and effort, when there are many patients sometimes, I even postpone and just rebook the poor children." (HCW-1122-13)

"We need more staff here, balancing our daily duties even during delegation, it's just the same, disclosure sessions require more time." (HCW-1122-14)

Another interesting response was from participant: HCW-1122-15), who said.

"I already have my own stress because I am overworked, I am also in an emotional break down, then again I am the same person give emotional and psychological aspects of disclosure. It's difficult to manage this honestly."

Another health care worker said:

"I sometimes struggle to find the right approach for each adolescent, as they all require individualized ones, that's another workload on top of what I have." (HCW-1122-16)

Participant HCW-0922-01 said:

"Caregivers and parents contribute to workload too, you need to engage them, convince them, counsel them about the whole disclosure process and this requires a lot of time and effort, which just disturbs my productivity, because I rush to finish, as I have other clinic services to attend to."

3. Family and Caregiver Involvement in ART care

Healthcare workers highlighted the importance of involving families and caregivers in the disclosure process, they also raised concerns that support from caregivers is very minimal, which sometimes hinders the success of the disclosure process. The verbatims below supports this:

Participant HCW-1122-16 said: "*When caregivers understand the importance of disclosure and adherence, they can provide better care at home, counsel adolescents on treatment compliance, and support their children's health and well-being, so we also need to capacitate them in the disclosure process."*

Participant HCW-1122-17 said: *"Involving parents and caregivers is very important because they provide the necessary support system for adolescents. Their involvement can make the* *disclosure process smoother and more effective, but in many cases, they are never there for their children, these children are on their own, and we need to find a way to change that otherwise efforts of the disclosure program will not work."*

Participant HCW-1122-18 said: *"We should really try to engage parents or guardians for these sessions of disclosing the HIV status, it helps adolescents to feel more secure. When they get this support, they feel that their well-being during the process is taken care of, this is one thig that caregivers fail to understand at times, and they send their children here alone."*

Participant HCW-1122-19 said: *"We should make it a must to have parents involved, because what we discuss at the clinic, they share it again and reinforce it at home, this can make it better for adherence to treatment and follow-up appointments for the kids."*

4. The need of strengthened Disclosure Program

Healthcare workers emphasized the significance of a robust disclosure program in adolescent ART care. Such a program helps mitigate emotional challenges, mental health issues like depression, self-blame, and even suicidal thoughts that can arise when adolescents learn about their HIV-positive status at a young age. Strengthened disclosure programs equip healthcare workers with the skills to provide sexual health education to adolescents, helping them understand how to practice safer sex to reduce the transmission of the virus to others. The verbatims below supports this Theme.

Participant HCW-1022-04: *"In Namibia we need a strong disclosure program to help children cope with the emotional challenges and mental health issues that can arise after learning that they are HIV-positive, there is too much stigma in this country, this is really important for their well-being."*

Participant HCW-1122-08*:"when our disclosure program is nicely organised, we can address those feelings of depression, blame, and even suicidal thoughts that many children experience."*

Participant HCW-1122-09*:"This program helps us health workers a lot, even the parents of these kids, we both learn how to provide sexual health education to these children, which is very important, because at this age they start doing adult things, so our ministry must make sure all efforts are made to this."*

Participant HCW-1122-07:*"When adolescents understand their condition and how to practice safer sex, it not only helps them but also reduces the risk of transmitting the virus to others, and once the ministry ensures there is enough staff, equipment and everything else needed, our children will be safe and will be well taken care of."*

Participant HCW-1122-18*:"A strong disclosure program allows us to support adolescents in a way that helps them accept their status and drink their treatment well, and it can help us to also offer the best health care, guidance and support to bot the children and their guardians."*

Overall, the insights from healthcare workers underscore the multifaceted nature of disclosure programs for adolescents living with HIV. They highlight the importance of not only informing adolescents about their HIV status but also addressing emotional and psychological aspects, involving caregivers, and ensuring staff stability to enhance the success of these programs and improve adherence to ART among adolescents.

4.3 Chapter summary

This chapter clearly presented the research findings and displayed them according to the statistical tables and graphics for clear understanding especially in the quantitative aspect. It is evident that there is an association between adherence to ART and disclosure of HIV status. The need of strengthened disclosure programs is supported by the findings of the study. The next chapter will discuss and conclude the study findings and highlight recommendations made with reference to the findings.

CHAPTER 5: DISCUSSIONS, CONCLUSIONS AND RECOMMENDATIONS

5.1 Introduction

The previous chapter focused on presentation of results and findings. This chapter discusses the findings of the research findings and conclusions with the aim to respond to the problem statement. This chapter also focuses on the recommendation of the research based on the findings presented in chapter 4, with emphasis on the responses of the participants for this research project

5.2 Discussions

The aim of this research was to assess the association between disclosure and adherence to ART among ALHIV. This mixed method study with an explanatory sequential design found improved levels of ART adherence with the act of disclosure to adolescents in the health care[1,10,22,23,30] facilities in Windhoek, Khomas region. Furthermore, it found improved levels of adherence with adolescents that were disclosed to their HIV positive status at a younger age and have been on ART for more than 12 months, which highlights that delayed disclosure predicts lower adherence outcomes. These findings were consistent with previous retrospective longitudinal and qualitative studies done in sub-Saharan Africa that found an improvement in mean ART adherence with the act of disclosure to adolescents and Qualitative studies that have described improved adherence with disclosure.

The findings of this study were consistent with other qualitative studies with exploratory designs, that as well described school commitments, strained teacher–learner relationships, household dynamics, especially those who were under care of non-biological caregivers were reported as major barriers to adherence[10,25]. In addition, treatment fatigue where adolescents had concerns about taking pills daily, where the suggestions of injections administered once every 3 months or twice a year came about, agreed with other qualitative studies on the challenges of HIV treatment [10,25]. This study suggests that the disclosure of HIV status is an important step in the management of HIV in children and adolescents and that early disclosure, starting as early as 5 years old, may lead to increased rates of adherence to treatment. This aligns with previous research conducted by Shivute, which emphasized the importance of disclosing HIV status and its complex consequences on adherence[25]. This study highlights that there is a problem with low rates of HIV status disclosure to children and adolescents, lack of specific tools and resources for low-resource settings, which hinders the success of the disclosure process among eligible adolescents, the lack of resources may contribute to the low disclosure rates. This is consistent with I-tech and MOHSS study where only 11% of the study participants knowing their HIV status, and extends its alignment to other qualitative studies that collected data through structured interviews and group discussions which showed improved treatment outcomes in adolescents disclosed in health care settings by the health care workers, compared to the adolescents that were accidentally disclosed and were deceived of reasons of taking treatment, which in conclusion pointed out significant barriers to disclosure[11,14].

Many of the reviewed studies discuss more on importance and challenges of disclosure and adherence but not much on the association between disclosure and adherence, it would have been a good opportunity to compare results of this study with the previous studies to have a more comprehensive insight of the association between disclosure and adherence.

5.3 Recommendations

The following recommendations were formulated from the results of the study:

5.3.1 Adolescents' recommendations to MoHSS

- Educating and training health care workers on ethics, and proper patient care treatment approach, as most of them are not rendering friendly services to the adolescents. Participant 228-1122-19 stated*: "Especially when it comes to counselling, most of our* *counsellors don't behave well, when a person is late for follow-up, they shout at the people, why are you late? you're supposed to come to the hospital or to the clinic on your day. And the face is already showing that this lady she's not friendly. So basically, I'm saying, the ministry could come in and teach the healthcare workers, counsellors on counselling procedures".* Another adolescent stated that:

- The MoHSS should consider conducting home delivery services on medications to the adolescent clients who stay far from the health facility, and for those who always struggle with transport money. Participant 134-1122-01 stated: *"Us the young people, we miss our follow updates because we stay far from the clinics, and sometimes we are tired from walking from school and don't have taxi money to go to the hospital, then we just go another day. I'm not saying the ministry should start giving people taxi money because again people will become dependent. So, the Ministry of Health can start having these ideas of delivering medicine at home, because I don't have to always come to the hospital, especially for a pharmacy date. Sometimes I'm missing my school to just come once at the hospital, when this problem can be solved if there's someone that can pick up my medication at the health facility and then drop them at my house or anywhere, I prefer. So yes, there should be something like that in the community"*.
- MoHSS to come up with support groups for the parents and care givers of theses adolescents, to teach and capacitate them on the skills on how to carry out disclosure to their children at home, to also understand the importance disclosure, because in most cases they delay full disclosure to the adolescents under their care, simply because they are in so much fear. Participant 419-1122-02 stated; "*I think the ministry should come up with like a support group for parents, so that they will teach them when it comes to things like disclosure, the importance of disclosure because they are the ones who more delay the process, if they delay, the more it also becomes harder for the teenagers, because now*

especially in the holidays we like social medias and see everything they say there. If they read, there about HIV then they will know and will not be happy with their parents".

- MoHSS should ensure that peer support is strengthened and enhanced, through formation of a good number of teen clubs across all health facilities in the country, as these are peer support systems are beneficial to the adolescents as they get to engage with other adolescents, through games and activities, where they get to learn about the greatest importance of ART treatment, and tips on how to care of themselves.
- Awareness campaigns to be one of the activities that MHSS can carry out to disseminate information pertaining HIV/AIDS, this information should be in a way that it can attract the attention of the adolescents, e.g., giving information in form of role plays on TV and radio, can be in animations or just real human beings acting out. Participant 419-1122-04 stated "*The Ministry of health should just like try to spread awareness campaigns, so that the information is out there because a lot of people are still negative about HIV. Because of this negativity, young people are not getting involved in HIV activities. If they don't, then they don't understand the importance of medicine and will not 100% come for follow-up every day".*
- Most of the adolescents suggested that the MOHSS tries by all means with their medical experts and scientists to develop an ARV injection that can replace pills, the injection to be administered at least 6 monthlies, so that the clinic visits can reduce, then the problem missing appointments or follow up dates can be reduced.
- The ARV pills were reported by a number of adolescents, to be very big, with a very bad taste which is too sour or bitter, they recommend that the ministry of health and social services looks into the manufacturing system of their medicines, to work on improving the taste to flavours like strawberry, chocolate, vanilla, and reduce the size of the pill just so it can be attractive to the adolescents to be motivated to drink.

- Some adolescents reported to not enjoy the waiting at the health facility during their clinic visits, they also reported not to like the health facility environment at all, others reported to have transport issues since they stay far from the facilities, so they made recommendations to the MoHSS, to have mobile vans to deliver medicines to adolescent clients' homes.
- Most of the young adolescents within the age 10-14 years old, indicated that they need toys in the health facilities, to play with when they are waiting to be assisted, for them not to get bored, they hope for the MOHSS to avail any kind of toys and story books like peter pan and Tarzan or anything interesting to keep them busy.
- Another recommendation to the MOHSS was to build an ART clinic specific for the young, at least from 0 to 20 years old, this will create a good health environment that will be at the utmost comfort of the adolescents, this will assist in retaining in care of the adolescents, as they will look forward attending their scheduled clinic visits.
- One of the adolescents recommended that the MOHSS ensures that the health care workers use the correct size of needles when they use them for blood drawing, because at times, they tend to stay away from the hospital when it's their follow-up date because of the fear of needles.
- Organising platforms on Radio or TV for young people to talk or discuss about HIV and medicine, is one of the recommendations that was pointed out by 3 adolescent participants, it was further explained that this will help youngest people to know the importance of ARVs.
- *"The ministry should employ enough nurses, so that us young people don't wait for long in the ques, when the queues are long, I can just turn back and go home"* Participant 134-1122-05. This was one of the adolescents who felt that he's waiting at the facility was long and had this as his recommendation.

- Many adolescents recommended that the MOHSS organises more fun activities where the adolescents can come together even every weekend with other adolescents to have activities like games, quiz game, sports activities, just so they create relationships among themselves, which will really ease the load on their mental well-being, especially when they worry about their HIV infection that they never planned for.
- Some recommendations were suggested to the MOHSS, they should create training sessions for the care givers or parents, as most of them according to a few adolescents, seems not have many ideas and skills on how to care for the adolescents, they seem to be uncomfortable with talking about HIV, treatment, sex, pregnancy etc. The teachers and hostel staff not to be left out as well since these are the primary care givers to adolescents when they are in the hostel.

5.3.2. Adolescents' recommendation to fellow adolescents on ART care

- Coming to terms with their HIV infections, engaging with their parents, by asking them anything pertaining HIV, if uncomfortable with parents at home, they can always reach out to nurses, doctors or counsellors to ask questions about things they don't understand, which help the, drink their medicine on time.
- Most of them recommended that their fellow adolescents enrols or takes part in the HIV teen clubs that are available at all the health facilities in the district, these are very interesting peer support groups where adolescents can come together and learn a lot on how to take responsibility of their own health, they also learn from other adolescents on how they are coping and able to live positively with their HIV infection at a young age. In these teen clubs, they will overcome the feelings that most of them have, for being alone, feeling pity for themselves by asking God why he allowed this awful infection to be in them, they will gain confidence in opening up to their parents/ caregivers and to the health care workers at the health facility.

- Setting alarms on their phones or alarm clocks or ensuring that they remind their parents or caregivers to remind them, just so they remember to take their medicines every day.
- Adolescents can learn to engage themselves in activities like reading information books, take part in youth activities, like TV and radio programs, should opportunities be availed, this will help them much in boosting their confidence in being owners of their health.
- There are some adolescents that are being stigmatized at home or school, especially those with HIV status that are known, they are encouraged to speak out, reach out to their care givers or health care workers, which may include social workers at the health facilities. HIV is not a death sentence, one thing most adolescents should understand, if they are struggling with keeping up with their treatment, the social workers, will step in to help them in their struggles. These were a few recommendations made by adolescent participants to other adolescents on ART at large.

5.3.3. Health care workers recommendations to MoHSS

- Most health care workers recommended that the Ministry of health looks into the need of significant costings to health care workers in the ART department, refresh them of the paediatric disclosure requirements and processes, which includes reaching out to the adolescents at the right age to enrol them in the program, proper disclosure leads to good adherence, which leads to the suppression of viral load, which will result in significant cost cutting measures as the financial burden will be reduced.
- Ensuring integrated services at all ART services, that will allow adolescents to access all kinds of health care health care services they need, e.g., family planning, health education, other treatment services and support services like accessing social workers and other

support group services. The MoHSS can do this by ensuring that all departments of health care e.g., Pharmaceuticals, procurement, clinical supplies etc. have the needed funds to be able purchase required items, equipment or personnel that will make these recommendations happen.

- Formal trainings on paediatric disclosure of HCWs especially Health assistants or counsellors, to fully equip them on disclosure skills, which will create a comfortable environment for both caregivers and adolescents, as there will be trust among all, if the HCWs knows what they are doing.
- Some health care workers have indicated that they have deaf and mute adolescent clients, which makes it very difficult to provide comprehensive health care services, especially in the area of counselling and disclosure, these clients show up most of the time alone at the health facility with no caregiver accompanying them. A recommendation in this regard was made to MoHSS to assign sign language interpreters to the health care facilities that has these clients. The interpreters will not only focus on conveying information from the HCW to the child or adolescent but will also enrol some deaf and mute clients who are not fully equipped with sign language sessions, to teach them during scheduled sessions.
- Health care workers further recommended that the MoHSS, designs the children/adolescent departments to a view that will attract the children/adolescents to make them as comfortable as possible, especially in their waiting area. They can paint famous cartoons or puzzles on the walls, have colourful tables and chairs around the waiting area and in their consultation rooms, with some toys and story books for the younger adolescents. This usually occupies them and keeps them busy and hardly feel the pinch of waiting, because this is a very impatient age group.
- Other HCWs are willing to join school health activities to support HIV/AIDS programs in school, where they can conduct activities like generalised health education to all the

learners and teachers at the schools to try to reduce stigma, but they do not have an entry point to the schools, so the recommendations are for the MoHSS to look into these issues and liaise with the Ministry of education to work out a working collaborative on how things can be done.

- Saturday health care services provision for adolescents, was another recommendation, so that the adolescents can access services in weekends. Because during the weekdays they are mostly occupied with school activities, at times they miss school to come for their clinic appointments, which might compromise their focus at school. For the services to be offered during weekends, the MoHSS needs to authorise the arrangement, then avail funds to pay overtime allowances to health care workers who will be rendering these services to the adolescents. The MoHSS can look at this as an initiative which will reduce the number of adolescents missing their clinic visits, as they will have the ability to access the services during weekends.
- A few health care workers recommended to their fellow health care workers that they try to avail time in engaging into capacity building activities, that will help them strengthen or improve their health education skills to adolescent clients. These capacity building activities can as well include skills on identifying, good treatment supporters for the adolescents, that can take responsibility of the child’s health.

5.3.4. Health care workers recommendations to adolescents on ART care

- Uniting with other adolescents in their peer groups like teen clubs is a good practice that will enable them to learn more from each other. The teen club gatherings will be an opportunity for the adolescents to better themselves in terms of health care, and their wellbeing in general.
- Health care workers recommends that adolescents seek assistance from HCWs if they have any issues on health or any confusions or doubts about their medicines.

5.4. Summary of the study recommendations

This chapter presented the research recommendations that focused mainly on strengthening the health care system in the disclosure program, which addressed the needs of adolescents, caregivers and health care workers, to address the challenges in the findings that revolved around fear of inflicting emotional distress as a major barrier for many caregivers and health care workers to disclose HIV positive status to adolescents, and emotional distress experienced by adolescents after disclosing HIV positive status. Adolescents knowing their HIV status, was found to be a crucial turning point for them, which influenced consistency to treatment, Hence the need to for the ministry of health to come up with strategies to improve the disclosure program.

5.5 Areas for Future Study

The scope of this thesis was broad, aiming to assess the association between disclosure and adherence to treatment among adolescents living with HIV. This was done through a review of adolescent PCBs and interviews with adolescents and healthcare workers. The researcher suggests that future research should explore factors that help adolescents accept their HIV-positive status with reduced distress and examine their experiences during and after disclosure sessions, including their psychosocial support needs. Additionally, future studies should evaluate the effectiveness of strategies used in healthcare facilities to conduct disclosure sessions. This research could help identify the most relevant interventions to address the psychosocial needs of adolescents, supporting their well-being after learning about their HIV-positive status. It would also contribute to better identification and implementation of effective interventions to address the challenges faced by adolescents, caregivers, and healthcare workers during the disclosure process.

5.6 CONCLUSIONS

The study discussed the findings in the context of existing literature on disclosure and adherence, as well as the conceptual framework used in the program. The limitations of the study, such as incomplete patient care records and lengthy data collection due to delayed consent and participation, were well mitigated as outlined in the inclusion and exclusion criteria.

The study reviewed patient/client records from the PCBs, QePMS, and EDT systems for quantitative data, and conducted face-to-face interviews for qualitative data. The findings suggested a significant difference in HIV treatment adherence levels and disclosure status among adolescents living with HIV in Windhoek district. The null hypothesis stated that there is no significant difference in HIV treatment adherence levels and HIV disclosure status among adolescents in Windhoek district, while the alternative hypothesis stated that there is a significant difference. The Pearson's Chi-square test showed a p-value of 0.048, which is less than the 5% significance level. This meant that the null hypothesis was rejected, concluding that there is an association between HIV paediatric disclosure and ART adherence. It is important to note that understanding HIV and its implications for adolescents' daily lives is a crucial part of care associated with disclosing HIV-positive status. Adolescents need to acquire basic knowledge about HIV, such as modes of transmission, the importance and benefits of adherence, and the risks of non-adherence to ART. This underscores the necessity for a strengthened disclosure program.

5.7 Chapter Summary

This chapter has given a comprehensive discussion and conclusions on the study findings, Recommendation from the study participants were outlined, reflecting the importance of service providers and clients' views, to help in strengthening the disclosure program to contribute to the enhancement of adherence among adolescents on ART care.

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7. APPENDICES

APPENDIX A: UNIVERSITY OF NAMIBIA ETHICAL CLEARANCE CERTIFICATE

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ETHICAL CLEARANCE CERTIFICATE

Ethical Clearance Reference Number: DEC OSH 0016 Date: 04/-04/2022

This Ethical Clearance Certificate is issued by the University of Namibia Ethics Committee (REC) 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 ethics committee.

Title of Project: THE ASSOCIATION BETWEEN DISCLOSURE AND ADHERENCE TO ANTIRETROVIRAL THERAPY AMONG ADOLESCENTS LIVING WITH HIV IN WINDHOEK, KHOMAS REGION, NAMIBIA

Principal researchers: MARTHA KACHANA MANVWALI

Staff Number/ Student number: 201072491

Remarks: Low Risk Approved

Centre for Research Services

Take note of the following:

1. Any significant changes in the conditions or undertakings outlined in the approved Proposal must be communicated to the ethics committee. 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 ethics committee
3. The Principal Researcher must report issues of ethical compliance to the ethics committee (through the Chairperson) at the end of the Project or as may be requested by the ethics committee
4. The ethics committee retains the right to:

i) Withdraw or amend this Ethical Clearance if any unethical practices (as outlined in the Research Ethics Policy) have been detected or suspected,

ii) Request for an ethical compliance report at any point during the course of the research.

The ethics committee wishes you the best in your research.

Prof Hans J Amukugo (Oshakati Campus Chairperson Decentralized Ethics Committee)

Prof. Davis Mumbengegwi (Head, Multidisciplinary Research)

APPENDIX B: UNIVERSITY OF NAMIBIA RESEARCH PERMISSION LETTER

CENTRE FOR RESEARCH SERVICES
Office of the Pro-Vice Chancellor: Research, Innovation & Development
University of Namibia, Private Bag 13301, Windhoek, Namibia
340 Mandume Ndemufayo Avenue, Pioneers Park, Office F223 - Fblock, Second Floor
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UNAM
UNIVERSITY OF NAMIBIA

RESEARCH PERMISSION LETTER

Date: 22/04/2022

Student Name: MARTHA KACHANA MANVWALI

Student Number: 201072491

Programme: MASTER'S DEGREES IN PUBLIC HEALTH

Approved Research Title: The Association Between Disclosure and Adherence to Antiretroviral Therapy Among Adolescents Living with HIV In Windhoek, Khomas Region, Namibia.

TO WHOM IT MAY CONCERN

I hereby confirm that the above-mentioned student is registered at the University of Namibia for the programme indicated. The proposed study met all the requirements as stipulated in the University guidelines and has been approved by the relevant committees.

The proposal adheres to ethical principles as per attached Ethical Clearance Certificate. Permission is hereby granted to carry out the research as described in the approved proposal.

Best Regards

Dr. AEE Shikongo
Head: Postgraduate Support Services
Tel: +264 61 206 3129
E-mail: aeshikongo@unam.na

CENTRE FOR RESEARCH SERVICES
Office of the Director
2022 -04- 22
University of Namibia
UNAM

APPENDIX C: PERMISSION LETTER FROM THE MINISTRY OF HEALTH AND SOCIAL SERVICES: OFFICE OF THE EXECUTIVE DIRECTOR

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/ MKM
Enquiries: Mr. A. Shipanga

Date: 24 May 2022

Mrs. Martha K. Manvwali
PO Box 51120
Bachbrecht
Windhoek

Dear Mrs. Manvwali

Re: *The association between disclosure and adherence to antiretroviral therapy among adolescents living with HIV in Windhoek, Khomas region, Namibia.*

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.

MY NAMIBIA

APPENDIX D: PERMISSION LETTER FROM THE MEDICAL SUPRINTENDENT OF INTERMEDIATE HOSPITAL KATUTURA

Republic of Namibia

Ministry of Health and Social Services

Private Bag 13215
WINDHOEK
Namibia

Intermediate Hospital Katutura
Independence Avenue
WINDHOEK

Telephone (061) 203 4004/5
Telefax (061) 222706

Enquiries: Sr. I. Thele

Date 06 June 2022

OFFICE OF THE MEDICAL SUPERINTENDENT

Ms. Martha Kachana Manvwali-Siboleka
University of Namibia

Ms. Siboleka

RE: THE ASSOCIATION BETWEEN DISCLOSURE AND ADHERENCE TO ANTIRETROVIRAL THERAPY AMONG ADOLESCENT LIVING WITH HIV IN WINDHOEK

The above mentioned subject refers:

This office hereby grants you permission to do a research on the association between disclosure and adherence to antiretroviral therapy among adolescents living with HIV at Intermediate Hospital Katutura, Windhoek, Khomas Region, Namibia.

Please provide this office with a copy of your findings.

Thank you

Yours in Health,

8/6/2022
....

DR. F.M. SHIWEDA
CHIEF MEDICAL OFFICER

MINISTRY OF HEALTH
AND SOCIAL SERVICES
P/BAG 13215
WINDHOEK NAMIBIA
06 -06- 2022
INTERMEDIATE HOSPITAL KATUTURA

APPENDIX E: PERMISSION LETTER FROM THE REGIONAL DIRECTOR, KHOMAS DIRECTORATE: MOHSS

REPUBLIC OF NAMIBIA
MINISTRY OF HEALTH AND SOCIAL SERVICES

OFFICE OF THE REGIONAL DIRECTOR

Private Bag 13322 Windhoek Namibia	Khomas Directorate Florence Nightingale Street Windhoek	Tel: (061) 203 5016 Fax: (061) 235997 International: (264 61 235997)
Enq: Ms. P. N. Ambambi/Charly Ilunga	Ref: PF	Date: 22 June 2022

STAFF MATTER: CONFIDENTIAL

MRS. MARTHA KACHANA SIBOLEKA
P. O. BOX 51120
BACHBRECHT
WINDHOEK

RE: THE ACADEMIC RESEARCH PROPOSAL, THE UNIVERSITY OF NAMIBIA, MASTERS OF PUBLIC HEALTH.

Dear Mrs. Siboleka

I have pleasure to inform you that on recommendation of the Executive Director, permission has been granted for you to conduct a study on "the association between disclosure and adherence to antiretroviral therapy among adolescents living with HIV" in Windhoek, Khomas Region, Namibia] for a period of five (5) days from 27 June 2022 until 01 July 2022.

The office wishes you success with your research.

Yours sincerely

MR. TOMAS UKOLA
DIRECTOR: KHOMAS REGION

MINISTRY OF HEALTH
AND SOCIAL SERVICES
P/BAG 13322 WINDHOEK
2022 -06- 27
HUMAN RESOURCE OFFICER
REPUBLIC OF NAMIBIA

All Official Correspondence must be addressed to the Regional Director

APPENDIX F: DATABASE AND QUATIONNAIRE LINKAGE DOCUMENT

This is an encrypted (password protected) document, if found please delete it instantly
*This document will not be shared with anyone including the supervisor
*This document will be destroyed as soon as data collection method is done, and no information will be retrieved from here

No	Unique ART No	Facility code	Questionnaire No.	Contact number	Physical Address
1					
2					
3					
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5					
6					
7					
8					
9					
10					
11					
12					
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APPENDIX G: QUANTITATIVE DATA COLLECTION CHECKLIST

RESEARCH CHECKLIST

This research checklist is for gathering data from the adolescent's documents (Patient care booklets, Pharmacy EDT) for the study titled: ***The association between disclosure and adherence to antiretroviral therapy among adolescents living with HIV in Windhoek, Khomas region.***

By: Mrs Martha Kachana Manvwali

University of Study: University of Namibia

Date: October/November 2022

The Purpose of the Research Checklist: The observation checklist for the research is designed to review the documents of the participating adolescents living with HIV, to determine their demographic data, duration on ART, disclosure status and their adherence levels (good or poor). Data will be observed from the Patient care booklets, EDT and the EPMS/Quantum system. All that are observed will be indicated by a cross (×) in the appropriate column.

Email address: marthamanvwali@yahoo.com

Acronyms

CND Complete non-disclosure
PD Partial disclosure
FD Full disclosure
D Deception
AD Accidental disclosure
P Poor
G Good
HF Health facility

Instructions:

Please tick [✓] in the box that best describe the response. Where explanation and description is required, fill in the blank spaces provided.

i

SECTION A					**SECTION B**												
Data col. date	***HF***	***Client code***	***Age***	***Gender***	***Duration on ART in months***		***Adherence level***				***Disclosure status***					***Contact details***	***Next F/up***
					≤12	***≥12***	***EDT***		***PCB***		***CND***	***PD***	***FD***	***D***	***AC***		
							G (≥90%)	***P (<80%)***	***G (≥90%)***	***P (<80%)***							

The end.

ii

APPENDIX H: INFORMED PARENTAL CONSENT FOR QUALITATIVE STUDIES

UREC Annex 5C: Informed Parental Consent for Qualitative Studies

UNAM
UNIVERSITY OF NAMIBIA

INFORMED PARENTAL CONSENT FORM

Informed Consent for the parents or guardians of the adolescents participating in the research titled: *The association between disclosure and adherence to antiretroviral therapy among adolescents living with HIV in Windhoek, Khomas region.*

Name of Principal Investigator:	Ms Martha Kachana Manvwali
Name of Supervisors:	Dr Anna Alfeus Mr Desderius Haufiku

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 Martha Kachana Manvwali, I'm student at the University of Namibia studying towards the Master of public health programme. I am inviting you to have your children partake in this research I'm conducting which might help your clinic/hospital do more to help the adolescent girls and boys become or stay healthier and comply to the care they are enrolled in. Whenever researchers study children and adolescents, we talk to the parents or guardians to ask for permission. After you agree I will the ask your daughter/son for their agreement as well. Both of you must agree before I commence. Before you decide to consent to the research, you may talk to anyone you feel comfortable with about the research and may take time to reflect whether you want your child to participate or not, you do have to decide today. If you do not understand some words or concepts in this research, I will take time to explain as you go along and you may ask questions at any time.

Purpose of the Research

It is possible that the commitment or the degree to which your son/daughter correctly follows medical advice may be influenced by their understanding and awareness of why they are taking their treatment from the clinic/hospital. In this study we want to review the adolescents' documents and records to see if they are following prescribed treatment and coming back on their given follow-up dates, we will also ask them if they know why they are taking their treatment. I will not by any chance mention that the treatment is for HIV/AIDS as I am fully aware that some of them might not know this situation. I also understand that the parent or guardian might be afraid to disclose to their child that the medicine they are taking is for HIV/AIDS as fear of rejection and resentment from their children are highly to occur. The researcher is of the opinion that the research results will contribute to the understanding of successful disclosure programs to health care workers, policy makers and other stakeholders in the health ministry, and as well as to inform policy makers and implementers to adopt programs that will not hinder the adolescent's health but promote good adherence and understanding to their HIV treatment, and to as well help the parents and guardians in dealing with or handling the process of informing their son/daughter about the true reason of why they are on treatment.

Type of Research Intervention

This research will involve your son/daughter's participation in the individual interview that will take about 3-6 minutes.

Participant Selection

The researcher wants to talk to many adolescents who are on HIV care to assess their understanding and awareness of the treatment they are taking, we would like to ask your son/daughter because S/he is part of the group of interest and also lives in this region, Khomas.

Voluntary Participation

You do not have to agree that your son/daughter can talk to us, you can choose to say no and any services you are receiving at this clinic/hospital will not change or be hindered in any way. We understand how difficult it can be to make decisions involving your child and especially when it involves sensitive topics like HIV. You can ask as many questions as you can, and we will provide you with answers. You may also not decide today, you can inform me whenever you have made the decision and inform me later.

Procedures

If your son/daughter does not wish to answer any of the questions during the interview, we will move to the next question. The interview will take place at the clinic/hospital in where they are receiving care, and no one else but the interviewer will be present unless your child asks someone to be there. The information that will be recorded is confidential, no one else except the authorized UNAM staff and my supervisor and I, will have access to the information documented during the interview.

Duration

We are asking your child to participate in an interview which will take about 5-10 minutes. We can do this after school hours.

Risks

We will ask your son/daughter to tell us if she knows why s/he is taking the medicine s/he gets from the clinic/hospital, some adolescents might feel uncomfortable to answer these questions, however, s/he does not have to take part in the interview or answer any question if s/he doesn't wish to, s/he does not have to give reasons for not responding or refusing to take part in the interview.

Benefits

There will be no immediate or direct benefit to your child or to you, but the participation of your child will help us find effective strategies and approaches to successful HIV status disclosure process, that will as well assist you as a parent/guardian in disclosing the status to your child. Overall, the participation of your son/daughter will assist in improving the HIV care services provided to the adolescents.

Reimbursements

Your son/daughter will not be provided with any payment for partaking in the research, however. s/he will be provided with N$30 for travel expenses, should the participant be requested to come to the clinic/hospital on a day which is not a scheduled follow-up date.

Confidentiality

The information collected from your son/daughter will be treated as confidential and protected. If it is used in a publication or thesis, your son/ daughter's identity as a participant will remain anonymous, a number or code will be used to identify him/her in the interview. All interview data will be stored in a safe and secure place, and only authorised University officials, my supervisor and I will have access to it.

Sharing the Results

At the end of the study, we will be sharing what we have learnt with the ministry of health and its stakeholders in the HIV/AIDS programs. Nothing that your child will share with us today will be attributed to him/her by name. we will also publish the results in order that other interested people may learn from our research.

Right to Refuse or Withdraw

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. Choosing to participate or not will not affect either your own or your child's future treatment at the Centre here in any way. You and your child will still have all the benefits that would otherwise be available at this Centre. Your child may stop participating in the interview at any time that you or she/he wish without either of you losing any of your rights here.

Who to Contact

If you have any questions, you can ask me (the researcher) name: martha Kachana Manvwali, contact #: 0813511229 or my research supervisor: Dr Anna Alfeus (aalfeus@unam.na) cell #: If you wish to ask questions later.

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 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. The study will only commence after consent from both guardian and the adolescent are obtained

2. The interview will take about 5-10 minutes, and all questions and clarifications needed during the interview will be attended to.

3. should the participant decide to discontinue with the interview, they may do so without any negative consequences towards them.

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/Person taking Consent (print) 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 they understand that the following will be done:

1. The study will only commence after consent from both guardian and the adolescent are obtained

2. The interview will take about 5-10 minutes and all questions and clarifications needed during the interview will be attended to.

3. should the participant decide to discontinue with the interview, they may do so without any negative consequences towards them.

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)

APPENDIX I: ADOLESCENT – QUESTIONNAIRE

HREC-NH Annex 5G:
INTERVIEW QUESTIONNAIRE
ADOLESCENTS

This semi-structured guide is designed to assess, evaluate, and gather opinions and perceptions for the study titled: ***The association between disclosure and adherence to antiretroviral therapy among adolescents living with HIV in Windhoek, Khomas region.***

By: Ms Martha Kachana Manvwali
University of Study: University of Namibia
Date: October 2022
Items required for interview: Hard copy of research proposal, Pen, Writing pad, Conducive and comfortable place and Voice recorder.
Email address: marthamanvwali@yahoo.com
Introduction:

Dear Participant

Introduction
My name is Martha kachana Manvwali, student number 201072491. I am studying towards a Master of Public health degree at the University of Namibia (UNAM), and I am conducting research about the association between disclosure and adherence to antiretroviral therapy among adolescents living with HIV in Windhoek, Khomas region, Namibia. (Tittle will be withheld from adolescents to avoid accidental disclosure, the tittle will be replaced with the following statement: the research that seeks to assess your understanding of the medicines you are receiving at the health care facility).

I have selected you to participate in my study, because you belong to the target group of the study, which is the Adolescent group. I would therefore like to invite you to take part in this interview.

1. The research I am conducting has been approved by the UNAM Research Ethics Committee and the MoHSS. I would appreciate it very much if you participate in the interview, and I would like to assure you of the following:
    a. You do not have to partake if you do not want to.
    b. You can stop participating at any time if you want to, and there will be no negative consequences for you.
    c. Your participation is completely anonymous. This means that, even if I ask information that might identify you or if I know you, I am not allowed to make your identity known to anyone. When I report on my interviews' data and results, I will not mention any personal information about participants that might identify them but rather numbers.
    d. All interview data will be stored in a safe and secure place, and only authorised University officials, my supervisor and I will have access to it. After five years, data will be destroyed in an environmentally friendly way.

2. If you have any questions about this interview, or if you do not understand anything, please feel free to ask me, and I will be happy to explain it to you.
3. If you want to know more about the research doing, please feel free to ask me, and I will be happy to tell you more.
4. It should take about 5-10 minutes for us to complete the interview.
5. You can reach me on my cell phone at 0813511229, or send an e-mail to marthamanvwali@yahoo.com

If you want to contact the UNAM Centre for Research Services for more information or because you have a comment or complaint about this research or about me, please call (+ 264 61) 206 4673, or write an e-mail to research@unam.na. Please provide specific information. You can as well contact my supervisors; Dr P Angula Telephone Number: +**264 652232253** and Mr D. Haufiku +**264 652232308**

6. Thank you very much for your willingness to participate in this research!

Instructions:

Please tick [√] in the box that best describe the response. Where explanations and descriptions are required, fill in the blank spaces provided.

<u>Part A: Demographic Information</u>

1. Which of these describes your gender.

Gender	Tick [√]
Male	
Female	

2. Indicate your age group.

Age group	Tick [√]
10-14	
15-19	

3. Primary care giver

Relationship	Tick [√]
Mother	
Father	
Both parents (Mother and Father)	
Brother	
Sister	
Other close relatives (Uncles, aunties, grandparents, cousins)	

4. What is your current grade or highest academic qualification?

5. How would you describe your type of work? *(If other, mention/state)*

No.	Type of work	Tick [√]
1.	Learner in School	
2.	Student at the University	
3.	Administration officer	
4.	Financial clerk/officer	
5.	Technician	

6.	Supervisor	
7.	Middle management	
8.	Senior management	
9.	Executive	
10.	Unemployed	
11.	Other	

6. Duration on ART.

Duration	Tick [√]
6 months-4 years	
5-10 years	
11-15 years	
>15 years	

Section B: Client (Adolescent) Questions

1: Do you know why you are taking the medicines you are getting from the health facility?

____

____

____

2: Do you think it is important to drink these medicines? And why?

____

____

3: How do you feel about taking these medicines daily?

____

____

4: How did you find out about your HIV+ status? (*This question is only asked to those who are aware of their HIV+ status*)**.**

____

____

5: What would you want the MOHSS and fellow adolescents to do to improve the understanding and adherence to antiretroviral therapy among adolescents? *(This question is only asked to those who are aware of their HIV+ status)*

____

____

☺ ☺ *Thanks for participating in this study* ☺ ☺

APPENDIX J: INFORMED CONSENT FORM HEALTH CARE WORKERS

INFORMED CONSENT FORM
Health care workers

UNAM
UNIVERSITY OF NAMIBIA

Informed Consent for the health care workers participating in the research titled: *The association between disclosure and adherence to antiretroviral therapy among adolescents living with HIV in Windhoek, Khomas region.*

Name of Principal Investigator:	Ms Martha Kachana Manvwali
Name of Supervisor: **Co-supervisor:**	Dr Penehafo Angula Mr Desderius Haufiku

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 Martha Kachana Manvwali, a 4th year student at the University of Namibia studying towards the Master of public health program. I am inviting you to partake in this research I'm conducting which might help your clinic/hospital and MoHSS do more in areas of adherence and disclosure to help the adolescent clients/patients enrolled in HIV care at your clinic become or stay healthier and comply to the care you are offering them. If you do not understand some words or concepts in this research, I will take time to explain as you go along and you may ask questions at any time.

Purpose of research

It is possible that the commitment or the degree to which your HIV+ adolescent clients correctly follow medical advice may be influenced by their understanding and awareness of why they are taking their treatment from the clinic/hospital. In this study we want to review the adolescents 'documents and records to see if they are following prescribed treatment and coming back on their given follow-up dates, and to as well obtain information from you as a healthcare worker about your experiences in providing ART to adolescents that are aware of their HIV+ status and those that aren't aware, your views on disclosure program and adherence among these adolescents.

Your participation

You are being invited to take part in the study. You are selected to participate in the study because you meet the participation criteria. You will be asked questions about HIV+ adolescents in areas of disclosure and their adherence to treatment. Whatever you say will be kept entirely confidential. The researcher will be summarising information from many respondents and will not link any responses to you in the report. We appreciate that you will give honest answers to the questions to help us better understand this issue.

Voluntary participation and withdrawal

You are free to choose whether to take part in this study or not. If you choose not to take part, you will not be negatively affected in any way. If you choose to participate, you may stop at any time without any penalty. You are also free to choose to not answer questions that are asked during the discussion.

Type of Research Intervention

This research interview will take about 3-6 minutes.

Participant Selection

The researcher wants to talk to health care workers who are working at the ART sites in the state health facilities, as they are the key informants in supplying in-depth and detailed information about disclosure and adherence through their observations and experience, they so far have.

Procedures/confidentiality

The interview will take place at the clinic/hospital where the ART services are provided to the HIV+ adolescents, and no one else but the interviewer will be present. The information that will be recorded is confidential, no one else except the authorized UNAM staff, my supervisor and I, will have access to the information documented during the interview.

Risks

There is no risk that will be physically Imposed on you as we are only going to ask you a few questions and you'll be done.

Benefits

Your participation will help us find effective strategies and approaches to successful HIV status disclosure process, that will as well assist you as a healthcare worker in disclosing the status to your adolescent clients and yield and adherence improvement. Overall, your participation will assist the MOHSS in improving the HIV care services in paediatrics and adolescents.

Reimbursements

You will not be provided with any payment for partaking in the research, as this will be done during your working hours, with permission to interview you from your employer which is the MOHSS and your final consent to take part in the study as well.

Sharing the Results

At the end of the study, we will be sharing what we have learnt with the ministry of health and its stakeholders in the HIV/AIDS programs. Nothing that you will share with us today will be attributed to you by name. We will also publish the results in order that other interested people may learn from our research but only with approval from MOHSS.

Who to Contact

If you have any questions, you can ask me (the researcher) name: martha Kachana Manvwali, contact #: 0813511229 or my research supervisors: Dr Penehafo Angula, cell #: 0812489408 or Mr Desderius Haufiku cell #: 0812453388. If you wish to ask questions later.

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 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.

Signature of health care worker………………………………..

Date (day/month/year……………………………….

Statement by the Researcher/Person taking Consent

I have accurately read out the information sheet to the health care worker as a participant, and to the best of my ability made sure that the participant understands that the following will be done:

1. The study will only commence after consent from him/her is obtained

2. The interview will take about 3-6 minutes and all questions and clarifications needed during the interview will be attended to.

3. should the participant decide to discontinue with the interview, they may do so without any negative consequences towards them.

I confirm that the health care worker 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/Person taking Consent (print) Signature

APPENDIX F: HEALTH CARE WORKERS – QUESTIONNAIRE

HREC-NH Annex 5G:

INTERVIEW QUESTIONNAIRE

HEALTH CARE WORKERS

UNAM UNIVERSITY OF NAMIBIA

This semi-structured guide is designed to assess, evaluate, and gather opinions and perceptions for the study titled: ***The association between disclosure and adherence to antiretroviral therapy among adolescents living with HIV in Windhoek, Khomas region.***

By: Ms Martha Kachana Manvwali
University of Study: University of Namibia
Date: October 2022
Items required for interview: Hard copy of research proposal, Pen, Writing pad, Conducive and comfortable place, and Voice recorder.
Email address: marthamanvwali@yahoo.com
Introduction:

Dear Participant

Introduction
My name is Martha kachana Manvwali, student number 201072491. I am studying towards a Master of Public health degree at the University of Namibia (UNAM), and I am conducting research about the association between disclosure and adherence to antiretroviral therapy among adolescents living with HIV in Windhoek, Khomas region, Namibia.

I have selected you to participate in my study, because you meet the participation criteria as a health care worker. I would therefore like to invite you to take part in this interview.

7. The research I am conducting has been approved by the UNAM Research Ethics

Committee and the MoHSS. I would appreciate it very much if you participate in the interview, and I would like to assure you of the following:

a. You do not have to partake if you do not want to.
b. You can stop participating at any time if you want to, and there will be no negative consequences for you.
c. Your participation is completely anonymous. This means that, even if I ask information that might identify you or if I know you, I am not allowed to make your identity known to anyone. When I report on my interviews' data and results, I will not mention any personal information about participants that might identify them but rather numbers.
d. All interview data will be stored in a safe and secure place, and only authorised University officials, my supervisor and I will have access to it. After five years, data will be destroyed in an environmentally friendly way.

8. If you have any questions about this interview, or if you do not understand anything, please feel free to ask me, and I will be happy to explain it to you.
9. If you want to know more about the research doing, please feel free to ask me, and I will be happy to tell you more.
10. It should take about 5-10 minutes for us to complete the interview.
11. You can reach me on my cell phone at 0813511229, or send an e-mail to marthamanvwali@yahoo.com

If you want to contact the UNAM Centre for Research Services for more information or because you have a comment or complaint about this research or about me, please call (+ 264 61) 206 4673, or write an e-mail to research@unam.na. Please provide specific information. You can as well contact my supervisors; Dr P Angula Telephone Number: +**264 652232253** and Mr D. Haufiku +**264 652232308**

12. Thank you very much for your willingness to participate in this research!

Instructions:

Please tick [✓] in the box that best describe the response. Where explanations and descriptions are required, fill in the blank spaces provided.

Part A: Demographic Information

7. Which of these describes your gender.

Gender	**Tick [✓]**
Male	
Female	

8. Indicate your age group.

Age group	**Tick [✓]**
10-14	
15-19	
20-25	
26-30	
30+	

9. Indicate marital status.

Status	**Tick [✓]**
Single	
Married	
Living with a partner	
Separated/divorced	
Widow/widower	

10. What is your highest academic/ professional qualification?

11. How would you describe your type of work? *(If other, mention/state)*

No.	**Type of work**	**Tick [✓]**
1.	Nurse:	
2.	Health assistant:	
3.	Doctor:	
4.	Others (specify):	

12. Indicate for how long you have been working in the ART clinic.

Duration	**Tick [✓]**
6 months-4 years	
5-10 years	
11-15 years	
>15 years	

What is your experience working with HIV positive adolescents who are aware of their HIV status and those who are not aware of their HIV status? (*Mention as many experiences as possible.)*

____

____

Do you think it is important to have a strengthened disclosure program for the adolescents in ART care? Yes ☐ or No ☐ *(Please explain why)*

____

____

What factors do you think can escalate successful disclosure among adolescents in this program?

____

____

What are you recommendation to the MoHSS and to the adolescents with regards to disclosure and adherence to antiretroviral therapy?

____

____

☺ ☺ *Thanks for participating in this study* ☺ ☺

APPENDIX K-1: ADOLSCENT/CAREGIVER CONSENT FORM (NON-DISCLOSED ADOLESCENTS).

Agreement to participate in the health research (Adolescent/Caregiver): by: Martha Kachana Manvwali

- *I have read/heard the information sheet and had the opportunity to have my questions answered.*
- *I understand that whatever I say will be treated confidentially and will not be linked to my name.*
- *I understand that I can stop participating at any point and this decision will not affect me negatively.*
- *I understand that this is a research project, and it will not necessarily benefit me personally.*
- *I am aware of the telephone number of a person I can contact should I have any questions or concerns about this study.*
- *My signature confirms that I am willing to participate in this study and agree to respect other participants' privacy and confidentiality.*

I confirm that I agree to participate in the study and my questions have been answered

No	Qr No. e.g., XXX-MM-YY-SEQUENCE	Adolescent Assent/signature	Caregiver signature	Date
1	134-1122-01	Assent	[illegible]	11/11/2022
2	134-1122-11	Assent	[illegible]	17/11/2022
3	228-1122-15	Assent	[illegible]	02/11/2022
4	421-0123-24	Assent	[illegible]	06/03/2023
5	420-0123-25	[illegible]	[illegible]	06/03/2023
6	134-0123-26	[illegible]	[illegible]	06/03/2023
7	134-0123-27	Assent	[illegible]	07/03/2023
8	134-0123-28	Assent	[illegible]	07/03/2023
9	128-0123-29	[illegible]	[illegible]	09/03/2023
10	134-0123-30	[illegible]	[illegible]	09/03/2023
11	218-0123-31	Assent	[illegible]	09/03/2023
12	218-0123-32	Assent	[illegible]	15/03/2023
13	218-0123-33	Assent	[illegible]	15/03/2023
14	110-0123-34	Assent	[illegible]	15/03/2023
15	114-0123-35	Assent	[illegible]	16/03/2023
16	121-0123-36	Assent	[illegible]	16/03/2023
17	115-0123-37	Assent	[illegible]	16/03/2023
18				
19				
20				

Researcher's signature [illegible] **Date:** 17/03/2023.

APPENDIX K-2: ADOLSCENT/CARE GIVER CONSENT FORM (DISCLOSED ADOLESCENTS)

Agreement to participate in the research (Adolescent/Caregiver): The association between Disclosure and adherence to antiretroviral therapy among adolescents living with HIV in Windhoek, Khomas region, by: Martha Kachana Manvwali

- *I have read/heard the information sheet and had the opportunity to have my questions answered.*
- *I understand that whatever I say will be treated confidentially and will not be linked to my name.*
- *I understand that I can stop participating at any point and this decision will not affect me negatively.*
- *I understand that this is a research project, and it will not necessarily benefit me personally.*
- *I am aware of the telephone number of a person I can contact should I have any questions or concerns about this study.*
- *My signature confirms that I am willing to participate in this study and agree to respect other participants' privacy and confidentiality.*

I confirm that I agree to participate in the study and my questions have been answered

No	Qr No. e.g., XXX-MM-YY-SEQUENCE	Adolescent Assent/signature	Caregiver signature	Date
1	419-1122-02	[illegible]	[illegible]	11/11/2022
2	419-1122-03	[illegible]	[illegible]	13/11/2022
3	419-1122-04	Assent	[illegible]	15/11/2022
4	134-1122-05	[illegible]	[illegible]	15/11/2022
5	134-1122-06	Assent	[illegible]	15/11/2022
6	134-1122-07	Assent	[illegible]	16/11/2022
7	134-1122-08	Assent	[illegible]	16/11/2022
8	128-1122-09	Assent	[illegible]	17/11/2022
9	134-1122-10	Assent	[illegible]	18/11/2022
10	134-1122-12	Assent	[illegible]	18/11/2022
11	134-1122-13	Assent	[illegible]	18/11/2022
12	422-1122-14	Assent	[illegible]	21/11/2022
13	422-1122-16	Assent	[illegible]	21/11/2022
14	134-1122-17	Assent	[illegible]	21/11/2022
15	128-1122-18	Assent	[illegible]	22/11/2022
16	228-1122-19	[illegible]	[illegible]	22/11/2022
17	134-1122-20	[illegible]	[illegible]	22/11/2022
18	122-1122-21	[illegible]	[illegible]	22/11/2022
19	134-1122-22	K.L.M.	[illegible]	23/11/2022
20	134-1122-23	Assent	ZKCM.	23/11/2023
Researcher's signature [illegible]		**Date:** 18/12/2022		

APPENDIX K-3: CHARACTERISTICS OF ADOLESCENTS (QUANTITATIVE & QUALITATIVE STRANDS)

Participants (unique identifier)	Age	Gender	Educational level	Facility (use pseudonyms)	Duration on ART	Regimen line
134-1122-01	10	M	Primary School	C	≤12 months	TDF/3TC/DTG
419-1122-02	19	F	Tertiary	HC	>12 months	TDF/3TC/DTG
420-1122-03	18	M	Secondary School	C	>12 months	TDF/3TC/DTG
419-1122-04	18	F	Secondary School	HC	<12months	TDF/3TC/DTG
134-1122-05	18	F	Secondary School	C	>12 months	TDF/3TC/DTG
134-1122-06	19	M	Secondary School	C	>12 months	TDF/3TC/DTG
134-1122-07	18	F	Tertiary	c	>12 months	TDF/3TC/DTG
398-1122-08	18	F	Secondary School	C	>12 months	TDF/3TC/DTG
128-1122-09	19	F	Secondary School	C	>12 months	TDF/3TC/DTG
134-1122-10	11	F	Secondary School	HC	>12 months	TDF/3TC/DTG
134-1122-11	12	F	Primary school	HP	>12 months	TDF/3TC/DTG
217-1122-12	16	M	Secondary School	HC	>12 months	TDF/3TC/DTG
134-1122-13	15	F	Secondary School	HP	>12 months	TDF/3TC/DTG
422-1122-14	17	F	Secondary School	HC	>12 months	TDF/3TC/DTG
421-1122-15	11	F	Primary school	HC	>12 months	TDF/3TC/DTG
421-1122-16	14	M	Secondary School	C	>12 months	TDF/3TC/DTG
134-1122-17	11	M	Secondary School	HP	>12 months	TDF/3TC/DTG
128-1122-18	17	F	Secondary School	HP	>12 months	TDF/3TC/DTG
228-1122-19	11	F	Primary school	HP	>12 months	TDF/3TC/DTG
134-1122-20	13	F	Primary school	HP	>12 months	TDF/3TC/DTG
122-1122-21	14	M	Secondary School	C	>12 months	TDF/3TC/DTG
134-1122-22	16	F	Secondary School	C	>12 months	TDF/3TC/DTG
134-1122-23	12	F	Primary school	HP	>12 months	TDF/3TC/DTG
134-1122-24	12	F	Primary school	HP	>12 months	TDF/3TC/DTG
134-1122-25	12	M	Primary school	HP	>12 months	TDF/3TC/DTG
134-1122-26	18	F	Primary school	HP	≤12 months	AZT/3TC/DTG
134-1122-27	15	F	Primary school	C	>12 months	TDF/3TC/DTG
134-1122-28	15	F	Secondary School	HP	≤12 months	TDF/3TC/DTG
134-1122-29	19	M	Tertiary	HP	>12 months	TDF/3TC/DTG
134-1122-30	19	M	Secondary School	HP	>12 months	TDF/3TC/DTG
134-1122-31	12	M	Primary school	HP	>12 months	TDF/3TC/DTG
134-1122-32	15	M	Secondary School	HP	>12 months	TDF/3TC/DTG
134-1122-33	17	M	Secondary School	HP	>12 months	TDF/3TC/DTG
134-1122-34	10	M	Primary school	HP	>12 months	AZT/3TC/DTG
118-1122-35	11	F	Primary school	HP	>12 months	TDF/3TC/DTG

APPENDIX L: HEALTH CARE WORKERS CONSENT FORM

Agreement to participate in the research (Health care workers): The association between disclosure and adherence to antiretroviral therapy among adolescents living with HIV in Windhoek, Khomas region, by: Martha Kachana Manvwali

- *I have read/heard the information sheet and had the opportunity to have my questions answered.*
- *I understand that whatever I say will be treated confidentially and will not be linked to my name.*
- *I understand that I can stop participating at any point and this decision will not affect me negatively.*
- *I understand that this is a research project and it will not necessarily benefit me personally.*
- *I am aware of the telephone number of a person I can contact should I have any questions or concerns about this study.*
- *My signature confirms that I am willing to participate in this study and agree to respect other participants' privacy and confidentiality.*

I confirm that I agree to participate in the study and my questions have been answered

No	Qr No. e.g., XXX-MM-YY-SEQUENCE	Participant signature	Date
1	HCW-0922-01	[illegible]	08/09/2022
2	HCW-1022-02	[illegible]	05/10/2022
3	HCW-1022-03	[illegible]	05/10/2022
4	HCW-1022-04	[illegible]	05/10/2022
5	HCW-1022-05	[illegible]	05/10/2022
6	HCW-1022-06	[illegible]	06/10/2022
7	HCW-1022-07	[illegible]	31/10/2022
8	HCW-1122-08	[illegible]	01/11/2022
9	HCW-1122-09	[illegible]	02/11/2022
10	HCW-1122-10	[illegible]	02/11/2022
11	HCW-1022-11	[illegible]	13/10/2022
12	HCW-1022-12	[illegible]	13/10/2022.
13	HCW-1122-13	[illegible]	02/11/22
14	HCW-1122-14	[illegible]	02/11/22
15	HCW-1122-15	[illegible]	02.11.22
16	HCW-1122-16	[illegible]	02.11.22
17	HCW-1122-17	[illegible]	02/11/22.
18	HCW-1122-18	[illegible]	02/11/2022.
19	HCW-1122-19.	[illegible]	04.11.2022
20	HCW-1122-20	[illegible]	11/11/2022.
Researcher's signature [illegible]		Date: 13/11/2022	

APPENDIX M: CHARACTERISTIC OF HEALTH CARE WORKERS.

HCW#	Gender	Age group 1. <19 2. 20-25 3. 26-30 4. 30+	Marital status 1. Single 2. Married 3. Cohabiting 4. Separated/ divorced Widow/Widower	Highest academic/professional qualification	Type of work 1. Nurse 2. Health assistant 3. Doctor 4. Other	How long you have worked in the ART department 1. 6months-4 years 2. 5-10 years 3. 11-15 years 4. 15+ years
HCW-0922-01	M	4	1	Honors degree	4-HIV Nurse mentor	2
HCW-1022-02	F	4	2	Diploma	2	2
HCW-1022-03	F	4	1	Certificate	2	4
HCW-1022-04	F	4	2	Diploma	1	2
HCW-1022-05	F	2	1	Certificate	1	1
HCW-1022-06	M	4	2	Postgraduate diploma	4-senior health program officer	2
HCW-1122-07	F	4	1	Master's degree in public health	3	1
HCW-1122-08	F	2	1	Bachelor's degree	1	1
HCW-1122-09	F	3	2	Certificate	1	2
HCW-1122-10	F	4	1	Certificate	2	2
HCW-1022-11	F	3	1	Honors degree	1	1
HCW-1022-12	F	4	1	Honors degree	3	1
HCW-1122-13	F	4	1	Certificate	2	2
HCW-1122-14	F	4	1	Diploma	1	1
HCW-1122-15	F	4	1	Master's degree	2	2
HCW-1122-16	F	3	1	Bachelor's degree	1	1
HCW-1122-17	F	4	2	Honor's degree	1	2
HCW-1122-18	F	4	1	Honor's degree	1	2
HCW-1122-19	F	3	1	Honor's degree	1	1
HCW-1122-20	M	3	1	Diploma	1	1