

THE EFFECT OF HIV STATUS DISCLOSURE AND NON-DISCLOSURE ON THE
PSYCHOSOCIAL WELLBEING, ADHERENCE LEVELS AND TREATMENT
OUTCOMES OF ADOLESCENTS ON HIGHLY ACTIVE ANTI-RETROVIRAL
THERAPY (HAART) AT KATUTURA STATE HOSPITAL, NAMIBIA

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ABSTRACT

Background: With the advent and wide availability of highly active antiretroviral therapy (HAART), HIV- infected children are currently living health lives and growing into adulthood. There has been mounting evidence on the benefits of appropriate HIV disclosure to adolescents. However, various researches reported contradicting results as disclosure having both negative and positive social and psychological impacts on children. This study aimed to determine the effect of HIV status disclosure on the psychosocial wellbeing, adherence to treatment and HIV treatment outcome of adolescents who are taking ART at Katutura State Hospital, pediatric HIV Clinic.

The study also aimed to determine the risk of Psycho social “deviations” in HIV status disclosed adolescents as compared to undisclosed adolescent on HAART and to compare the adherence level, CD4 count, and viral load of disclosed and non-disclosed adolescent children also on HAART at the same clinic.

The newly implemented Pediatric HIV disclosure program in Namibia prompted this study. The program is guided by the World Health Organization which reported mixed effects after HIV status disclosure on the adolescents and it was deemed necessary to assess whether HIV status disclosure results in a better psychosocial wellbeing, higher CD4 count and lower viral load among adolescent children put on HAART.

Methods: A Cross-sectional Analytic research design was employed where the prevalence of being psychosocially unwell and the level of HIV treatment adherence, CD4 count and viral

load was compared in two groups of HIV positive adolescents enrolled in HIV care and put on HAART at Katutura Hospital for at least 12 months.

Results: Two-hundred HIV-infected adolescents took part in the study, data was analyzed, 99 (49.5%) were disclosed and 101(50.5%) were undisclosed. The mean age of the study participants was 12 years.

The findings revealed no association between disclosure status and psychosocial well-being; as 97 (98%) and 98 (97%) of the participants from the disclosed and undisclosed groups were assessed to have been psychosocially well.

It was also noted that both groups scored high on adherence to anti-retroviral therapy with an adherence level of above 98%. The results show no difference in viral load suppression between the disclosed and undisclosed group.

In addition, the result did not show significant difference in CD4 count between the two groups of adolescents which concludes that disclosure of HIV status is not associated with decreased CD4 count for adolescent living with HIV.

The results suggest that disclosure doesn't affect the psychosocial wellbeing of adolescents, neither does it affect the treatment outcomes of HIV positive adolescents on HAART.

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LIST OF ABBREVIATIONS

AAP - The American Academy of Pediatrics

AIDS – Acquired Immune Deficiency Syndrome

ART - Antiretroviral therapy

DRC - Democratic Republic of the Congo

HAART - Highly Active Anti-retroviral Therapy

HIV – Human Immune Deficiency Virus

HRQOL - Health related quality of life

MOHSS – Ministry of Health and Social Services

KATT - Kids and Teens Talk

PedsQL - Pediatric Quality of Life

UNICEF – United Nations Children’s Education Fund

WHO – World Health Organization

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DEDICATION

I dedicate this achievement to all the people who supported me, especially my supervisors, my immediate family members, colleagues for their encouragement and financial support. May the Almighty God bless you abundantly.

DECLARATION

I declare that the thesis is my own work and effort and it has not been submitted anywhere for any award. Where other sources of information have been used, they have been acknowledged. All the sources have been quoted and acknowledge by means of complete references which I submit for examination.

CHAPTER 1: INTRODUCTION AND BACKGROUND INFORMATION

1.1 Introduction

This chapter outlines the orientation of the study on the effect of HIV status disclosure on the psychosocial wellbeing, adherence levels and treatment outcomes of adolescent children receiving highly active antiretroviral therapy (HAART) at Katutura Intermediate Hospital (KIH) and Health Centre. The chapter also highlights the problem statement, the purpose and the significance of the study.

1.2 Orientation of the proposed study

In 2011, the World Health Organization (WHO) estimated that there were 3.4 million children less than 15 years of age living with the Human Immunodeficiency Virus (HIV), and an estimated 330,000 children were newly infected in 2011 alone (UNAIDS, 2011). Sub-Saharan Africa is home to over 90% of the paediatric HIV-infected population. According to the report of the Ministry of Health and Social Services (MOHSS) in 2010, Namibia was one of the top five countries in the world most affected by HIV and AIDS pandemic. At that time, a total of 174 000 people were living with HIV/AIDS of which 16 000 were children aged 0 – 14. Adolescent represented 23% of population in Namibia by 2009 and the HIV prevalence among children age 15 – 19 was estimated at 6.6% (MOHSS, 2010).

The advent of antiretroviral therapy (ART) and expanded access to treatment has resulted in more HIV-infected children reaching adolescence and adulthood, especially in resource-limited settings like sub-Saharan Africa (UNAIDS, 2011).

As HIV-infected children live longer, there are emerging challenges to comprehensive HIV care for adolescents. These include, supporting high rates of adherence to treatment, preventing secondary transmission, and promoting overall physical and mental health. For these children, learning about their HIV diagnosis, often referred to as disclosure, is an important step towards long-term disease management and necessary for the transition from paediatric care into adolescent care settings (Wiener, Herber, Segnan, 2007).

The scientific literature reports that many children in sub-Saharan Africa who are receiving ART have no knowledge of their HIV status, and thus have little understanding of how their medicines work to keep them healthy (Vreeman, 2010).

In the United States, recommendations for disclosure of HIV status to children endorse a gradual process of giving age-appropriate information as the child develops the cognitive and emotional maturity to process this information. Globally, institutions such as the World Health Organization (WHO) have issued similar guidelines. The WHO guidelines state that the disclosure of HIV status is fundamental to the management of HIV, especially in terms of adhering to complex treatment regimens (WHO, 2003).

Supporting the WHO efforts, the American Academy of Pediatrics (AAP) issued guidelines for disclosure of HIV serostatus to children and adolescents. Thus, HIV disclosure to a child became “an increasingly common clinical issue.” The AAP strongly recommended that older school-age children and adolescents living with HIV be informed of their HIV diagnosis (WHO, 2003). In 2010, Namibia’s Ministry of Health and Social Services (MOHSS) published guidelines for HIV counseling and testing, which recommended that the HIV status should be disclosed to all patients

and clients (MoHSS, 2011). However, there are few published data on standardized, culturally appropriate disclosure protocols in resource-limited settings (WHO, 2011).

There are different models of HIV status disclosure worldwide. A program Model in Brooklyn, New York called KATT (Kids and Teens Talk) support children and adolescents after disclosure to cope with the disease and prevent psychosocial effects caused by disclosure.

On this program, children and adolescents would talk about their HIV status, concerns, struggles, and learn about coping strategies. The program includes having meetings for every member of the family or caregivers and children between ages nine and 16 for six months after disclosure until the adolescents are coping and the relationship with parents and care givers is solidified (Abadia-Barrero, 2006).

Another tested model is the four-phase model of HIV disclosure in which HIV-positive parents and children are proposed to go through four phases when preparing their children for full disclosure. In the first phase (secrecy), parents tell their children nothing while parents absorb the news of their diagnoses. In the second phase (exploratory), parents begin to provide limited details of the disease (without mentioning its name) to their children, such as indicating that the parents are attending clinic visits and/or taking medications for a chronic illness. Parents also begin to make future tentative disclosure plans. In the third phase (readiness), parents provide even greater details of their illnesses to their children and start initiating disclosure plans. They attend support group meetings to speak with peers and disclose to trusted loved ones and/or healthcare professionals whom they want to be present when fully disclosing to their children. Finally, in the

fourth phase (full disclosure), parents tell their children all the details of their illnesses including its name (Tasker, 1992).

There were no models used for pediatric HIV disclosure by the MoHSS in Namibia in ART clinics until 2009 when the country adapted a model from the Botswana Baylor Pediatric Center of Excellence using a disclosure tool called “WHY I TAKE MY MEDICINES”. The model covers several components from preparation of caregivers for HIV status disclosure, partial and full disclosure as well as post disclosure counseling. The model has been piloted in few hospitals for children age six and above and health care worker should get permission from each adolescent’s parent in order to start the process of HIV status disclosure. In Namibia, any person below the age of 16 is regarded as a minor by law and parents or guardians should grant permission for any activity to be performed on or by the child (MoHSS, 2010).

Katutura Intermediate Hospital (one of the pilot facilities for HIV status disclosure program) is a referral hospital in Windhoek and provides HIV care and support services for adults and children. The hospital has enrolled 754 children on HAART.

By September 2012, the HIV status had been disclosed to 459 out of the 754 children. The non-disclosed group, that is 295 children, were those adolescents who attended the ART clinic but whose parents had not yet granted permission for disclosure. The main reason for their status was due to parents or guardians’ refusal to grant permission for disclosure or not present for several visits at the clinic as it is required by the clinic for them to accompany their children to the clinic for follow up visits. It is usually during the follow up visits that clinic staff acquire such consent.

Both negative and positive social and psychological impacts of disclosure to children have been reported by researchers. The benefits of disclosure to the child include improved adherence to treatment and better understanding of HIV infection control, but potential risks may include stigma, discrimination and violence (WHO, 2003).

“Psychosocial well-being” refers to the state of being which an individual has the ability to make sense of and have a degree of control over their world and hope for the future (Johannes, 2005). According to Letteney (2004), psychosocial well-being includes many different aspects of the child’s life, such as physical and material aspects, cognitive, psychological, social, cultural, spiritual aspects and their interpersonal relationship. The focus of psychosocial well-being need not be just on the individual, but can include households, families and communities (Letteney, 2004).

According to a study done in Zimbabwe, 56% of adolescents living with HIV and of which HIV status was disclosed reported psychosocial problems and lack of resources to help them with these issues. Respondents described the main psychosocial stressors for adolescents as stigma, difficulty in identifying with HIV-negative peers, anxiety about sexual relationships and future planning, and low self-esteem and feelings of hopelessness (WHO, 2011).

In contrast, a study done by Battler finds that those who know their status reported feeling more self-competent with peers. In addition, they disclose to peers and they do not have to worry about whether a friendship will continue post-disclosure. This allows the HIV-positive teen to have more open/satisfying relationships with friends, explain the positive relationship between disclosure and fewer posttraumatic stress symptoms (Battler, 2002).

Despite the importance of HIV disclosure, there has been limited research addressing pediatric HIV/AIDS disclosure for adolescents particularly in sub-Saharan Africa.

1.3 Problem statement

Some studies and clinical reports have indicated positive outcomes associated with disclosure including improved adherence to treatment and better long-term health outcomes. However, reports from facilities where the program was piloted in Namibia reported cases of psycho-social problems after HIV status disclosure, which has necessitated a follow up intervention to address the issues raised.

Adolescents reported rejection, and some were found to be depressed, isolated, and some were not adherent to ART as reported by the ART clinic in Rehoboth (MOHSS, 2010).

Therefore, KIH and Intermediate Hospital Oshakati have initiated a “Teen Club” where HIV positive children meet and discuss disclosure related issues. Additionally, a request for placement of Psychologists to address the psycho-social problems of children after HIV status disclosure was submitted to the management of the MOHSS (MOHSS, 2010).

Furthermore, the effectiveness of HIV status disclosure on children's behavior, relationships with family and other members of the community and adherence to care lacks conclusive evidence. The current literature review made recommendations for more research on the topic (Anne, 2008). As much as there are reported benefits of HIV status disclosure to adolescents, disclosure has the potential to impact adolescents in a negative way (WHO, 2003), especially if it is not done properly.

The lack of conclusive global experience on the benefits of disclosure of the HIV status to HIV infected adolescents, and the fact that the program is relatively new to the Namibian HIV/AIDS treatment and care program, justifies the need for the assessment of its impact.

1.4 Purpose of the Study

The main objective of the study is to determine the effect of HIV status disclosure on the psychosocial wellbeing, adherence level and HIV/AIDS treatment outcome of adolescent children receiving HAART at Katutura Intermediate Hospital.

1.5 Objectives of the study

- Determine the risk of Psycho-social "deviation" in HIV status disclosure among adolescent children receiving HAART.
- Compare the adherence level, CD4 count, and viral load of disclosed with that of non-disclosed adolescent children receiving HAART.

1.6 The research question

Does HIV status disclosure result in a better psychosocial wellbeing, higher CD4 count and lower viral load among adolescent children receiving HAART?

1.7 Significance of the study

The outcome of the study will inform implementers and policy makers on the level of effectiveness of HIV status disclosure on adolescent children and dictate the formulation of a realistic program that put in place a practical client identification, counselling and follow up guideline that works for the Namibian context.

1.8 Limitation of the study

The research will only be conducted with adolescents attending the KIH ART clinic. This may limit national or regional generalization of conclusions.

Since cross-sectional analytic designs measure both exposure and outcome at one point in time, they have the inherent weakness in inferring causal relationship. The research will seek information on psycho-social wellbeing through application of assessment tool and interviews with adolescents of which parents and guardians should grant permission; this might limit access to eligible adolescents to be interviewed.

1.9 Summary

Adolescents constitute 23% of the Namibian population with an estimated HIV prevalence of 6.6%. Both positive and negative outcomes associated with HIV status disclosure was reported as affecting the psychosocial wellbeing of adolescent children.

Namibia guided by the World Health Organization implemented the disclosure program on a pilot basis. In view of this it was deemed necessary to undertake this study and assess whether HIV status disclosure results in a better psychosocial wellbeing, higher CD4 count and lower viral load among adolescent children receiving HAART.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

Literature review is a critical component of any research and for this specific study, the literature review seeks to analyse and compare published views on the topic of HIV status disclosure and its effect on psychosocial wellbeing of adolescents. The findings of other studies conducted help to identify knowledge gaps and allows critic or support of previous knowledge as per outcome of the study hypothesis. The chapter will cover definitions of terms before the actual literature review. The function of the literature review is to enable the researcher to determine what is known and unknown in the area of interest (Burns & Grove, 2001).

2.2 Definition of terms

HIV

HIV stands for the Human Immunodeficiency Virus, which is the virus that causes the Acquired Immunodeficiency Syndrome or AIDS. HIV attacks the immune system, which gives the body the ability to fight infections. It destroys a particular type of white blood cell within the body, known as the CD4-positive T-cells or CD4 cells, which are needed by the immune system to fight diseases. HIV is found primarily in the blood, semen or vaginal fluid of an infected person (Centres for Disease Control, 2008).

HIV-Positive Status

HIV-positive status is defined as infection with the Human Immunodeficiency Virus (HIV), as determined by a screening assay known as Elisa and a confirmatory assay called the Western Blot, which identify the presence of antibodies to HIV (Whitfield, 2009).

HIV Status Disclosure

HIV Status Disclosure is defined as the act of informing another person or persons of the HIV-positive status of an individual (Vreeman, 2013).

Psycho: Refers to the mind or mental processes of a person (unique feelings, emotions, thoughts, understanding, attitudes, and beliefs) an individual has (Angner, 2008).

Social: Refers to human beings living together as a group in a situation in which their dealings with one another affects their common welfare. In other words also means interpersonal relationships and what goes on in the natural environment (Angner, 2008).

Psycho-social: Means the dynamic relationship between social and psychological experiences where the effects of one continually influence the other.

The interconnection is that:

- Social experiences may lead to psychological consequences.
- Some individuals with psychological problems will experience social consequences.
- In HIV/AIDS, psychosocial issues pertain to how HIV infection and disease affects the relationship between the affected person and the social environment in which they lives (Angner,2008).

Wellbeing: The absence of negative conditions and the prevalence of positive attribute; wellbeing is more than the absence of illness or pathology and can be measured at the level of individuals or society and it accounts for elements of life satisfaction (Angner, 2008).

Psychosocial Well-Being

Richter, Foster and Sherr (2006) define “psychosocial well-being” as the positive age and stage with appropriate outcome of children’s physical, social, and psychological development. It is determined by a combination of children’s capacities and their social and material environment. Psychosocial well-being is essential for children’s survival and development especially in chronically difficult circumstances (Anger, 2008).

Adherence levels

This is measurement of self-reported adherence to medication usually obtained by using either a continuous or categorical variable constructed from patient that distinguishes “optimal” from “sub-optimal” adherence based on the 95% threshold (MoHSS, 2014).

Treatment Outcomes

Treatment outcome is the measurement of the effect of HAART on the individual living with HIV, at a specific time period. Clinical outcomes can include among others adherence levels, viral load, weight and CD4 count (MoHSS, 2014).

Adolescent

The World Health Organisation (WHO) defines adolescents as children between 10-19 years of age (WHO, 2013).

2.3 HIV status disclosure and psychosocial impact

Although clinical reports suggest that adolescents with HIV infection are more likely to report limitations that are behavioral and emotional rather than physical (Remafedi, 1998), there are few

research studies which have focused on the complexity of their impairment. Moreover, the prevalence rates of psychosocial disorders in HIV-infected children and adolescents are unknown.

Understanding the cause of behavioral problems in HIV-infected children and adolescents is critical for improving their mental health and quality of life and psycho-social wellbeing. Also, given the evidence that mental health problems are associated with poor medication adherence even in adults, improving the mental health of HIV-infected children and adolescents may have an impact on their overall growth and development and the quality of life of the individual and the entire family (Mellins et al., 1999).

Anne (2008) found that children with HIV who knew of their diagnosis scored significantly lower on depression and anxiety measures than children who did not know their diagnosis. Other studies that examined the psychosocial impact of disclosure found little or no difference in psychosocial functioning between disclosed and non-disclosed children (Anne, 2008).

This view is supported by Lester (2002) who stated that disclosure has been associated with reduced rates of anxiety, depression, and others such as internalizing behavior problems (Lester, 2002). In contrast, Lourie (2000) points out that increased problems were identified in disclosed children such as anxiety, depression, withdrawal and less adherence to care following disclosure (Lourie, 2000).

A study conducted in Ghana on the effects of HIV status disclosure for adolescent and young children reported poor academic achievement, lack of pro-social behaviour (cooperation, helping, trust), sexual risk-taking, substance abuse as outcomes (Delaney *et al.*, 2009).

The study further finds significant association between HIV non-disclosure and psychological problems such as anxiety, depression and phobias (Murphy, 2002).

Similarly, fear of the unknown, fear of death or separation, and denial or loss of social relationships was one of the key findings in a study conducted in South Africa (Winstead *et al.*, 2002).

Studies from the United States and abroad suggest that children and adolescents who know they are being treated for HIV have higher self-esteem and better acceptance of medical care than those who are being treated but are unaware of their HIV status. Moreover, Adolescents living with HIV experience numerous psychosocial stressors over an extended period of time according to Paxton (Paxton, 2002).

These may be related to the initial diagnosis and disclosure of their HIV status, He further stated that disclosure of HIV status to adolescence can be an extremely stressful process, because it makes one vulnerable to perceived stigma of friends, family or the community (Paxton, 2002).

The etiology of behavioral abnormalities in HIV-infected children and adolescents is likely to be multifactorial, including factors such as prenatal drug exposure, difficult family environment, age of parents, level of parental education, absence of parent, changes in caregivers, nutrition and

poverty, however some researchers found HIV status disclosure to be a contributor to some social problems (Leserman, 2005).

In one study, the prevalence rates for psychosocial problems including psychiatric disorders in HIV infected children were reported to vary from 55% to 61%. The most common disorders found were anxiety disorders, followed by attention-deficit hyperactivity disorders, conduct disorders, oppositional defiant disorders, and mood disorders (Leserman, 2005).

A psychos-social assessment conducted in several countries under the World Health Organisation reported that in Brazil and the Democratic Republic of the Congo (DRC), children reported feeling sadness, grief, and worry upon learning about their HIV infection, but these negative feelings were followed by some feelings of relief. Congolese children reported feeling calmer after disclosure because knowing their HIV status removed some of the uncertainty surrounding their illness. Despite the negative emotions of sadness and worry, a number of studies reported that children felt that knowing HIV status was important and necessary (Abadia-Barrero et al, 2006).

Disclosure of HIV status is an important part of parenting principles. Roffman (2002) identifies and describes five basic principles of parenting. One of those principles is “Information”. The author states that children need factual knowledge and concepts and these must be presented in an ongoing and age related manner. Roffman’s principles are critical in assisting parents and health professionals to communicate with children and adolescents about embarrassing issues such as sex and sexuality as well as difficult issues like self-esteem, identity and social issues. Several benefits of HIV status disclosure are highlighted in literature of which some include freedom from physical

and mental harm, early treatment, knowledge of positive living, better psycho-social functioning, potential family and community support, and most importantly, the reduction of stress by sharing knowledge in a supportive environment (Roffman, 2002).

Disclosure process should be ongoing and does not end with telling an HIV-infected child the name of their illness or diagnosis. After the HIV diagnosis has been disclosed to the infected child, follow-up calls and visits are needed to monitor the child and family's understanding of the illness and their emotional and psychological adjustment. Evaluating the child/adolescent pre- and post-disclosure may help the health care team and families to identify those who require additional support and services. Some children who learn of their HIV status may experience guilt and shame and may isolate themselves as a result of the stigma and secrecy surrounding the disease. Changes in behavior and school functioning may occur in these children which may lead to depression and psychological problems (Brumfitt, 2010).

This is in line with the Ericson's Theory of Development that states that one of the main developmental tasks for the adolescent is the search for identity, and those adolescents who achieve a sense of identity will experience well-being, a sense of knowing where they are going and have a comfort feeling with their body. In their search for identity, adolescents wrestle with the perception that they are different from their peers. Moreover, social acceptance is one of the major concerns for adolescents. Rejection by and isolation from peers may contribute to even greater stress (Mellins et al, 2004).

Adolescence is a period often characterized by experimentation with sexual and drug risk behavior and other health risk behaviors such as non-adherence to medication in the context of increasing autonomy for medical treatment and care (Mellins et al, 2004). According to Erickson theory of Development, the following defines middle childhood to adolescent's characters in each of the stages.

Middle Childhood (approximately 6-12): This stage is characterized by increased competence to take on additional roles and responsibilities and the development of broader social networks. This stage is also marked by increased behavioral self-regulation and identity development. Although increased competence might reduce vulnerability to maltreatment, this stage has been identified as a period when mental health issues emerge (Adams, 2006).

Adolescence (approximately 13-18): This stage is often characterized by complex changes across multiple developmental domains, including identity creation, primacy of peer group relations, and movement towards independence. Academic, mental health and social functioning are often the indicators of wellness for this age group (Adams, 2006).

Related to Ericson's Theory, in a different theory that highlights psycho-social wellbeing and adolescent with regards to their self-esteem and identity, Adams (2006) mentioned that adolescent years are one of the most important developmental stages prior to adulthood. Youth pass through three periods during this transition. Early adolescence focuses on a shift in attachments, from

parents and caregivers to peer groups. During middle adolescence, youth work on their self-image and begin to develop abstract reasoning. Late adolescence is when youth begin to feel comfortable with who they are becoming as adult members of the greater society. They also gain awareness of others and their relationships. Youth living with HIV encounter additional challenges while passing through these three stages (Adams, 2006).

If the disease is untreated, the youth may have a delay in physical development, including pubescent changes. Consequently, HIV-positive adolescence may appear younger and smaller than other adolescents which can lead to psychological problems (Adams, 2006).

If adolescence looks different from their peers, they have a harder time bonding with them, adversely affecting the adolescents' peer attachments and making it difficult for them to separate from their parents. These changes may also contribute to a negative self-image. As a result, the adolescent living with HIV may feel unable to identify with their peers or feel singled out from others because of stigma which leads to psycho-social problems. This sense of identity comes from actions within a social context and is based on whether their decisions are accepted or rejected by others in the group. Rejection from the group can have a serious negative influence on one's self-esteem and identity (Adams, 2006).

Furthermore, the World Health Organization (WHO) also states that for adolescence, learning about their HIV status is clearly an emotional and pivotal point in their life and can lead to psychological problems. Children react with sadness and grief, as well as anxiety and worry about what their diagnosis means for the future. In qualitative studies, many adolescents reported initial

emotional difficulties, some of which were mitigated over time. In a qualitative study of 25 South African adolescents, almost all found disclosure to be emotionally difficult (WHO, 2011).

Other elements that can lead to wellbeing in adolescence to which HIV status have been disclosed to are, for example, independency. Emerging autonomy is a key aspect of adolescence. It is especially important to encourage independence and self-management in adolescents who are living with HIV, as they need to be able to take responsibility for their lives and their HIV care by the time they are adults.

When adolescents are supported to live independently, they find ways of supporting themselves, pursue their studies or other goals, interact with health providers and take responsibility for themselves, they are more able to adhere to treatment, remain engaged in HIV care, seek psychosocial support, cope with stigma, and face the other challenges of adolescence and demands of everyday life (WHO, 2014).

A psychological assessment is the attempt of a skilled professional, to use the techniques and tools to learn either general or specific facts about another person, either to inform others of how they function now, or to predict their behavior and functioning in the future (Brumfitt, 2010).

With the above mentioned background and theories in mind, evaluating the child/adolescent pre- and post-disclosure may help the healthcare team and families to identify children who require additional support and services. Some children who learn of their HIV status may experience guilt and shame and may isolate themselves as a result of the stigma and secrecy surrounding the

disease. Changes in behavior and school functioning may occur in these children as potential symptoms of depression. Thus, patients and families who have a difficult adjustment to HIV disclosure without progress over time should be referred for mental health services and additional psychosocial support (Lerner, 2002).

2.4 Disclosure and Treatment outcomes

The World Health Organization recommends strict adherence to antiretroviral therapy (ART) as key to sustained HIV suppression, reduced risk of drug resistance, improved overall health, quality of life, and survival, as well as decreased risk of HIV transmission. Conversely, poor adherence is the major cause of therapeutic failure. Achieving adherence to ART is a critical determinant of long-term positive outcome in HIV infected patients (WHO, 2010).

The desired HIV treatment outcomes for HIV programs includes viral suppression, good adherence levels to care, retention in care and high CD4 count for all started on ART to avoid treatment failure and poor reaction of clients to medications (WHO, 2010).

One of the biggest psychosocial challenges that health care providers and parents face in Sub-Saharan Africa is disclosure of status to perinatal infected HIV-positive children. Disclosure has the potential to affect a child's psychosocial wellbeing, in addition to his or her physical health. From a clinical standpoint, there is general agreement in the literature on the benefits to the patient and their families when the child is disclosed of his or her status, however, according to a recent systematic review on disclosure of pediatric HIV infection, the debate on the psychosocial outcomes of disclosure versus non-disclosure is ongoing and inconclusive. Yet in the context of

all chronic illnesses, Wiener, et al. (2008) note that the disclosure of health conditions to children does provide psychosocial benefits to the child and the family (Wiener, 2008).

It was also noted that the association between HIV disclosure and adherence is inconclusive. A study conducted in Belgium concerning children 6-18 years of age found that some children and adolescents reported a higher level of adherence when they were aware of their HIV status (Hammami, 2004).

In Uganda, a study was conducted with 42 participants who were caregivers of 42 HIV-positive children aged 5-17 (median 12 years) Among those 42 children, 29% were fully disclosed, 38% were partially disclosed, and 29% were not disclosed their HIV status. Results demonstrated that when children were non-disclosed and caregivers were the only ones to know a child's HIV status, the child was three times less likely to adhere to HAART

(Bikaako-Kajura, 2006).

Among children in the Ugandan study who were aware of their status, the majority never missed a HAART dose, however, other literature has reported a lower level of adherence after disclosure for example: Mellins et, al. (2004) report borderline significance of a positive association between non-adherence and HIV disclosure ($P < 0.07$) in univariate analysis of children ages 3-13 years in two urban pediatric HIV programs (Mellins et al, 2004).

According to reports by the World Health Organization (WHO), at least one study found that children who knew their HIV status showed greater improvements in CD4 cell counts than children who were not disclosed to, which may suggest better health outcomes after engaging social support through the disclosure process. Additionally, in a study conducted in Western Kenya, caregivers and parents of adolescents believed that disclosure might lead to positive changes, including the child asking fewer questions, improved adherence to medications, and better psychosocial functioning (WHO, 2011).

Likewise, another cross-sectional study conducted in Ghana using quality of life assessment tool, assessing the change in CD4 count and viral load among HIV patients with disclosed status and those that have not been disclosed to after 12 months, found weak correlations between CD4 count and psychosocial wellbeing. For example, higher depressive symptom scores would be associated with lower CD4 cell counts causing individuals to be psychosocially unwell (Dalmida, 2009).

In line with the above, another study conducted to determine the relationship between change in CD4 count and quality of life measures in a Ugandan cohort of people living with HIV, found no association between disclosure and change in CD4 count among the study participants (WHO,2008). In contrast, some studies showed that HIV status disclosure was associated with higher CD4 counts, and nondisclosure was associated with virologic failure at 48 weeks after initiating treatment (WHO, 2010).

In addition, a study conducted in Botswana revealed that Adolescent living with HIV/AIDS who were on lifesaving medications with disclose status had better adherence levels to care compared

to their peers. A significant proportion (81.3%) of those with known HIV status were adherent to ART care compared to 77% in the non-disclosed adolescents. The same study participants reported high levels of viral load suppression as more than 80% had an undetectable viral load in both groups (Nachega, 2004).

A study conducted to examine the impact of HIV disclosure on adolescent's quality of life and psychological functioning found that 40% had viral load ≤ 400 copies per ml (non-detectable status) (Lipson, 1994).

The effect of HIV status disclosure on the psychosocial wellbeing of adolescences is thus not conclusive. There are contradictory evidence on the effect of HIV status disclosure on both the psychosocial wellbeing and treatment outcomes.

2.5 Summary of the chapter

The literature review was conducted in order to unpack views and opinions of different authors regarding the knowledge on the effects of disclosure of HIV status on the psychosocial wellbeing of adolescent patients. Using different models and tools to assess psycho-social well-being in adolescence, both positive and negative outcomes were observed. Additionally the literature conveys conflicting evidence on treatment outcomes for example: it was found that disclosure was associated with good viral suppression and improved CD4 count responses to ART while for other patients this was not the outcome.

CHAPTER 3: RESEARCH METHODOLOGY

3.1 Introduction

The chapter describes the research methodology in terms of research design, the study population, sample size and sampling process, research instrument, data collection procedures and ethical considerations.

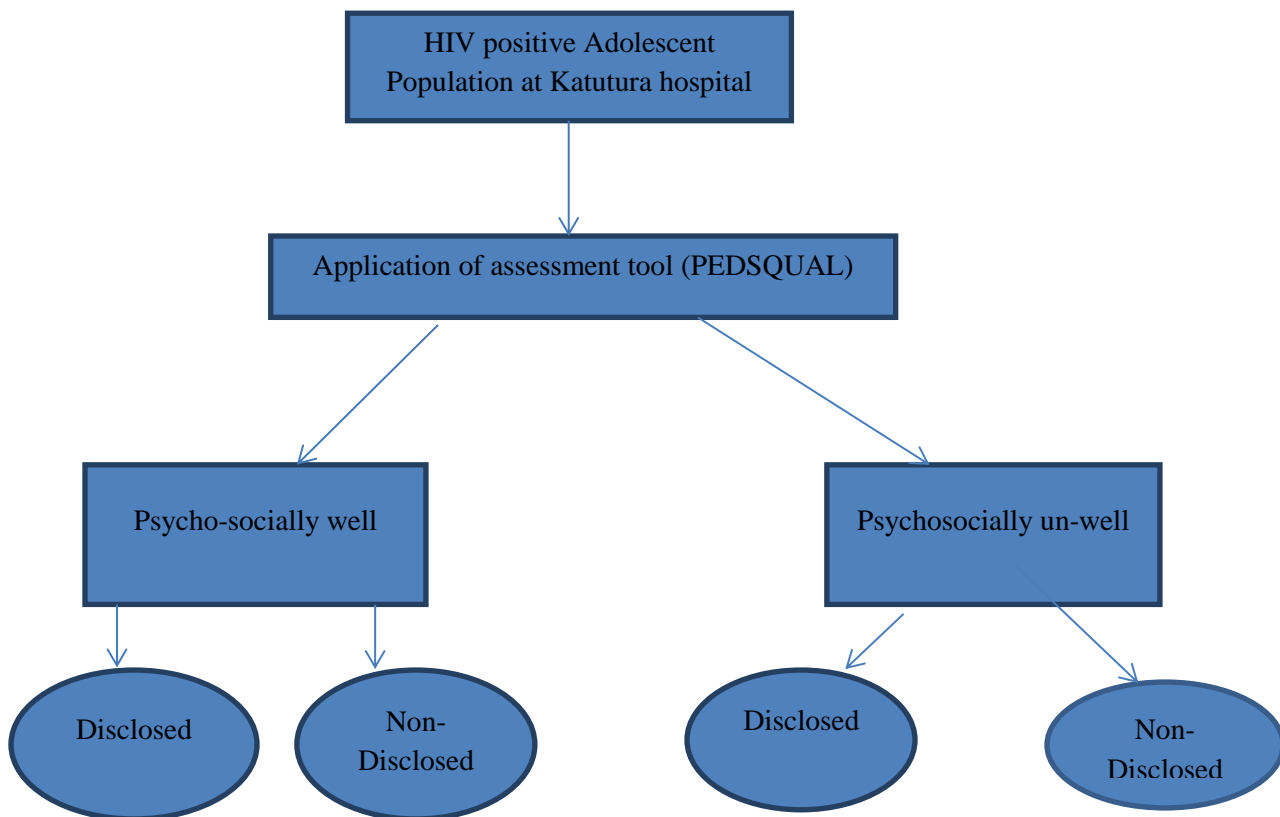
3.2 Research Design

The term "research design" refers to how a researcher puts a research study together to answer a question or a set of questions. Research design works as a systematic plan outlining the study, the researchers' methods, details on how the study will arrive at its conclusions and the limitations of the research. Research design is not limited to a particular type of research and may incorporate both quantitative and qualitative analysis (Lawrence, 2009).

A Cross-sectional analytic research design was employed whereby the total HIV adolescent population formed part of the study population. The research instrument (Pedsqual) was applied to the sampled participants to determine their psycho-social wellbeing. Among the sampled participants, some were assumed to be psychosocially well and some unwell as displayed in figure1. Treatment outcomes data were abstracted from patient's records using the designed data abstraction tool. With the above mentioned information, the prevalence of being psychosocially unwell and the level of HIV treatment adherence, CD4 count and viral load was compared in two

groups of HIV positive adolescents enrolled in HIV care and put on HAART at Katutura Intermediate Hospital for at least 12 months.

Figure 1: The flow of the cross-sectional design for the study



The benefit of a cross-sectional study design is that it allows researchers to compare many different variables and at the same time, it provides good, quick picture of prevalence of exposure and prevalence of outcome.

3.3 Study Population

The study population comprises of 754 HIV positive adolescent children age 10 – 19 years that were on HAART at the Katutura Intermediate Hospital ART Clinic. All HIV positive adolescent children who were enrolled in the HAART program at the KIH for at least 12 months formed part of the study population.

3.4 Sample and sampling process

Sampling refers to the process of selecting the sample from a population in order to obtain information regarding a phenomenon in a way that represents the population of interest (De Vos, 1998).

Sample size

The sample size for this study was calculated using Epi info version 3.5 for cross-sectional analytic design where adolescent children’s HIV status disclosure (disclosed vs non-disclosed) was taken as the exposure factor and psychosocial wellbeing (“normal” vs “abnormal”) as the outcome factor. One group was the “disclosed” meaning that the adolescent knew their HIV status while

the other group was “non-disclosed” and didn’t know their HIV status. Based on the Epi-Info statistical calculation, to obtain a confidence level of 95% and a power of 90% when comparing these two proportions, a ratio of 1.5:1 was determined indicating the required sample size to be 204 for unexposed and 136 for the exposed.

Sampling

A convenience sampling method was utilized for this study. Those adolescent children age 10 -19 formed part of the sampling frame and as they were coming to the Katutura Hospital for routine follow up on a daily basis during the period of data collection (November 2014 to December 2015) they were enrolled into the study. Those who were enrolled in the disclosure program and are disclosed to as per their medical records were enrolled as cases up to a total of 136 and the non-disclosed under the control group up to a total of 204 as per the sample size calculated. The assessment tool was only applied to the study participants with a signed consent by parents or guardians on the same day of their visit. Participants selected were those enrolled into the disclosure program between 2013 and 2015 calculating at least 12 months in care for both the cases and the control group. The participant’s unique identifiers were recorded to avoid duplication in data collection. The process took one year (November 2014 to December 2015) until the sample size was completed.

3.5. Data Collection

3.5.1 Research Instruments

There are various tools that can be used to assess the wellbeing of adolescent such as the Strength and difficulties questionnaire, the pediatric quality of life Inventory, the adolescent coping with stressful events (A-COPE) to mention a few (WHO, 2003).

The study utilized the 23-item Pediatric Quality of Life (PedsQL) psychosocial assessment tool, which was designed to measure the core dimensions of Health Inventory as delineated by the World Health Organization (Varni,1998). The tool has four sections. The first section assesses physical functioning with 8 items. The remaining three sections had 5 questions each and assessed emotional, social and school functioning. The items in these scales are scored on five point Likert scale, ranging from “never a problem” to “almost always a problem”. Higher PedsQL scores indicate better Health related quality of life (HRQOL) and better psycho-social well-being. This tool was found to be appropriate for the assessment of psychosocial well-being for children and adolescents in the age of 9-18 years. Each study participant answered the 23 items with a total score of 92. The items in these scales are scored on five point Likert scale, ranging from “never a problem” to “almost always a problem”. When scoring on the PedsQL tool, a score of <46 (50%) categorizes the subject as “psychosocially unwell while a higher score of ≥ 46 (50%) categorizes the study participant as “psychosocially well” (Varni,1998).

The assessment tool which was initially designed in English was translated into two local languages Oshiwambo and Afrikaans and was field-tested at a different facility in the same region for validity purposes. Minor alterations was done on the tool after the field test of which most were related to the meaning of some word in different languages compared to English.

3.5.2 Procedure for Data Collection

Data was collected from the participating adolescent children by two trained data collectors who were community counselors at the same unit. An informed consent was requested from either parents or guardians before the data collectors applied the PedsQL psycho-social assessment tool on the same day of visit for those with signed consent.

In addition, a check list was developed and used to abstract demographic data and clinical/treatment outcomes (CD4 count and viral load data) from the individual medical records of the study participants kept with Katutura Intermediate hospital. The data on treatment outcomes for adherence to treatment was collected for three consecutive visits during the patient visits. Adherence is calculated using different methods such as pill count and adhering to follow up visits. Participants with adherence levels of over 95% at all three visits were recorded as having good adherence as per Namibian national treatment guidelines. The viral load is collected at six month after starting treatment and the latest viral load recorded in the patient record within the year of data collection was captured on the data collection tool.

3.6. Data Analysis.

“Data analysis is the process of bringing order, structure and meaning to the mass of collected data” (De Vos, 2002). The data collected using the PEDsQL tool to assess the psycho-social wellbeing was analyzed in Epi-Info and scored following the scoring instructions of the tool of which a score of <46 (50%) categorizes the subject as “psychosocially unwell while a higher score

of ≥ 46 (50%) categorizes the study participant as “psychosocially well”. A higher PEDsQL score indicates better psycho-social well-being.

The demographic data of the study population for selected key study characteristics were analyzed using frequency distribution table. Demographic characteristics assessed included adolescent age, gender and parents/caregivers information.

The mean score of outcome variables such as CD4 count were calculated, and a cutoff point of CD4 less than 500 was used to measure good outcomes while a CD4 count of >500 was regarded as poor as per the 2014 Namibian National treatment guidelines. Viral Load (VL) and adherence to care in the disclosed and non-disclosed groups were also calculated using proportions to compare the two groups of patients. A cutoff point of ≤ 40 copies per ml for viral load was used in line with the national guidelines for those suppressed and above 1000 copies per ml for being unsuppressed. These was counted as good outcome because patients which are adherent to treatment reach the level of viral suppression within six month of treatment. The Odds ratios was also calculated to measure association between exposure (disclosure – referring to knowing your HIV status) and outcome (referring to being psycho-socially well) factors. The 95% confidence interval and P-value was calculated for significance of association

3.7 Research Ethics.

Research ethics is important for any study to be undertaken, specifically when people are involved as participants in research. There are three objectives in research ethics. The first and broadest objective is to protect human participants. The second objective is to ensure that research is conducted in a way that serves interests of individuals, groups and/or society as a whole. Finally, the third objective is to examine specific research activities and projects for their ethical soundness, looking at issues such as the management of risk, protection of confidentiality and the process of informed consent (Hawkins, 2008).

The study proposal was submitted to the University of Namibia's Post Graduate Studies Committee for approval. Additional permission for ethical clearance was also obtained from the Ministry of Health and Social Services (MoHSS) Research Committee.

The researcher further obtained informed consent from all the adolescents enrolled at the hospital and their caregivers. Permission to obtain data from the patient's records was sought from the hospital management. Obtaining informed consent is a basic ethical obligation and a legal requirement for researchers. According to Kenneth, (2011), informed consent is one of the primary ethical considerations in research involving human participants. The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research describe the purpose of an informed consent as the mechanism to ensure that participants understand the study and voluntarily agree to participate (Kenneth, 2011).

To ensure confidentiality, the subjects under study were not identified using their names, only patients ART clinic unique identifiers were used and the data was not accessible to unauthorized persons.

3.8 Validity

Validity is defined by Brink et al (2006) as being concerned with the accuracy and truthfulness of scientific findings. There are two types of validity namely internal and external validity. **Internal validity** is described by Brink et al (2006) as the extent to which conclusions effectively represent empirical reality and, secondly, assessing whether constructs devised by researchers represent or measure the categories of human experience that occur. **External validity** is further described as the degree to which the results of a study can be generalized to other people and settings.

The following paragraphs describe efforts made in this study to ensure validity.

Firstly, validity was ensured through the use of standardized data collection tool. The study utilized the 23-item Pediatric Quality of Life (PedsQL) psychosocial assessment tool, which was designed and approved by the World Health Organization (WHO) to measure the core dimensions of Health Inventory (Varni, 1998). The tool was field tested in one of the health facilities after translation in different local languages for the study. The clinical data was collection from the MoHSS routine patient booklets which is kept at the health facility.

During the data collection process, the participant's unique identifiers were recorded to avoid duplication in data collection.

The PEDsQL tool which was utilized to assess the psycho-social wellbeing of adolescence has a strict scoring method which was followed to determine the final scores of the participants.

Lastly, the study used frequency distribution table to analyze key study characteristics as well as utilizing means score and proportions to calculate outcome variables.

3.9 Reliability

Reliability is described by Brink et al (2006) as being concerned with the consistency, stability and repeatability of the informant's accounts, as well as the researchers' ability to collect and record information accurately.

To ensure reliability of the study, the tools were piloted at one of the facility in the district and the data collectors were trained on the data collection tools before commencement of the study. The information was entered by a trained data clerk into the Epi-info. At this stage clinical data values which were unclear were returned and re-collected from patient files at the facility.

3.10 Summary of the chapter

The chapter described the methods that were used to carry out the study. A cross-sectional analytic study design was selected to enable the study to compare the psycho-social wellbeing of adolescent children in the two groups of "disclosed" and "Non-disclosed" at the Katutura Intermediate

hospital and Health center. The sample (n=200) was divided into two groups: a group that knew and a group that did not know their HIV status. Data was collected using a standard PedsQL tool as well as data abstraction from patient's records.

Data was entered into the Epi-info data base in which analyses (statistical inferences including the mean scores and odd ratios, correlation, association between variables and descriptive analysis) were run after a process of cleaning and validation. Various ethical aspects were considered in the study to safeguard the identity of the patients.

CHAPTER 4: DATA ANALYSIS AND ITS INTEGRATION INTO LITERATURE

4.1 Introduction

The findings from the information collected using the tools described in the previous chapter will be presented, analyzed and interpreted in this chapter. The purpose of the study was to determine the effect of HIV status disclosure on the psychosocial wellbeing, adherence level and HIV/AIDS treatment outcome of adolescent children receiving Highly Active Anti-retroviral Therapy (HAART) at Katutura Intermediate Hospital.

4.2 Presentation and interpretation of data

4.2.1 Socio-Demographic data

Data from 200 study participants was analyzed. Ninety-nine (49.5%) of the study participants underwent full HIV disclosure while the remaining 101(50.5%) didn't. One hundred and seven (59.1%) of study participants were females. Fifty six (52.3%) of all female study participants did undergo HIV disclosure process and reached full HIV status disclosure. This didn't show a statistically significant difference as compared to 52.7% of the males who also did undergo through full HIV disclosure, OR=1.01, 95% CI (0.56, 1.83). The mean age of the study participants was 12.05 ± 2.72 . The mean ages for female and male study subjects were 12.07 ± 2.8 and 12.29 ± 2.9 years respectively. There was no statistically significant difference between the disclosed and undisclosed based on gender of the overall study participants; $P= 0.68$. From the total of 200 participants, only 107 responded to the question on whether they live with parents or any other

caregivers. The 107 caregivers were distributed into three categories: parents, who constituted the majority, legal guardians, and others as stated in Table 1.

Table 1. Socio-demographic Characteristics of the Study Population

Characteristic	All patients (N=200)	D group* (N=99)	ND (N=101)	P-value
Age, years (mean \pm SD)	12.05 \pm 2.72	12.07 \pm 2.8	12.29 \pm 2.9	T=0.98
Males, n (%)	74 (40.9)	39 (52.7)	35 (47.3)	P=0.32
Females, n (%)	107 (59.1)	51 (47.7)	56 (52.3)	
Primary Caregiver n (%)				
Parent	72 (67.3)	32(60.4)	40 (74.1)	P=0.68
Legal	31 (29.0)	18 (34.0)	13 (24.1)	
others	4 (3.7)	3 (5.7)	1 (1.9)	

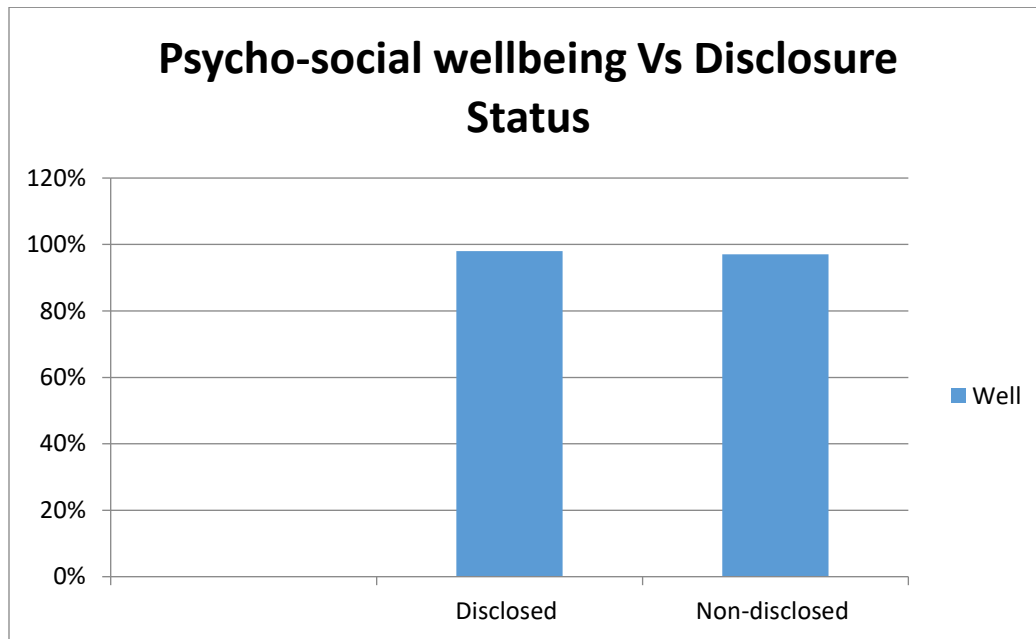
Seventy two (67.3%) reported to have parents as their primary care givers only, whereas 31 (29%) and 4 (3.7%) reported to have guardians and others such as elder siblings as their primary caregivers respectively.

4.2.2 Psycho-social well-being based on Disclosure Status

Disclosure status is hereby referred to as either *disclosed or non-disclosure* of the study participants HIV status. The aim of the study was to determine whether disclosure of HIV status is affecting the psychosocial wellbeing of the adolescence living with HIV and on antiretroviral therapy.

The majority of the participants (97.5% (n=195) were found to be Psycho-socially well above the cutoff point of ≥ 46 scores. Cross tabulation of two samples' proportion was utilized to examine if there was any association between disclosure status and psychosocial well-being. In this analysis, disclosure status was taken as an exposure (independent) variable and psychosocial well-being as an outcome (dependent) variable. Accordingly, the analysis didn't show any association between disclosure status and psychosocial well-being; as 97 (98%) and 98 (97%) of the participants from the disclosed and undisclosed groups were assessed to have been psychosocially well, OR=1.49 (95% CI, {0.24, 9.08}, P=0.35). (See Figure 2 below)

Figure 2: Psycho-social wellbeing versus Disclosure Status



When the data was analyzed, the figure above illustrates that 98% of the study participants with a disclosed HIV status were psychosocially well, while in the undisclosed group 97% were also found to be psychosocially well.

Using two sample means, the average score for each participant was also calculated. As per the standardized assessment tool using its scoring method, the wellness threshold was taken as a total score of 46 and above. The mean psycho-social assessment score for all study participants was found to be 14.35 ± 12.30 . When the data was analyzed based on disclosure status, it was found that the mean score for disclosed participants was 13.91 ± 12.16 and for the undisclosed group it was

14.78±12.50. This didn't show statistically significant difference between the two groups (T=0.50, P=0.61).

4.2.3 Treatment outcomes (Adherence levels, viral load, and CD4 Count)

Table 2. Treatment outcomes

VL Suppression	Not suppressed	Suppressed	OR (95% CI)	p-value
Undisclosed	7(11.7%)	73 (88.8%)	1.48 (0.24-9.08)	p-0.9
Disclosed	8(9.9%)	53 (90%)		
Adherence level	Low	High	OR (95% CI)	p-value
Undisclosed	N (3%)	N (97%)	1.0 (0.6.16.7)	P-0.5
Disclosed	N (2%)	N (98%)		
CD4 Count	High	Low	OR (95% CI)	p-value
Undisclosed	60(72.0%)	23(28.0%)	0.9 (0.4, 1.9)	P- 0.9
Disclosed	59(72.3%)	23(27.7%)		

The study found that 90% and 88% of the disclosed and undisclosed adolescents had the suppressed virus levels less than 40 RNA copies/ml. The subjects in the undisclosed group had slightly higher percentage of sub-optimal suppression. However, this difference in viral suppression between the groups was not statistically significant.

Viral load helps identify people who may be having trouble sticking to their treatment and need support, helps identify those who are failing their treatment because the virus has become resistant to the drugs they are taking and who need to be switched to another treatment regimen. Having an undetectable viral load is important for a number of reasons. First of all, because the immune system is able to recover and become stronger, which means that a person can have a very low risk of becoming ill because of HIV. It also reduces the risks of developing some other serious illnesses such as opportunistic infections.

Secondly, having an undetectable viral load means that the risk of the HIV becoming resistant to the anti-HIV drugs taken by the patient is very small (WHO, 2010).

The results showed high level of viral load suppression in both groups with no statistically significant difference between the two as 90% of the disclosed and 88.8% of the undisclosed group had a suppressed viral load (OR= 1.48 (95% CL (0.24-9.08), P= 0.9. These means that HIV status disclosure doesn't affect viral load suppression in adolescents after HIV status disclosure.

Furthermore, both groups scored high on adherence to anti-retroviral therapy with an adherence level of above 98%. According to the Namibian ART guidelines, patient would be categorized as having good adherence levels when she/he takes at least 95% of the doses at the right time and the right way. This means that higher adherence levels are not associated with HIV status disclosure OR=1.0 (95% CI, 0.6.16.7) P=0.9)

The CD4 count for people living with HIV is a good predictor of being healthy and well while on treatment. Keeping one's CD4 count high can reduce complications related to HIV disease and extend patients life by having a healthy and productive life. A CD4 count might range from 500–1,200 cells/mm³ in healthy adults/adolescents. The higher your CD4 count, the better able one can fight HIV and other opportunistic infections.

In reference to table 2 above, the study also find that 72% of the disclosed group had a CD4 count of more than 500 cells while only 28% of them had a CD4 count of less than 500 cells. Similarly

in the non- disclosed group 72% had a CD4 count of more than 500 with just a 27% of less than 500 CD4 count. The outcome indicates no difference in improved CD4 count between the two groups (OR=0.9 (95% CI, (0.4, 1.9) P= 0.9).

4.3 Discussions

This study attempted to explore if pediatric HIV disclosure had any effect on the psychosocial wellbeing, level of adherence to treatment and HIV treatment outcomes of adolescents on ART at Katutura Intermitted Hospital.

4.3.1 Disclosure and Psycho-social wellbeing

Several researches documented positive effects of appropriate pediatric HIV disclosure to adolescents including psychosocial wellbeing. Lester (2002) reported that timely HIV disclosure to children was associated with reduced rates of anxiety, depression, and other behavioral problems such as internalization and stress-disorder or related symptoms. Delaney et al; (2009) also examined the effects of pediatric HIV disclosure to adolescent and young children which reported psychosocial problems such as poor academic achievements, lack of pro-social behaviour (cooperation, helping, trust), sexual risk-taking, substance abuse as outcomes (Delaney et al. 2009).

The World Health Organization also cited potential risks to adolescents when HIV status is disclosed to them. The risks mentioned include stigma, discrimination and violent behaviors. (WHO, 2003)

This study attempted to examine gross psychosocial effect of disclosure using the PedsQL assessment tool. Although the scoring for this elements were not done in isolation as in many other psychosocial assessment tools, the tool assessed physical functioning, emotional, social and school functioning of adolescents which are the core dimensions of health to determine the psychosocial wellbeing in children and adolescents by the World Health Organization (WHO).

The results of this study suggest that disclosure of HIV status did not affect psychosocial wellbeing of adolescents as both groups did not show any negative effects on psychosocial well-being after HIV status disclosure. This finding was consistent with the results from some other researches. Anne, (2008) conducted a study which examined the effect of HIV status disclosure on adolescents and found no difference in psychosocial status among the disclosed and undisclosed groups. According to the PedsQL tool utilized for this study, participants scored higher on psychosocial wellbeing with a score of more than (>46) that indicates that the study participant are “psychosocially well”. Accordingly, the analysis in the current study didn’t show any association between disclosure status and psychosocial well-being; as 97 (98%) and 98 (97%) of the participants from the disclosed and undisclosed groups were assessed to have been psychosocially well, OR=1.49 (95% CI, {0.24, 9.08}, P=0.35.

These are in contrast with the result in one study where the prevalence rates for psychosocial problems including psychiatric disorders in HIV infected children were reported to be high and varied from 55% to 61% (Leserman, 2005).

Some researchers reported that unlike adults, children tend not to react negatively to disclosure of HIV status. This has been believed to protect children from being hurt and developing psychosocial problems in the process or after HIV status disclosure (Stein, 2003). In a separate study conducted in Ethiopia, Deribe (2008) also reported little or no difference in psychological functioning between disclosed and non-disclosed children. However, this particular study did not measure reaction of children to HIV disclosure. This could possibly be an area of future research in Namibia.

These findings, however, contradict the results of the study from New York City on the psychosocial functioning of children after HIV status disclosure. In this study, the disclosed group were significantly less anxious and less depressed than the non-disclosed ($t=2.67, df=86, p=0.011$) (Kenneth, 2011).

Additionally, the result also contradicts several studies conducted with adolescent children in France and Zambia. In a meta-analysis of two studies in France and Zambia, significantly fewer 5- to 15-year old HIV-positive children who had been disclosed reported psychological distress (RR=.64, CI .41–1.00, $p=.05$, low quality) than those HIV-positive children not disclosed to.

In several US studies of moderate quality, there were no significant combined or singular

mean differences between HIV-positive children disclosed to and those not disclosed to on measures of depression/dysthymia (ages 6–13) general anxiety (ages 6–11 years) or separation anxiety (WHO, 2010)

In a prospective, longitudinal, multi-city United States study following paediatric cases (ages 5–19) three years before and three years after disclosure, Butler found no significant changes after disclosure in caregiver reports on child well-being on four health measures (general health, distress related to symptoms, physical functioning, health care utilization), mental health (psychological status) and social behaviour or social role functioning (Butler, 2009).

4.3.2 Treatment outcomes (Adherence levels, Viral load, and CD4 Count)

Overall, studies of adolescents have found that disclosure was associated with improved clinical outcomes as measured by increased CD4 cell counts and high levels of adherence to care. A study conducted in Botswana revealed that Adolescent living with HIV/AIDS who were on life saving medications with disclosed status had better adherence levels to care compared to their peers on life saving medications. A significant proportion 81.3% of those with known HIV status were adherent to ART care compared to 67% in the non- disclosed group of adolescents (Nachega, 2004). In a study conducted in New York among HIV seropositive patients, over 60% reported poor adherence to ART among participants who had not disclosed their status (Kenneth, 2011)

Although the World Health Organization recommends HIV status disclosure to all children and adolescents enrolled in HIV care due to the benefits of improving adherence to treatment and better

understanding of HIV infection control, this study did not find any significant difference on adherence levels between the disclosed and none disclosed adolescents.

Both groups scored higher on adherence levels to antiretroviral treatment with a score of over 98%. The Ministry of health and Social Services have a threshold for good to excellent adherence level at 95 – 100 % (MoHSS, 2014).

The current study adds to the mounting evidence suggesting that disclosure is not associated with worse treatment outcomes.

One of the objectives of the study was to compare the adherence levels, CD4 count and viral load of disclosed and non-disclosed groups of adolescent on Highly Antiretroviral treatment at Katutura Intermediate hospital HAART clinic.

The increased CD4 count and viral suppression for people living with HIV is a good predictor of being healthy and well while on treatment (WHO, 2008).

According to the Ministry of Health and Social Services in Namibia, Treatment or Clinical outcomes can include among others measuring the adherence levels, viral load, weight and CD4 cell count. Low CD4 cell counts are associated with poor quality of life, and leads to progression to AIDS-related illness or death (MoHSS, 2014).

Some studies indicated that patients who learned about their status turned to have psycho-social problems which leads to poor treatment outcomes.

In this study, the latest performed CD4 count for all study participants were collected for both groups in the study population and analyzed. A normal CD4 count ranges from 500–1,200

cells/mm³ in healthy adults/adolescents. The higher your CD4 count, the better one is able to fight HIV and other infections (WHO,2010).

The results of this study showed that 72% of the participants in both groups had a CD4 count of more than 500 cells. The result did not show significant difference in CD4 count between the two groups. The result concludes that disclosure of HIV status is not associated with decreased CD4 count for adolescent living with HIV.

The study findings concurs with the results from the study conducted in Ghana, assessing the change in CD4 count among HIV adolescents with disclosed status and those that have not been disclosed to after 12 months which found weak correlations between CD4 count and psychosocial wellbeing (Dalmida, 2009).

Furthermore, both group showed high level of viral load suppression with no statistically significant difference between the two. These means that HIV status disclosure doesn't affect viral load suppression in adolescents after HIV status disclosure.

The non-disclosed group however has 11% of adolescence with un-suppressed viral load compared to 9.9% in the disclosed group. Although this doesn't show statistical difference between the two groups, this is relevant for clinical management as these patients might be at risk of developing HIV drug resistant or failing treatment. The results are consistent with reported outcomes of other

studies in Ghana and Uganda that showed no association of disclosure status and viral suppression (Dalmida, 2009).

4.4 Summary of the chapter

This chapter covered the presentation of the data analysis and its interpretation. The respondents' biographical data and treatment were also presented.

Although literature cited potential risks to adolescents when HIV status is disclosed to with regard to psychosocial wellbeing, the results of this study suggest that disclosure did not significantly affect the psychosocial wellbeing of adolescents as both groups did not show any negative effects on psychosocial well-being.

One of the objectives of the study was to compare the adherence level, CD4 count and viral load of adolescence in the disclosed and non-disclosed group at Katutura Hospital. The result did not show significant difference in CD4 count, adherence levels and viral load between the two groups. The result concludes that disclosure of HIV status is not associated with decreased CD4 count for adolescent living with HIV or viral suppression. In addition the result also concludes that adherence level in this study is not affected by disclosure of HIV status to adolescents.

CHAPTER 5 CONCLUSION, LIMITATION AND RECOMMENDATIONS

5.1 Introduction

This chapter completes the research by discussing the limitations of the study, as well as providing recommendations for future research. The purpose of this study was to determine the effect of HIV status disclosure on the psychosocial wellbeing, adherence level and HIV/AIDS treatment outcome of adolescent children on Highly Active Anti-retroviral Therapy (HAART) at Katutura Intermediate Hospital.

The following were the Specific objectives:

- To determine the risk of Psycho social “deviations” in HIV status disclosed adolescent children as compared to undisclosed adolescent children put on HAART
- To compare the adherence level, CD4 count, and viral load of disclosed and non-disclosed adolescent children put on HAART

5.2 CONCLUSION

The results from the current study suggest that the HIV status disclosure have no significant impact on the psychosocial wellbeing of adolescents. From a public health point of view, the results suggest that the psychosocial effects of disclosing a positive HIV diagnosis can be beneficial with no psychosocial effects to adolescents.

It is encouraging to note that over 97% of all respondent were rated as being psychosocially well regardless of knowing their HIV status. Disclosure was also found not to affect treatment

outcomes of adolescents. The two groups scored higher on adherence level with no significant difference in viral load suppression.

5.3. LIMITATIONS

Several methodological limitations of this study should be noted in interpreting the results. The sample size was small and therefore results cannot be generalized to the whole Namibian population or regions.

In addition, the initial sample size based on the Epi-Info statistical calculation, to obtain a confidence level of 95% and a power of 90% when comparing these two proportions, a ratio of 1.5:1 was determined indicating the required sample size to be 204 for unexposed and 136 for the exposed. Due to a change in policy by the government to speed up the process of disclosure, the facility was instructed to decentralize their services to other smaller health centers and some of the adolescents targeted for this study were referred out of the facility. The study population therefore was decreased. The sample size was recalculated using a ratio of 1:1 which brought the sample size to 100 in the unexposed group and 100 in the exposed group.

Furthermore, the study occurred at a single clinic of Katutura Intermediate hospital which may not fully represent the catchment area of the region and may also present different clinical procedures regarding HIV status disclosure than the other clinics in the same region.

Moreover, the data are self-report and subject to issues of social desirability. Because it was not permissible for data collectors to directly ask adolescents if they knew their status, it is also possible that some of them in the not disclosed group actually knew their status even though they were not enrolled into the program for disclosure.

With these slide changes in the methodology, all participants in the study were eligible and received consent from either parents or caregivers and the validity of the study was not affected. This indicates the need to replicate the study with a larger sample size and more health facilities.

There were incomplete data in some areas of analysis for example for date of birth and date of interview which limits the study to analyze some demographic and outcome data.

Since cross-sectional analytic designs measure both exposure and outcome at one point in time, they have the inherent weakness in inferring causal relationship. The research would seek information on psycho-social wellbeing through interviews with adolescents of which parents and guardians should grant permission, these process led to delays in data collection and most of the control group were lost in the process as some move to the disclosed group although they did not qualify to be included in the study as cases.

5.4 RECOMMENDATIONS

Based on the above conclusions, the following recommendations can be made to the different sectors that play a role in the process of HIV care and disclosure.

As stated by the World Health Organization, disclosure of HIV status should be prioritized without much fear of psycho-social impact to adolescent.

Psychosocial support should be rendered to all children prior to disclosure and continuous support by social worker should be part of the care package. The Ministry of Health and Social Services

should consider appointing Social workers at main ART clinic for psycho-social support. Although the number of adolescence with psycho-social issue are low, there is still a need to address the psychosocial issues identified as they will have significant impact on the child life and family. The program should continue to assess the Adolescents health outcomes and provide support were necessary.

5.5 CONCLUSIVE REMARKS

The main objective of the study was to determine the effect of HIV status disclosure on the psychosocial wellbeing, adherence level and HIV/AIDS treatment outcome of adolescent children receiving HAART at Katutura Intermediate Hospital. Although there was a good justification to conduct this study as suggested in the current literature for more research on the topic, the study did not show any statically significant changes in the psycho-social wellbeing of HIV positive adolescent and HAART in both the disclosed and non-disclosed groups.

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ANNEXURES

Annexure 1: Data Collection tool

DEMOGRAPHIC AND CLINICAL DATA

All data should be obtained from the patient ART clinic records; once completed this form should be attached to the Adolescent PEDSQUAL Inventory form of a study child with corresponding UNIQUE ART NUMBER

1. Facility: _____
2. Date of data abstraction: _____
3. Unique ART Number: _____
4. Date of birth (dd/mm/yy): ____/____/____
5. Date enrolled in HIV Care(dd/mm/yy): ____/____/____
6. Gender (tick one): ____ Male ____ Female
7. Date began first line HAART (dd/mm/yy): ____/____/____
8. CD4 at HAART initiation (dd/mm/yy): ____/____/____
 - a. If on second line HAART, date started second line: (dd/mm/yy): ____/____/____
9. Last recorded weight: _____ date of recorded weight (dd/mm/yy): ____/____/____
10. Last recorded height: _____ Date of last recorded height: (dd/mm/yy): ____/____/____
11. Last recorded VL value: _____ copies/ml date of last recorded VL (dd/mm/yy): _____
12. Second to last recorded VL value: _____ copies/ml date(dd/mm/yy): ____/____/____
13. First post-HAART recorded VL value: _____ copies/ml_ date(dd/mm/yy): ____/____/____
14. Baseline CD4 count: _____ cells/mm³ , %: ____ date(dd/mm/yy): ____/____/____

Adherence levels at the last 3 visits	Date	Adherence level
1 st visit		
2 nd		

PedsQL™

Pediatric Quality of life Inventory

Version 4.0

CHILD REPORT (aged 10 – 19)

Directions

On the following page is a list of things that might be a problem for you. Please tell us how much of a problem each one has been for you during the past ONE Month by circling::

- 0** if it is **never** a problem
- 1** if it **almost never** a problem
- 2** if it is **sometimes** a problem
- 3** if it is **often** a problem
- 4** if it is **almost always** a problem

There are no right or wrong answers. If you don't understand the question, please ask for help.

Annexure 2. Informed consent

Consent form

Parents/Caregivers

Hello, my name is _____. I'd like to request your consent for your child to complete a form with few questions on HIV Disclosure. The questions are more about activities they are doing and how they feel generally. Other information will be collected from the child records/blue file that we have at the clinic. No names will be mentioned and information will be used to improve on services we provide.

- Are you willing to let your child participate in the study?

Sign

Thank you

Annexure 3. Research Approval letter

**REPUBLIC OF NAMIBIA***Ministry of Health and Social Services*

Private Bag 13198
Windhoek
Namibia

Ministerial Building
Harvey Street
Windhoek

Tel: 061 - 203 2560
Fax: 061 - 222558
E-mail: tkakili@mhss.gov.na

OFFICE OF THE PERMANENT SECRETARY

Ref: 17/3/3

Enquiries: Ms T. Kakili

Date: 07 July 2014

Ms Francina Tjituka
University of Namibia
Private Bag 13301
Windhoek

Dear Ms Tjituka

Re: The effect of HIV status disclosure on adolescent psychosocial wellbeing, adherence and outcome of antiretroviral treatment at Katutura hospital, 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 the completion of your Master degree in Public Health;
 - 3.2 No other data should be collected other than the data stated in the proposal;
 - 3.3 A quarterly report to be submitted to the Ministry's Research Unit;
 - 3.4 Preliminary findings to be submitted upon completion of the study;
 - 3.5 Final report to be submitted upon completion of the study;
 - 3.6 Separate permission should be sought from the Ministry for the publication of the Findings;

Yours sincerely,


Andrew Ndishishi (Mr)
Permanent Secretary

"Health for All"

