

## **Chapter One: Introduction**

### **1.1: Background**

Globally, HIV infection status amongst adolescents aged 13 – 24 years estimates high prevalence of infection among adolescents, most without knowing that they are infected. Half of these new infections are occurring amongst young people making it difficult for them to access necessary care and support (UNICEF, 2011). The World Health Organization (2008) estimates that globally 10.3 million youth aged 11-24 years are living with Human Immunodeficiency Virus and Acquired Immune deficiency Syndrome (HIV and AIDS). Each year, about 4 million people younger than 20 years are diagnosed with STIs including herpes, human papilloma virus (HPV), chlamydia, gonorrhea, and HIV.

According to UNAIDS (2009) update, worldwide there were 2.2 million children and adolescents living with HIV with 640, 000 infected each year. In the U.S, more than 9,000 children live with perinatal HIV infection. Early in the epidemic, HIV infected children faced very short life expectancies and few providers were concerned about disclosing the diagnosis to children (UNAIDS 2008). However, since the advent of antiretroviral (ARVs) and their use in children, increasing numbers of HIV – infected children are living longer, often into adolescents and young adulthood. Thus children are reaching a level of cognitive development that allows them to understand their HIV diagnosis and to participate in treatment decision (WHO, 2008).

More recent studies have reported that young people aged 15 – 24 accounted for about 42 percent of new adult HIV infection in 2010, and 5 million (4.4 – 5.9 million) young men and women are currently living with HIV. With the millions of new HIV infection predicted among young people in future years, AIDS will not be halted until young people have the knowledge and capacity to avoid behaviors that put them at risk (UNICEF, 2011).

This report covers youths generally and from this available information the gravity of the problem of HIV among adolescents and their need for care and support is evident.

Adolescents and young people need accurate and relevant information about HIV transmission, an enabling and protective environment in their communities where they can talk openly about risk behaviors (UNICEF, 2011). They also need preventive interventions, which include voluntary counseling and testing, HIV education and prevention of sexually

transmitted infections. The challenge is reaching the many young people who are not aware of their vulnerability to HIV or who do not understand the best ways to prevent becoming infected (UNICEF, 2011). Much is known about how to prevent HIV infection among adolescents and young people most at risk, but program generally have not been taken to scale up preventive measures.

Consistent with the UNAIDS (2008) report, it is indicated that many children infected perinatally with HIV and AIDS, are surviving to middle childhood and some to adolescence. By the end of 1997, there were over 8000 reported cases of AIDS in children younger than 13 years and over 3000 adolescents with AIDS. The mean survival age is between 8.6 to 13 years old. About 36% to 61% of perinatally infected infants are expected to survive to age 13 years (WHO, 2008). Consequently, the disclosure of a diagnosis of HIV infection to a child is becoming an increasingly common clinical issue. However, some family members have been reluctant to discuss the nature of the illness with their infected child or adolescent, this statement gives recommendations for disclosure of illness to HIV-infected children and adolescents.

The general picture of HIV and AIDS epidemic in Africa shows that, it has had devastating effects on children too. There were an estimated 330,000 under-15s living with HIV in 2009, a figure that has almost doubled since 2001(UNAIDS, 2010). The predominant mode of transmission has been identified to be through heterosexual sex, with mother-to-child transmission being the other main infection route. Eleven (11) percent of children born to HIV positive mothers become infected with HIV (UNAIDS, 2008).

In the sub-Saharan Africa region, the prevalence of HIV infection also appears to be on a high side as evidence shows from one of the countries in this region. This was reflected in the report from the cross – sectional national representative household survey, which was conducted from March to August, 2003 in South Africa. The focus of the study was to determine the prevalence of HIV infection and the factors associated with HIV infection amongst 11 904, adolescents (15-24 year olds) (Pettifor, 2005). The survey confirms the high prevalence among adolescents and young adults. It was recommended that program for adolescents and young adults must continue to promote partner reduction, consistent condom use and prompt treatment for sexually transmitted infections while also addressing contextual factors that make it difficult for them to implement behavior change (Pettifor, 2005). More revelations estimated 5.6 million people were living with HIV and AIDS in South Africa in

2009, the highest number of people in any country. In the same year, it is estimated that 310,000 South Africans died of AIDS-related causes (UNAIDS, 2010) reflecting the huge number of lives that the country has lost to AIDS over the last three decades.

This is just one sample of the sub-Saharan countries where HIV infection has impacted adolescents greatly as typical of most developing countries. It might not however mean that the picture is the same in all nations of this region, differences in prevalence, impact and prevention are expected except there is little research done in most of these areas to clear this fact. Co morbidity and mortality rates had been on the increase until the advent of ART in recent years. Contextual factors also play an important role in infection rates, predisposing factors, disclosure of HIV infection status, support systems, and its implication for psychological well-being.

Santamaria et al. (1991) posits that, adolescents' HIV and AIDS condition is unique and needs to be handled and managed differently from adults. These usually have challenges in accepting their HIV infection status, need long life treatment, and this has an impact on the future regarding their health, education, relationships and marriage. An adolescent is said to be an individual who gets infected with HIV once and stays infected and affected for life.

Adolescents in Zambia have equally been identified with other sub-Saharan countries that have been affected with this scourge. The government of Zambia, Non Governmental Organizations (NGOs) and other stake holders have come up with deliberate efforts through several programs to try and see how an adolescent can be helped to lead a more resource full life even when they are infected or affected with HIV and AIDS. One such identified program is highlighted below, in one of my primary sources of information for this study.

The primary source of information was obtained through an interview with the Coordinator of Pediatrics Centre of Excellence at UTH on the 1<sup>st</sup> March, (2012). It was reported that the centre deals with HIV infected children from 0 to 19 years old and endeavors to improve and maintain their quality of life in all possible areas. This includes physically, socially, psychologically and the general health status. They are working so far with about one thousand (1000) HIV positive adolescents who are maintained under their care.

Specifically, it was established that, 621 of these adolescents were young between 10-15 years old. Fifty (50%) of them were not aware of their HIV positive infection status yet and this was the population of interest for the study. Three hundred and seventeen (317) were

older adolescents between 16-19 years, almost all (97%) were already aware of their positive infection status.

It was further established however that, very little research has been done in this area (Zambia inclusive), to illustrate the impact of disclosure of infection status to adolescents and social support on their psychological well-being. Amongst the few studies that were done for example, (Menon et al. 2007) exposes the need to carry out more studies on disclosure and psychological well-being among HIV positive adolescents.

It was established from the same verbal interview that, very few studies were done in relation to disclosure. For example it was indicated that one of the studies that had been conducted focused on factors affecting adherence to ART in HIV positive adolescents. This study did not address disclosure. There was almost no indication of any study on disclosure and psychological well-being of adolescents that was conducted at the center.

It is a well known fact however that if the mind is not healthy; it affects the social, emotional, behavioral, spiritual, and medical aspects of an adolescent. The situation should not be left as it is because adolescents' stage is critical. This group is believed to comprise future leaders and so more research needs to be considered in the area of status disclosure to them. Their social support network is also vital as it is believed to have a mediating role on their psychological well-being. Understanding the nature of adolescents and why they are a special group for consideration in relation to sexuality and HIV also plays an important preventive and remedial role. This is because of their nature in terms of their vulnerability, sensitivity and to some extent immaturity as reflected below.

Adolescent is referred to by Miller (2003) as, the period between puberty and the cessation of physical growth, roughly from 11 to 19 years of age. Adolescents vacillate between being children and being adults, they are adjusting to physiological changes, their bodies are undergoing and are working to establish a sexual identification and to use these changes for personal benefit and for the benefit of society (Miller, 2003). This is an important stage because they are searching for personal identity and wanting freedom and independence of thought and action, but continue to have a strong dependence on their parents and suffer feelings of loss in separating from them. In reaction to this, they identify with their peers and tend to yield to peer pressure and conform to peer group values, behavior, and tastes in such things as clothing, food and entertainment (Miller, 2003).

It is the adolescent characteristic of searching for identity; seeking independence and immaturity that tends to expose them to risky behaviors through various experiments that makes this group special. Of significant value at this stage is also how they socially respond to social interaction pre and post disclosure of HIV infection.

Studies have suggested that the psychological, physiological and social development of adolescence is subdivided into early, middle and late adolescence. In the early stage (10-13 years), independence-dependence struggles are heralded by rapid physical changes with the onset of puberty (8-11 years in females and 9-11.5 years in males). The middle stage (14-16 years) is characterized by an increased scope of feelings, and increased importance of peer group values and more risk-taking behaviors. The late stage (17-19 years) represents emerging adults who have successfully transitioned into accepting responsibility for their behaviors.

It has been recognized in many studies that youths are our leaders of tomorrow; it lives us with no choice but to try and work out ways in which we can enhance their health and lives if we are to have health leaders who will lead a health nation to greater heights. One such suggested way is through disclosure of HIV infection to those that are positive so that they participate in their care and in return protect themselves, others and the nation at large.

The importance of adolescent disclosure of their HIV infection status to them cannot be overemphasized as this will enable them access further care and support, it enhances social support which in turn greatly contributes to their psychological well-being.

Studies acknowledge that adolescents constitute a considerable proportion 10.3 million youths. They are a rich human resource and an important part of the development process. Good health of adolescents will help in raising the healthy community status.

Adolescents are highly vulnerable to STIs, HIV and AIDS. The health of adolescent girls has an intergenerational effect. It is with regard to this fact that Miller (2003) recognizes adolescents in today's society as having special needs related to their lifestyle and health habits. About half of those between the age of 13 and 19 years are sexually active. Approximately 10% of the girls in this age group do become pregnant and many of their newborns are born prematurely or have difficulty at birth. As a result of these special health care needs for adolescents and especially that they increasingly become sexually active; this predisposes them to STIs, HIV infection and pregnancy. Those that have been infected perinatally who survive to adolescent stage and are on ART might actually pass the infection

on to their peers through social interaction. To make matters worse possibility of passing a drug resistant strain of HIV becomes even higher; this poses even greater danger to their health, their lives and the nation.

UNAIDS (2004), reports that the prospect of a longer lifespan brings new challenges related to impact of HIV infection. This is on physical, mental health; as well as on normative developmental processes such as growth, peer relationships, puberty, and sexuality.

With increased survival, one of the greatest psychosocial challenges that parents and caregivers of HIV-infected children face is disclosure of HIV sero positive status to their infected children. HIV diagnosis disclosure entails communication about a potentially life threatening, stigmatized and transmissible illness and many caregivers fear that such communication may create distress for the child (WHO, 2008).

The need for support is evident at this point because of the indications so far highlighted; support such as social, emotional and medical care need to be accessed pre and post disclosure of HIV infection among adolescents. Particularly social support has been related to increased psychological well-being and the general health status of adolescents and the general population.

Studies suggest the need to discuss the nature of the illness with infected adolescents for the enhancement of psychological well-being in both adolescents and the family at large. For example, Durkheim (1951) refers social support to the existence or availability of people who care about, value and love us. Actually the link between a lack of social support and reduced psychological well-being has been reported.

In one study, Symister (2003) reports that social support among adolescents has barely began and are characterized by the lack of reliable, general and convenient index. Bal et al. (2000) examined the role that social support plays on the well-being and coping after a stressful event in a group of non clinical adolescents. They found that a highly perceived availability of social support is directly associated with fewer trauma related symptoms.

Given the indications already reported, Dubler (2005) suggests consistent observations with the other findings that disclosure of HIV status to adolescents is very important and yet it can also be quite stressful. He also identifies social support i.e. from peers, family, and others as contributing factors to positive outcomes in the psychological well-being of HIV positive

adolescents (Dubler, 2005). This further facilitates access to care and support; making it easier for coping with disclosure of HIV infection status more tolerable and increased health seeking behaviors with a free mind. In addition to friends and family, social support enhances psychological well-being through counseling by a knowledgeable health care professional about disclosure and concerning other infection related concerns of an adolescent. Support may need to be repeated throughout the course of the child's illness (Dubler, 2005). Importantly the role of the family and friends is critical even when counseling is in place.

It has been suggested that, disclosure of the diagnosis to an HIV – infected child and adolescent should be individualized to include the child's cognitive ability, developmental stage, clinical status, and social circumstances (Turner et al. 1996).

### **1.2: Statement of the problem**

Literature for example, Wiener et al. (2007) reveals a relationship between adolescents' HIV status disclosure and psychological well-being. UNICEF (2011) also suggests that social support has an impact on psychological well-being in HIV positive adolescents. This research therefore endeavored to explore the relationship between HIV infection status disclosure on the psychological well-being of HIV positive adolescents. It further explored if social support plays a mediating role in determining the psychological well-being of those who know their HIV status.

Disclosure of infection status to adolescents has been recognized to be vital yet it has been received with mixed feelings by both adolescents and family members. Most studies acknowledge the need for disclosure of HIV infection to adolescents because evidence shows so. Some literature however, suggest no relationship between HIV disclosure and increased mental health problems; while on the contrary, other studies reveal psychological and social challenges post disclosure as we will notice in reviewed literature. In some parts of the world, particularly in the sub-Saharan Africa, were reports of relationships between HIV disclosure and increased psychological and social problems (Cohen et al. 2000).

How one deals with issues of status disclosure of HIV positive adolescents and to parents or by parents to the adolescent has multifaceted challenges. The adolescent being an emotionally vulnerable age group, their response to disease status can never be predicted (Cohen et al. 2000). To this regard adolescents need support of friends and family members if access to care and support has to be achieved. Additionally, social support enhances well-

being pre and post disclosure of infection to adolescents which in turn facilitates health seeking behaviors and improved psychological well-being.

In a verbal interview with the coordinator at the centre, it was reported that some adolescents were experiencing social problems especially with family and friends. Some had their status disclosed to them already while a few had not been disclosed to yet. This made access to needed care and support challenging especially for the undisclosed group. The situation is even more desperate and complex because of adolescents' sensitivity, emotional vulnerability and our inability to predict their reaction in response to disclosure.

In one study conducted in Lusaka, they reported knowledge of HIV infection status having a negative impact on mental health. Those who were aware of their status were more than 2.5 times less likely to score in the abnormal range for emotional difficulties, even after controlling for age, gender, and medication. Reports show little previous research concerning the impact of disclosure of HIV status to young people within the sub-Saharan Africa, and results from studies in developed countries are inconclusive (Menon et al. 2007). In one study that was conducted in Zambia by Menon et al (2007), the focus was on disclosure with regard to emotional difficulty which is a component that is related to the psychological aspect. Emotions are governed by heightened feelings which are as a result of the psychological interaction, were as the psychological status is that which affect the mind and the mental processes. There is a thin line between the two as they cannot be categorically separated because what affects the mind (psychological) affects the feelings (emotions) and all this sums up to action (Behavior). Hence, social support and psychological well-being had to be considered in this study. The other study was looking at factors affecting adherence in HIV positive adolescents who are on ART. It also did not address disclosure in any way hence living more gaps.

Additionally, the verbal interview with the coordinator of the centre revealed inconsistencies with reviewed literature, which found no relationship between disclosure and mental health problems. It was established that there were elements of psychological and social challenges post adolescent disclosure due to stigma and discrimination among some friends and families. A few were reported to have been isolated or forced out of home to stay on their own or with friends of the same status. The worst scenario was of those who were forced into early marriages.

Now the major question that still remained unanswered was; if most of these adolescents had been exposed to counseling, peer support groups and other forms of care and support, why

was it that a good number of them still were reported facing psychological and social problems? Of course some children were reported to have been coping well generally, yet for others, social and psychological concerns were still a toll to them. One therefore remains wondering where the problem could be. To this regard, this study was intended to explore the relationship between HIV status disclosure to adolescents and their psychological well-being. It further explored the effects of social support on their psychological well-being.

### **1.3: Justification of the Study**

Disclosure issues abound both in developed and developing worlds, medical benefits to disclosure of HIV infection status to children and adolescents have been recognized. Children and adolescents who know their HIV status appear more likely to accept medical care and have a higher self-esteem as compared to those unaware of their status (Lester 2002).

Most findings report few cases of those with disclosed infection status even when the importance has been acknowledged. As can be seen, there are inconsistencies arising from the literature and the situation on the ground. Generally, studies appear to suggest a relationship between adolescents' status disclosure of HIV infection and psychological well-being, where as others report contrary views. From the Zambian perspective, there still is need for more research in this area as it was discovered from my search that this area has grossly been understudied. From the very few studies conducted, one publication by Menon et al. (2007) focused on disclosure in relation to emotional well-being, while the other by Silvia (2009) concentrated on factors affecting parental disclosure of status to adolescents. There was almost no evidence of any studies on effects of HIV status disclosure to adolescents on their psychological well-being, hence the need for this study.

There seems to be a dearth of literature in this area with regard to Zambia. It is hoped therefore that this study portraying the Zambian situation would help fill in the gaps in the area of disclosure with regard to psychological well-being of adolescents and that it has exposed the true picture. Furthermore, it is hoped that this study would facilitate improvements to holistic health care and service delivery to this population.

## **1.4: Research Objectives**

### **1.4.1: General Objective**

The main objective of this study was:

To investigate the relationship between HIV status disclosure to HIV positive adolescents and their psychological well-being.

### **1.4.2: Specific Objectives**

The specific objectives of this study were:

- 1) To determine if there was a difference in the psychological well-being of HIV positive adolescents who have their HIV status disclosed and HIV positive adolescents who did not have their HIV status disclosed to them.
- 2) To determine the relationship between social support from friends and family on the psychological well-being of HIV positive adolescents.

### **1.4.3: Research Questions**

The research questions that guided this study were:

- 1) Is there a relationship between HIV status disclosure and psychological well-being in HIV positive adolescents?
- 2) What is the relationship between social support from friends and family on the psychological well-being of HIV positive adolescents?

### **1.4.4: Research Hypothesis**

The study tested the following alternative hypotheses:

- 1) Participants whose HIV positive status has been disclosed to them will have better psychological well-being than those whose status has not been disclosed.
- 2) Disclosed participants with social support from friends and family will have even a better psychological well-being than disclosed participants with no social support.

### 1.5: Operational definitions of Variables

The following are the definitions of variables that were used in the study

| Variable                 | Definition   | Measure   |
|--------------------------|--|---|
| Adolescent               | Those in the age group of 11-15 years  | Socio demographic questionnaire   |
| Disclosure               | If HIV positive status has been disclosed to the participants                                  | Information from health professionals and confirmed privately by care giver.  |
| Social support           | Perceived Support received from friends and family as measured by Social Support questionnaire | Social Support questionnaire (PSS- Fr) (Weinert at al 1987).                  |
| Psychological well-being | Psychological well -being as measured by Strengths and Difficulty Questionnaire –Youth version | Strengths and Difficulty Questionnaire- Youth Version (SDQ-Y) (Goodman 1997). |

### 1.6: VARIABLES

The following were the independent and dependent variables:

#### 1.6.1: Independent Variables

- Adolescent HIV status disclosure
- Social support.

#### 1.6.2: Dependent Variables

- Psychological well- being

## 1.7: Theoretical Framework

Stress comes in different ways such as health related problems, economical, emotional, social, psychological and so on. HIV infection status disclosure to adolescents can also be so stressful depending on the personal coping resources obtaining and other factors related to disclosure such as social support. To this regard there is need to examine how coping with disclosure of infection can either positively or negatively impact on HIV positive adolescents whose status has been disclosed to them and vice versa. Dimensions of coping and personal coping resources can help explain why psychological well-being is affected differently between the disclosed and the undisclosed status groups.

Dimensions of Coping: Different ways of coping have been found to be more or less adaptive. Suls and Fletcher (1985) have compiled studies that examined the effects of various coping modes on several measures of adjustment to illness. The authors concluded that *avoidant* coping strategies seem to be more adaptive in the short run whereas *attentive-confrontative* coping is more adaptive in the long run. Some researchers have come up with two basic dimensions-such as instrumental, attentive, vigilant, or confrontative coping on the one hand, in contrast to avoidant, palliative, and emotional coping on the other (Parker & Endler, 1996). Another conceptual distinction has been suggested between *assimilative* and *accommodative* coping, the former aiming at an alteration of the environment to oneself, and the latter aiming at an alteration of oneself to the environment (Brandtstädter, 1992). This pair has also been coined "*mastery versus meaning*" (Taylor, 1989); or "*primary control versus secondary control*" (Rothbaum, Weisz, & Snyder, 1982). These coping preferences may occur in a certain time and order, when for example, individuals first try to alter the demands that are at stake, and after failing, turn inward to reinterpret their plight and find subjective meaning in it.

Coping has also a temporal aspect, one can cope before a stressful event takes place, while it is happening (e.g., during the progress of a disease), or afterwards. Beehr and McGrath (1996) distinguish five situations that create a particular temporal context:

(a) *Preventive coping*: Long before the stressful event occurs or might occur; for example, an adolescent might quit drinking well in time to avoid problems with drug interaction.

(b) *Anticipatory coping*: when the event is anticipated soon; for example, an adolescent might decide to comply with the rules of taking ART while trying to live a health life to avoid quick progression into AIDs to avoid problems related to peers interaction.

(c) *Dynamic coping*: while it is ongoing; for example, the adolescent may resort to diverting attention to other productive activities such as school to reduce chronic anxiety that can come as a result of disclosure of infection status

(d) *Reactive coping*: after it has happened; for example, changing one's life post disclosure of HIV infection status to maintain a good health.

(e) *Residual coping*: long afterward, by contending with long-run effects; for example, controlling one's intrusive thoughts years after knowing their HIV positive status or a traumatic accident has happened.

Any of the above coping resources can apply to these adolescents as they endeavor to cope with knowledge of their HIV positive infection status or vice versa. According to this theory, those adolescents that have their status disclosed to them but tend to be avoidant of the realities of their status will tend to have short term stress free life but soon problems set in as a result of the coping resources applied. Those with the attentive confrontative coping resources will be stressed at the beginning of the process but will soon learn to cope well with the situation on the ground. Additionally, the theory also suggests that those with confrontative coping resources will try to change some things about themselves to the demands of the environment or they will try to change things in their environment to their needs accordingly to enhance psychological well-being. This theory explains why there are all these variations in the psychological well-being of adolescents between the two status groups.

Social support on the other hand is supported by theory suggested by (Ogden 2000) Berkman and Syme (1979) in Ogden 2000. They report the results of a prospective study where they measured social support in 4700 men and women whom they followed up for 9 years. They found that increased social support predicted a decrease in mortality rate. This indicates the role social support has on health. More studies report that birth complications are lower in women who have high levels of social support, suggesting a link between social support and health status (Oakley 1992; in Ogden 2000).

She further suggests two theories that describe the role of social support in health status, and the possible mechanism for which social support influences or mediates the stress illness - link as follows:

1). *The main effect hypothesis* suggests that social support itself is beneficial and that the absence of social support is itself stressful. This suggests that social support mediates the stress – illness link, with its very presence reducing the effect of the stressor and its absence itself acting as a stressor (Ogden 2000).

2). *The stress buffering hypothesis* suggests that social support helps individuals to cope with stress, therefore mediating the stress - link by buffering the individual from the stressor; social support influences the individual's appraisal of the potential stressor (Ogden 2000). This process, which has been described using social comparison theory, suggests that the existence of other people enables individuals exposed to a stressor to select an appropriate coping strategy by comparing themselves with others. For example, if an individual was going through a stressful life event, such as divorce, and existed in a social group where other people had dealt with divorces, the experience of others would help them to choose a suitable coping strategy (Ogden, 2000).

## **Chapter Two: Literature Review**

### **2.1: Introduction**

This chapter provides a review of literature on HIV status disclosure to adolescents' and its relationship to psychological well-being. It has been drawn from various studies done cross culturally but mostly in developed countries and very little in developing countries. An interview with pediatrics HIV and AIDS coordinator at the centre of excellence in Lusaka comprised the primary source of the review. It endeavored to investigate, the relationship between adolescents' HIV infection status disclosure to them and their psychological well-being. The study reviewed the available research findings on, HIV sero positive status disclosure, and the effects of disclosure and social support on psychological well-being. The key words for the study included: adolescents, status disclosure, social support and psychological well-being whose primary source was an interview with the centre staff. Internet and relevant books comprised the secondary source of data.

### **2.2: HIV Sero Positive Status Disclosure**

Since the advent of HAART, infected children experience less symptomatic early course and survive to older ages (Berk 2005). This increasingly raises questions about disclosure of the diagnosis; many families are reluctant to discuss the nature of the illness with their infected child or adolescent, yet delays in disclosure of HIV infection may potentially result in negative consequences. Lack of disclosure may impair treatment understanding, participation and increase in psychological and behavioral problems (Butler 2009).

UNAIDS (2004), highlights in one report that, many HIV infected children, particularly those younger than 15 years, do not know they are HIV infected. The same report noted that, one of the difficult issues that families with HIV infected children face are when and how to talk about HIV to their children. HIV disclosure to infected children and adolescents are recommended to take place in a supportive environment with collaboration and cooperation among caregivers and providers. Disclosure is contingent on the caregiver's acknowledgement of the illness, the readiness to disclose, and the child's cognitive skills and emotional maturity (Santamaria et al 1991).

As opposed to the above writer, Mellins (2002) argues that, caregivers who decide to disclose the diagnosis to their child cite many reasons for this decision including opposing or tiring of secrets, believing in a child's right to know their health status, concern that their child will learn the diagnosis elsewhere, fear the child would get involved in sexual activities without protection and hope that disclosure will lead to improved health care or motivate their child to improve medication adherence.

Waugh (2003) argued that Children who have been informed of their diagnosis by their caregivers tend to be older, have a higher IQ, and have increased parent-rated child anxiety and a greater number of major life events.

Menon et al. (2007) also observed a strong presumption in the medical literature that adolescents, in particular, should be informed of their HIV status to promote adherence to treatment and to encourage safe sexual practices. The role of disclosure in promoting access to social and psychological support has received less attention. Although self-disclosure to others has been shown to enhance well-being, peer support interventions have also shown promising results (Menon et al. 2007).

Clinical reports have indicated positive outcomes associated with disclosure including the promotion of trust, improved adherence, enhanced access to support services, open family communication, and better long – term health and emotional well-being in children (American Academy of Pediatrics Committee, 1999).

So far the gaps that appear not to be addressed is how the care givers or adolescents can disclose the infection status to each other depending on who knows the status first even when the value may well be understood. There appears to be lack of knowledge on both ends on how this can best be achieved, this fact poses the need for studies to establish the best way this can be done. Only then will it enhance access to health services, support services and behavior change among adolescents.

Though one important point has been observed that disclosure takes many forms and it is done at different levels. The ultimate result irrespective of the process or procedure should be disclosure in its clear sense, i.e. the child should know the actual illness and its implications in the long life that they still are to live, for those positive outcomes to take effect. The importance of disclosure has already been mentioned but mixed views on how it is done exist also vary.

For example, in one of the studies done to assess the prevalence and predictors of disclosure and non disclosure; this work elucidated various patterns of disclosure, ranging from non disclosure, partial disclosure to full disclosure. Although complete nondisclosure (no mention of HIV or any illness) does take place, especially in early years, partial disclosure is actually more common(Melvin, 1999).

Partial disclosure is the term used for describing situations in which children are given some but not all information about their illness (Melvin 999). They may be informed of the need to take medicine in order to keep their virus or “illness” at bay or learn how their virus can be transmitted without learning that it is HIV or AIDs that they have. For example, a child in one study reported “I take pills so that my soldiers that are in my blood can be more efficient to fight gems” (Melvin, 1999).

When full disclosure occurs, children are told the name of the illness (HIV and/or AIDS), disease specific information (e.g., how the virus works, how it is transmitted), and how they acquired the disease, of course age appropriate information should be communicated. In a study by Funck-Bretano and colleagues (1995), among 35 Parisian families, they found that non-disclosure (23%) and deception (20%) were common, particularly in young children, with complete nondisclosure coinciding with secrecy about the illness or a caregiver’s denial of the child’s illness. Partial disclosure was the most common (40%) and was often viewed by some caregivers as a step towards full disclosure.

The variations portrayed in disclosure may suggest the possibility of some institutions working with or clinics treating pediatric HIV (where some studies were conducted) may foster different cultures of disclosure—some of which may be more inclined toward early disclosure and others that may tend towards later disclosure (Funck et al.1995).

Considering the sample in question, generalizing the results of participants from only 35 families may not be so accurate because 35 in itself may not be representative enough of many adolescent populations.

Funck-Bretano and colleagues (1995) further posits that, deception often entailed caregivers, frequently out of concern for the child’s psychological well-being, telling them only about a co-morbid condition (e.g. asthma, cancer). They attributed all medical needs (e.g., appointments, medication) to that less-stigmatized condition.

The reasons mentioned above seem to be in line with most of the reasons given by caregivers for non disclosure, deception or partial disclosure. But what is also vital for this study is understanding disclosure as the process.

However problems arise because the process of disclosure in some cases takes too long such that by the time parents feel ready to talk about their status, damage in many identified areas of adolescents will have been done, especially that deciding on when the right time to tell in itself is another huge challenge.

Literature indicates that numbers of children with knowledge of HIV are too low in most areas. For example in the case above; only 17% of their sample had been made fully aware of their HIV illness. Since then, other studies have focused on the prevalence of full HIV disclosure for school age children, adolescents and young adults and have produced inconsistent findings. Studies relying on caregiver report have found that 10% to 75% of HIV+ children in the samples have been told about their HIV status (Funck-Bretano et al 1995).

Just to emphasize levels of nondisclosure, the American Academy of Pediatrics (1999) report data from several centers revealing that, between 25% and 90% of school age children with HIV infection have not been told they are infected. As earlier mentioned some reasons given by family members for not disclosing HIV infection status are similar to reasons expressed by parents of children with other serious diseases, which include concern about the impact that disclosure may have on a child's emotional health and fear by the parents that the knowledge will negatively affect a child's will to live (Santamaria et al.1991).

A comparison of the study in question involving other serious illnesses which are not HIV as a reason for non disclosure may not hold; because of the tag that HIV carries in comparison to other conditions such as asthma, cancer and so on. Of critical importance also is the realization by most stake holders that disclosure is key for access to psychological, social and medical care. What still remains unclear is if caregivers are informed enough to understand the role of disclosure in relation the psychological well-being and social support of their children and adolescents.

In another study that was conducted, it was examining patterns of disclosure of HIV status to 77 perinatally infected ethnic minority children (12 – 15 years), and explored the association between knowledge of HIV status and emotional and behavioral outcomes. The majority in this study did not know their HIV status (70%). Child knowledge of HIV status was not associated with gender, ethnicity, caregiver education, parent – child relationship factors,

type of placement (biological or adoptive), or other health status indicators. Results show that, HIV status disclosure to infected children and adolescents did not result in increased mental health problems. There was a statistical trend for children who knew their HIV status to be less depressed than children who did not know.

The UNAIDS (2000), illustrates the importance of HIV infection disclosure to children by parents and, adolescents who may face dilemma in disclosing the status to others because it may lead to stigma and discrimination. Disclosing the HIV status is said to have the following benefits:

- It helps avoid enhancement of transmission among sex partners due to concealment.
- Help gain additional support, including access to treatment and help adhering to it, pregnancy planning, future planning and care.
- It influences others who fear disclosure and improves the existing knowledge about HIV and its transmission

Nehring et al ( 2000) notes that, developmentally appropriate and truthful explanations of the illness, validation of the child's concerns about the disease, clarifications of misconceptions, and ongoing support are the cornerstones for promoting a positive adjustment to living with HIV infection.

Regarding the situation on the ground i.e. UTH centre of excellence, the class of adolescents, which was the focus of interest for this study (11-15 year) olds totaled 621. Fifty (50%) of them still had their status not yet undisclosed to them. For the older adolescents (16-19 yr olds), about 97% of them had their status disclosed to them already.

There were no reasons advanced for the undisclosed status group. It was however, indicated that in some cases, children were in the process of been helped to know their status. She emphasized that disclosure is a process where an adolescent being a sensitive cadre should be helped through this process carefully, in other words readiness to be told should be ascertained in one way or another before disclosure is completely done. Usually they would assess readiness to disclose through peer group meetings or workshops, with a focus on those who do not know, by encouraging them to interact with their friends for support.

### **2.3: Psychological Well-being in Disclosed Adolescents**

Many countries have been faced with severe problems of HIV infection and the highest at risk being children and adolescent in the sub - Saharan Africa (Patterson, 2004). Zambia being one of the countries in this region has not been left out in terms of high infection rates and mortality due to AIDS and related illnesses. However, with the ever improving availability of antiretroviral therapy, HIV is increasingly been recognized as a chronic, rather than terminal, illness. This transition requires psychological adjustments, especially in the pediatric and adolescent populations (Patterson, 2004).

To this regard a longitudinal study was conducted in the United States in New York City between December 2003 and December 2005, to examined the prevalence and timing of HIV disclosure to (PHIV+) adolescents and the associations between the timing of disclosure and psychological functioning and other behavioral outcomes(Santa Maria et al,1991). The sample used included data from 196 PHIV+ adolescents and their caregivers: 50% of them were male, 58% African American, 42% Hispanic, with a mean age of 12.71 years. PHIV+ youth who had been told their HIV status did not show an increase of psychological problems and were more likely to have intentions to self-disclose to potential sexual partners (Santa Maria et al. 1991). Yet, almost one third was entering puberty without important information regarding their illness. It has been noted, that caregivers need support to address factors impeding adolescent HIV disclosure. Santa Maria et al. (1991) states that, consequently the disclosure of a diagnosis of HIV infection and AIDS to the child is becoming an increasingly clinical issue.

The study reflects important aspects which are key to disclosure of HIV infection, this study has been done among African Americans whose cultural practices and consideration of adolescent may be different from that of the African setting which makes generalization to the African setting a challenge.

Findings of another study conducted in the United States have provided evidence that disclosure does not represent a risk to mental health (Rotheram, 1997); other studies have suggested poorer outcomes. A recent study of 57 children aged 6 to 12 years found a higher incidence of internalizing and externalizing symptoms in children who were aware of their status (Rotheram, 1997). Another US study Rotheram, (1997) found a 6-fold increase in rates of admission for psychiatric disorders in children who knew their HIV status.

Revelations in this study depict evidence that is based on younger children and preadolescents in which physical, cognitive and social development is not similar to the mid adolescents. These conditions interfere with the results that can be found between the two groups due to the large differences in age.

Wiener et al. (2007) posits that, the optimal timing and psychological impact of disclosure of HIV infection to children and adolescents in a wide range of cultural and socioeconomic settings have been published. In this particular study from 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 status. Wiener et al. (2007) further states that nondisclosure can result in anxiety, depression, and phobias and excludes youth from peer support groups.

This is so because adolescents who are not aware of their HIV infection status usually do not see the need to seek support because they are not aware of what is going on even if they are constantly getting sick. But those that are aware of their HIV infection status, are most likely to adopt health maintaining behaviors especially with the availability of social support which will enhance psychological well-being as indicated in the study by (Riekert, 1991).

In fact Riekert (1991) adds that, most adolescents in these studies had come to terms with their diagnosis by 6 months post-disclosure. Importantly, parents who disclosed the HIV status to their children experienced less depression and considered disclosure as having an overall positive effect on themselves and their families. Reluctance to disclose the HIV status to adolescents is often based on the caregiver's concern for possible exposure to stigma and discrimination toward the whole family once the adolescent shares the diagnosis with partners, peers, or the public ( Wiener et al. 2007).

Effects of disclosure on the psychological well-being have been recognized and mostly consistency is maintained as mentioned in the above literature. Contributions made on the importance of disclosure on the part of the parent to the child are well appreciated, but it appears not to clearly state nondisclosure' psychological pattern. It is claimed that nondisclosure can result in anxiety, depression, phobias and other mental health problems (UNAIDS, 2003).

It is however, not clear to what children and adolescents were anxious since they are not aware of their HIV status. One wonders whether it is anxiety due to reactions towards drugs they are constantly taking, or it is their sickly life style which might lead to ineffective peer

interaction. If so, what about those that were not yet on drugs. I think there was need to be more explicit on what exactly affects the adolescents whose HIV positive sero status was not disclosed to them. But one of the factors is well identified that they lacked inclusion to peer support groups.

In a longitudinal analysis which was conducted to examine the impact of HIV disclosure on pediatric quality of life and to describe the distribution of age at disclosure in perinatally infected, youth =5 years of age. Age-specific quality-of-life instruments were completed by primary caregivers at routine study visits. The distribution of age at disclosure was summarized (Butler2009). Six quality-of-life domains were assessed, including general health perception, symptom distress, psychological status, health care utilization, physical functioning, and social/role functioning. For each domain, mixed-effects models were fit to estimate the effect of disclosure on quality of life (Butler 2009).Age at disclosure decreased significantly over time. There were no statistically significant differences between pre disclosure and post disclosure quality of life; therefore, disclosure should be encouraged at an appropriate time (Butler 2009).

In the study that was conducted in Zambia to examine emotional and difficulties among adolescents living with HIV. Menon et al (2007) aimed at examining emotional difficulties and to determine the relationship between disclosure of HIV infection status and mental health. In a cross sectional survey, 127 adolescents living with HIV aged 11 to 15 years were recruited and mental health was assessed using the youth report version of the Strength and Difficulties Questionnaire (SDQ). Caregivers completed the parent SDQ. Sixty two participants were invited for a semi structured interview which probed views on attending a peer group. Compared to a British community sample, participants had increased mental health problems (Menon et al. 2007). The majority of the study subjects were receiving ART, but only 37.8% had their HIV status disclosed to them. Those who had not their HIV status disclosed to were younger and less likely to be receiving antiretroviral treatment, their conclusion indicated that the high rates of emotional and peer problems were found in this sample but disclosure of HIV status did not have a negative effect on mental health (Menon et al. 2007).

This is one of the locally conducted studies which showed no negative effects of disclosure on adolescents. But its focus was more on the emotional difficulties which confirms almost the absence of research on psychological well-being.

Social and psychological support at centre of excellence were the study cohort was obtained was reported to have been obtained through programs organized for them. For example the coordinator through the verbal interview indicated that the adolescents were involved in programs such as peer support meetings, recreation activities, counseling sessions, group discussions on challenging issues affecting them, testimonies by those who have made it in life (i.e. are in universities, colleges or are working), debates and so on. But it was noticed that despite having all these support programs mentioned above, it appeared a number of adolescents still experienced psychological and social issues, which if attended to would to a great extent reduce these problems.

Additionally, some studies on disclosure of adolescents' HIV infection were done on restricted sample sizes, and many of the samples, recruited to single institutions, were simply too small to allow detection of significant differences between disclosure groups and psychological well-being especially when controlling for important demographic variables such as the age of the child. For example, the study by Rotheran (1997) indicated that 57 children and adolescents were sampled and findings showed poorer outcomes amongst the disclosed group because they experienced higher incidences of internalizing and externalizing symptoms and there was an increase in rates of admission for psychiatric.

#### **2.4: Social Support**

Social support is defined as the existence or availability of people who care about, value, and love us (Sarason, 1983). Although the link between a lack of social support and reduced psychological well-being is well established, empirical research on social support among adolescents has barely begun, and is characterized by the lack of a reliable, general, and convenient index of social support (Tolsdorf, 1976).

From one study by the society for adolescents' health in the United States, they purported to examine the psychosocial factors associated with long term survival of pediatrics (HIV) infection.

Santamaria et al. (1991) indicates that, children infected with HIV enrolled in the clinical trials at the National Cancer Institute and their caregivers were interviewed and completed self report measures 3 times, approximately 12 months apart, using the child behavior checklist, social support scale for children, self perception profile for children and adolescents, and a structured interview designed by the investigator. Average age of the participants was 11.8 years at time one and 14 years at time 2. Fifty six (56.3%) of the original

sample were male, racial composition was 72.2% white, 13.9% African – American, 6.9% “other”, 38.9% of participants contracted HIV perinatally, 34.7% through hemophilia – related transfusion, and 26.4% through another type of transfusion (Santamaria et al. 1991). Pearson product moment correlations revealed that disclosure was found to be positively related to social support, self competence, and decreased behavior problems, except in the case of public disclosure, in which an independent – sample student’s t – test revealed that it was negatively associated with global self competence. Social support was significantly negatively correlated with problem behavior. Santamaria et al. (1991) reports the Chi – square analysis of the 5 year follow up data indicating that participants aged 18 years and older were less likely to complete their academic education than their health peers (national norms). It was concluded that Social support and open communication about the diagnosis are essential particularly at the age at which decisions about relationships, sexuality, drug use and plans for the future are the focus of adolescent development and individuation (Santamaria et al. 1991).

This study was done in comparison with the cancer patients whose findings might not be consistent due to differences in the way these two forms illnesses are viewed; additionally racial differences might affect these results differently.

Just as it has been indicated in the previous literature, young people are the most at risk of HIV infection and yet access to care is a challenge due to non disclosure of their HIV infection status and lack of social support. Social support has been reported to play an important role especially in the psychological well-being of an adolescent.

Ogden (2000) suggests several types of social support to include:

- *Self esteem*, where by other people increase one’s own self esteem;
- *Information Support*, whereby other people are available to offer advice;
- *Social companionship*, which involves support through activities;
- *Instrument support*, which involves physical help.

Obtaining any of this kind of support might to some extent depend on knowledge of status. Unfortunately, far too many HIV positive youth are unaware of their HIV positive infection status because they either have not been tested or have not been told of their status, there by compounding the challenge of the possibility of seeking social support in any of the described manner (Kaier, 2000).

The picture just highlighted from the literature above is very alarming because then one wonders how many youths are infected and how many more will infect others, especially those that have not been disclosed to, how will they get the much needed knowledge and support. How many of these adolescents if they knew their status would seek a shoulder to cry on and yet they are not able to because they don't. No wonder levels of depression among adolescents are on the increase. Though social support has been seen to play an important role in dealing with all these disclosure related concerns; there is still a lot that needs to be done. The White House office (2002) also observed that, linking HIV infected youth to health care is difficult. Most HIV infected youth do not receive adequate health care, even when it is available for the same reason of non disclosure.

HIV positive youth have a wide range of psychosocial needs. They need emotional support to promote quality of life and treatment adherence. They need support to end isolation and challenge discrimination, and additionally they need to deal with the developmental, cognitive, and emotional changes of adolescence (Kaier, 2000).

The goals of psychosocial care for HIV positive youths as stipulated by Futterman (2000) include:

- Identifying and addressing crises (i.e., suicidal behavior, homelessness)
- Assessing and expanding social support
- Supporting youth in self care and life – enhancing practices
- Identifying and treating chronic problems (depression, substances abuse)
- Promoting skills to live independently and to make the transition to adulthood
- Re enforcing and sustaining safer sex behavior
- Promoting harm reduction and encouraging drug treatment

For sustenance of comprehensive psychological well-being Futterman (2000) further suggested that, providers and caregivers need to assess the emotional support available to HIV positive youths. They can encourage youth to use resources and support. Support networks may include family, friends, sexual partners, healthcare providers, teachers, counselors, clergy, and adult role models.

This study was conducted to examine the association between depression among HIV-affected adolescents and their social support, adjusting for potential correlates of adolescent depression. Bal et al. (2003), five dimensions of social support (size, frequency of contact, perception, negative support and positive support) were considered as potential predictors of depression. They also examine the association between parental HIV disclosure and adolescent depression. These studies have shown that although HIV disclosure serves as an acute and ongoing stressor, it also facilitates emotional support for people living with HIV (PLH), which may lead to more effective coping and enhanced psychological adaptation (Holt et al. 1998).

The focus of this study was mainly on parental HIV disclosure, the effects of disclosure on these two cadres would yield different effects because in this case the adolescent is indirectly affected unlike when he / she is the one directly affected by the infection. Social support entails effective communication in relation to the illness status to enhance social support and psychological well-being.

To assess the impact of the child's knowledge of his/her diagnosis, Hardy et al. (1994) examined communication styles of three groups of preschool children (n=20 per group) one with cancer, the second with HIV, and the third healthy controls. Nineteen of the 20 children living with cancer and five of the 20 children living with HIV knew their diagnosis. Using a model of an examination room, children were asked to place dolls representing the child, parents, and medical staff in the room. Hardy et al. (1994) reports that, children with cancer (and healthy controls) placed dolls representing the staff and parents significantly closer to the child doll than children with HIV. More significantly children with HIV removed the staff/parent doll from the room or turned the staff/parent doll's back to the child doll, reflecting a common practice of talking about the child's HIV status in whispers or outside the room, and suggesting that communication around the child is closed and isolating (Hardy et al. 1994).

Applying the evidence-based knowledge being practiced with cancer patients to pediatric HIV infection is difficult given significant differences in epidemiology, the multigenerational nature of the illness, and the unique social stigma surrounding HIV transmission. Additionally, cognitive and developmental limitations of children as well as children's capacity for denial and magical thinking also play a role in a child's processing of the diagnosis. It may require multiple sessions and time for children to fully understand the name of their disease, its health consequences, and their medical needs. Investigations need to

capture the child's ability to cognitively and emotionally process this information accordingly.

Nehring et al. (2000) also shows the importance of social support on psychological well-being and general health status, children who receive social support by discussing age appropriate illness concerns with adults have fewer behavior problems and have improved social functioning, school performance, and adherence to medications. However, other studies have shown an increase in behavior problems and stress levels after disclosure (Nehring et al. 2000).

At the centre for HIV infected adolescents, centre of excellence, social support was reported be derived from the already mentioned activities i.e. counseling sessions, peer support groups, educational and recreational tours. Some had support from the family members too while others it was a sorry site all together. Social support plays a crucial role in facilitating disclosure and psychological well-being of adolescents.

## **2.5: Conclusion based on literature**

In conclusion from the literature so far reviewed, mixed observations have been observed with most literature suggesting a significant effect of adolescents' HIV status disclosure on the psychological well-being. The provision of social support showed significant improvement on psychological well-being pre and post HIV disclosure. Further recommendations to this regard have been made that children with HIV should not be delayed in telling them the results because of the perceived feared negative impact on their quality of life. Other contrary views were also found, these seem to show no significant relationship between status disclosure and the psychological well-being and these few studies seem to depict the opposite results. The latter is consistent with the situation on the ground; poses the need to find out more about the association between adolescent disclosure of their HIV infection status and social support on their psychological well-being.

## **Chapter Three: Methodology**

This section focused on the methods that the researcher intended to use in the study. These include study design, the target population, i.e. participants, how they were recruited, data collection procedure, measures used for data collection, inclusion and exclusion criteria of participants, ethical consideration, and data analysis process.

### **3.1: Study Design**

The study used an exploratory cross – sectional design. The cross sectional study design was used because participants were derived from across the nation and were admitted to the centre for further management. The researcher had little knowledge of the participants. Denzin et al (2008) states that, when the researcher is not clear about events for which little is known, an exploratory cross sectional study can be used to generate fundamental knowledge.

### **3.2: Target Population**

It was established from the records that there were approximately 1000 adolescents in the care of centre of excellence between 11-19 years old. The majority were young and mid adolescents aged 11 to 15 years. These accounted for about 621 children from where the study sample was drawn. This population was chosen because adolescents are sensitive in nature, need special care and social support to enhance their psychological well-being, hence the need to ascertain the same.

### **3.3: Participants**

The study cohort was derived from UTH centre of excellence in Lusaka through the list which was provided by the coordinator. It comprised 80 HIV positive adolescents who were selected from the larger population list of eligible adolescents. The researcher requested the coordinator to generate 2 separate lists of participants; one for those who have had their HIV positive status disclosed to them and the other for the undisclosed status group. Using the two separate lists, a random selection of 40 participants with disclosed and 40 with undisclosed HIV infection status were conducted. The generation of these two separate lists was done in the absence of participants to enhance confidentiality in the random selection process. Further, the lists did not contain names of participants but codes, gender and age only. The coordinator maintained the master list containing names against the codes. Only adolescents aged between 11 to 15 years were eligible to participate; all participants had been to school or

were still attending school and were able to speak, read or at least write English. The adolescents were then subjected to the questionnaires prepared for them; i.e. Strength and difficult questionnaire-youth version (SDQ) and Perceived Social Support questionnaires for friends PSS-fr.

### **3.4: Recruitment**

Health care providers were asked for 2 lists of eligible participations. One list was for participants whose HIV positive status had been disclosed to them already (disclosed group) and the other list for participants whose status had not yet been disclosed to them (undisclosed group). All were between 11 – 15 years. The researcher began by sampling randomly on the first list (disclosed group) by dividing them into two subgroups by age (i.e. 11 – 13 year olds and 14 - 15 year olds). The number of boys and girls in the two groups were determined, i.e. (11 – 13 years, how many males and females; 14 – 15 years, how many females and males). When that was determined, the researcher did the first selection from the list of the disclosed group by selecting every alternative participant by age and gender. I.e. alternative sampling of 10 males of 11 – 13 years for 10 females of the same age (11 – 13 years); then 10 males of 14 – 15 years for another 10 females of the same age (14 - 15). This made the sub total of 20 (11 – 13 year olds) and 20 (14 – 15 year olds) totaling 40 randomly selected participants with disclosed status. When the first group was determined, the focus was shifted to adolescents with undisclosed status. These were equally divided into two sub groups by age, i.e. 11 – 13 and 14 – 15 year olds. Since the characteristics of the first group were already established, the researcher selected the second group by matching it with characteristics of the first group, i.e. 10 male participants of 11 – 13 years for 10 female participants of the same age, and 10 male participants of 14 – 15 years for 10 female participants of the same age, making sub totals of 20 in each category. These added to 40 participants with undisclosed status. The overall matched sample of 80 participants was arrived at by adding 40 with disclosed status from the first sample list and 40 undisclosed from the second sample list. The simple systematic (Kth) randomization procedure was used because it allowed every member of the population to have equal opportunities for selection.

### Summary of Recruitment Process



Note: Alternative participant selection refers to the process of selecting the first person followed by the third, leaving one person in between each selected participant. For example (1,3,5,7 and so on). Secondly, the selection of the undisclosed status group was done after the disclosed status group was selected.

Participants who had accepted to take part in the study were divided and given specific days on which to be attended to in small groups of 10; for convenience and to avoid overcrowding. The total number of groups was eight (8), i.e. four (4) groups with disclosed and 4 with undisclosed status translating to 8 days of data collection from the participants. To maintain confidentiality, those who had their HIV status disclosed to them were given days different from those whose status had not been disclosed to them yet. The researcher ensured that the two groups' different knowledge status were attended to at different times to avoid contact between them. It should be noted that despite attempting to match the sample for age and gender as much as possible, the study was not intended to analyze these two variables, this was just done to ensure that the two comparison groups are homogeneous.

### **3.5: Data Collection Procedure**

After recruitment of the participants with the help of the coordinator, caregivers were invited. The researcher introduced herself to them when they came, explained the purpose of the study and provided them with information sheets. Questions were encouraged and answered accordingly, then informed consent was sought to allow their adolescent children participate in the study by filling in the consent forms provided. Assent was also obtained from the children. The three questionnaires provided were then administered, i.e. Socio demographic questionnaire, SDQ-Y, and the PSS - fr. These questionnaires were all pinned together and coded so that the researcher could easily identify the respondents (i.e. the first number on each child's file for the disclosed group and the last number on each child's file for the undisclosed group. The dates on which they came also helped in identifying them because sometimes numbers on the files were similar.

The researcher went through the questionnaires with the participants to clarify issues. All questions that were asked by participants were answered as clearly as possible to ensure that they all understood and were willing to take part in the study. Necessary instructions were given and participants were encouraged to answer the questionnaires as truthfully as possible. They were also assured that they were free to withdraw if they so wished at any time as that would not affect treatment or any form of support they received.

### **3.6: Measures**

The Strength and Difficulty Questionnaire- Youth version (SDQ-Y) was used in this study to determine the psychological well-being of HIV positive adolescents with regard to status disclosure. This instrument was developed by Goodman (1997) and is used to measure the mental health status and behavioral problems in children and adolescents. The SDQ asks 25 items rated on a three-point likert scale (Not True, Somewhat True, and Certainly True) divided on five subscales: i.e. emotional symptoms, conduct problems, hyperactivity, peer relationship problems and pro social behaviours. Each subscale of the SDQ has five items. For each subscale, the total score ranges from 0 to 10 after adding all the completed items on that scale. The sum of the first four subscales gives the total psychological difficulties per adolescent (psychological well-being). Lower scores on these four subscales indicated better well-being or strength while the lower scores on the pro social scale indicate difficulties. The study utilized only the self completion version. SDQ has demonstrated both good reliability and validity for use in this study because it has been used before in 40 countries with similar settings to Zambia including Ghana to assess children's psychological outcomes. In Zambia for example, Menon (2008) used the SDQ-Y to determine the emotional well-being of HIV positive adolescents. The findings of these studies confirm that the instrument can be effectively used to screen for psychological well-being of adolescents at UTH centre of excellence.

The perceived social support from friends (PSS - Fr) was used to measure the perceived social support status from friends and family with regard to status disclosure and psychological well-being. This scale was developed by Weinert et al. (1987) and was designed to measure the extent to which an individual believes that his / her needs for support, information and feedback were fulfilled by friends. It is equally a standardized and reliable instrument as it has been used before to screen adolescents with HIV in several developing countries with similar settings to Zambia.

### **3.7: Inclusion and Exclusion Criteria**

#### **3.7.1: Inclusion**

- 11 to 15 years old
- HIV positive
- Has been to school or is still attending school

- Can read, speak or at least understand English

### **3.7.2: Exclusion**

- If consent is not given by the caregiver
- Critically ill adolescents who are unable to participate
- no assent from participant

## **3.8: Ethical Consideration**

### **3.8.1: Informed Consent**

The researcher obtained permission from UTH and the centre of excellence management for collection of preliminary information and data collection for the study; informed consent was obtained from the parents of the adolescents and assent from the adolescents themselves at the time of research. The purpose of the study was explained to them with an additional information sheet provided for care givers together with the consent form to help them understand what exactly was involved.

### **3.8.2: Confidentiality and Storage of Data**

The researcher assured the clients of confidentiality, and that all identifiers would be removed from the questionnaire by making it anonymous. There were no addresses or phone numbers included; the researcher also assured them that all information obtained would be kept in a safe place (locked cabinet) and electronic information would be stored in such a way that no one else other than the researcher would have access to it. Confidentiality was further maintained by avoiding talking about HIV when dealing with children with undisclosed infection status.

### **3.8.3: Voluntary Participation**

Free and voluntary participation was encouraged and participants were assured that they could withdraw from the study if they so wished at anytime and that it would not affect access to treatment and care from the centre.

If after the study, status disclosure and availability of social support were found to have a positive impact on the psychological well-being, the researcher would recommend to the staff at centre of excellence to consider disclosure to adolescents at an earliest possible time. The

researcher got approval for the study from the Research and Ethics Committee at the University of Zambia.

#### **3.8.4: Compensation**

The researcher provided drinks to all participants who were part of the research process as a way of refreshments. Issues of drinks were only mentioned to the client upon completion of the questionnaires to ensure that it did not affect participation and the outcome there after. Those who did not want to take the drinks were not forced; this was an indication that participation was free and not conditional.

#### **3.8.5: Possible risks and benefits**

There were no direct benefits to the participants but it was hoped that the results would benefit the other children by improving the services, should the result prove that disclosure of HIV infection to adolescents and social support helps improve the psychological well-being of adolescents.

#### **3.9: Data Analysis**

The researcher used the Software Statistical Package for Social Sciences (SPSS) for analysis of data. Descriptive statistics included mean and chi square; here the researcher endeavored to describe the demographic data and the participants' psychological well-being. As the data was not normally distributed, comparison between the disclosed group and undisclosed group was done using the Mann Whitney U – test and the correlation analysis to explore the relationship of status disclosure and social support on the psychological well- being was used.

## Chapter 4: Results

### 4.1: Overview

This chapter presents the findings of the study. The chapter is arranged into the following sections: the demographical data which provides the descriptive statistics of demographic data, i.e. gender, age, educational level and the caregiver the participant lived with. It also highlights the findings of the study involving the relationship between HIV status disclosure and the psychological well-being and the relationship between status disclosure and social support on the psychological well-being.

### 4.2: Demographical Data

Out of the eighty (80) questionnaires distributed, seventy (70) were completed and returned, giving a response rate of 87.5%. Of the 70 participants, (42; 60.0%) were female from which 59.5% had disclosed status and 40.5% undisclosed status. Twenty eight (28; 40.0%) were male from which 67.9% had disclosed and 32.1% undisclosed HIV status. The average age was 13.5, the minimum age 11 while age 15 was the maximum. This shows more female participation in the study than males, but even though there was more female participation in this study; Status disclosure was more amongst males than females (Table 1).

**Table 1: Status disclosure, Gender, Age, Educational level and Care giver**

|                   |                   | HIV status disclosure (N=70) |            |                    |            |        |            |
|-------------------|-------------------|------------------------------|------------|--------------------|------------|--------|------------|
|                   |                   | disclosed status             |            | undisclosed status |            | Total  |            |
|                   |                   | Number                       | Percentage | Number             | Percentage | Number | Percentage |
| Gender            | Male              | 19                           | 67.9       | 9                  | 32.1       | 28     | 100.0      |
|                   | Female            | 17                           | 40.5       | 25                 | 59.5       | 42     | 100.0      |
|                   | Total             | 36                           | 51.4       | 34                 | 48.6       | 70     | 100.0      |
| Age               | 11-12             | 2                            | 10.5       | 17                 | 89.5       | 19     | 100.0      |
|                   | 13-15             | 34                           | 66.7       | 17                 | 33.3       | 51     | 100.0      |
|                   | Total             | 36                           | 51.4       | 34                 | 48.6       | 70     | 100.0      |
| Educational level | Grade 2-4         | 0                            | .0%        | 2                  | 100.0      | 2      | 100.0      |
|                   | Grade 5-7         | 4                            | 23.5       | 13                 | 76.5       | 17     | 100.0      |
|                   | Grade 8-9         | 16                           | 61.5       | 10                 | 38.5       | 26     | 100.0      |
|                   | Grade 10-11       | 12                           | 80.0       | 3                  | 20.0       | 15     | 100.0      |
|                   | Total             | 32                           | 53.3       | 28                 | 46.7       | 60     | 100.0      |
| Care giver        | mother and father | 14                           | 63.6       | 8                  | 36.4       | 22     | 100.0      |
|                   | mother only       | 6                            | 60.0       | 4                  | 40.0       | 10     | 100.0      |
|                   | father only       | 3                            | 75.0       | 1                  | 25.0       | 4      | 100.0      |
|                   | Other relatives   | 10                           | 43.5       | 13                 | 56.5       | 23     | 100.0      |
|                   | Total             | 33                           | 55.9       | 26                 | 44.1       | 59     | 100.0      |

### **4.3: Educational level**

Table 1 shows the educational attained so far by the participants as follows: There were more respondents from the lower secondary level (grades 8 and 9) which was represented by 37.2% and the least number 2.8% from the lower primary level (grades 2 and 4) both with undisclosed status. Twenty four percent (24.3%) of the participants were in the upper primary level (grades 5, 6, and 7), whereas 21.4% were in the upper secondary school. Fourteen (14.3%) did not state their educational level. This shows that all participants had been or were still in school and could either hear, read or write in English.

### **4.4: Care giver**

The same Table 1 above was intended to ascertain the type of caregiver the participants had, It revealed that the majority of participants were in the care of other relatives i.e. aunty only (2; 2.9%), uncle only (4; 5.7%), brother and sister only (7; 10.0%). Participants who were in the care of both parents (mother and father) were (22; 37.3%), ten (10; 16.9%) had their mother only as the caregiver while (4; 6.8%) had their father only. Eleven (11; 15.7%) participants did not state their care giver. The picture depicted above shows that for some reason there were more participants in the care of relatives other than the biological parents.

### **4.5: HIV Status Disclosure and Care giver**

The Chi square test was run to find out whether the type of care giver the respondents had, had any influence on their HIV status disclosure at a significance level of 0.05. The results were: ( $\chi^2 = 2.568$ ;  $p = 0.474$ ). This shows no association between type of care giver and HIV status disclosure. Meaning that there was no indication that care givers had any influence on adolescents' status disclosure.

### **4.6: Status disclosure and sub Scale Scores Well-being**

The SDQ score instrument asks 25 items rated on a three-point likert scale. This can be classified into subscale scores i.e. the 25 items are divided into five questions which if summed up by the represented numbers, the total gives the indication of that score in behavioural and psychological terms. These five subscales include: emotional subscale score (if participant scores high on 5 items(questions) such as, “many worries or often seems worried”), conduct problems (often fights with others), hyperactivity (Restless, Over active, Cannot stay still for a long time), peer relationship problems (Rather solitary, prefers to play alone) and pro social behaviours (Considerate of other people's feelings), pro-social sub scale indicated a better well-being when the score was lower as it was scored in reverse. These

when summed up represent the overall well-being (psychological well-being), with exclusion of pro social symptoms. Table 3 shows the description of sub scale scores with regard to status disclosure.

The researcher was interested to see if there was any significant association between status disclosure and each subscale. To that effect, the Mann Whitney U test was conducted to determine if there was a significant relationship between status disclosure and each sub scale scores at significant level 0.05. The results showed varied subscale scores amongst the participants. The general picture however depicted a significant relationship at three levels as follows: Emotional score ( $Z = -1.901$ ;  $p = 0.052$ ), Hyperactivity score ( $Z = -1.897$ ;  $p = 0.053$ ), and Peer problems score ( $Z = -3.192$ ;  $p = 0.001$ ). There was no significant relation on Conduct problems score ( $Z = -1.392$ ;  $p = 0.164$ ) and Pro social score ( $Z = -1.215$ ;  $p = 0.224$ ). The results for the first three sub scale scores show that participants who had their HIV positive status disclosed to them had better well-being emotionally, on hyperactivity scale and Peer problems sub scales. There was no association however on conduct problems and pro social score with regard to status disclosure. This means that whether the participants knew their HIV positive status or not had no effect on the two later variables (Table 2).

**Table 2: Status disclosure and Subscale score and Psychological Well-being**

| Subscale scores          | HIV Status Disclosure | N(70) | Mean Rank | Z      | p value |
|--------------------------|-----------------------|-------|-----------|--------|---------|
| Emotional score          | status known          | 36    | 32.14     | -1.901 | .05*    |
|                          | status unknown        | 34    | 39.06     |        |         |
| conduct problem score    | status known          | 36    | 32.89     | -1.392 | .16     |
|                          | status unknown        | 34    | 38.26     |        |         |
| hyper activity score     | status known          | 36    | 31.35     | -1.897 | .05*    |
|                          | status unknown        | 34    | 39.90     |        |         |
| peer problems score      | status known          | 36    | 28.58     | -3.192 | .001**  |
|                          | status unknown        | 34    | 42.82     |        |         |
| pro-social score         | status known          | 36    | 33.56     | -1.215 | .22     |
|                          | status unknown        | 34    | 37.56     |        |         |
| Psychological Well-being | status known          | 36    | 29.21     | -2.846 | 0.004** |
|                          | status unknown        | 34    | 42.16     |        |         |

\*Significant at 0.05 level

\*\* Significant at 0.01 level

#### **4.7: Status disclosure and Psychological Well-being**

To establish the overall association between psychological well-being and status disclosure, the Mann Whitney U test showed the results as follows:  $Z = -2.846$ ;  $p = 0.004$ , a very strong association was observed between the two variables. This therefore confirms that participants

who had their HIV positive status disclosed to them had a better psychological well-being than those who did not know their status; the first hypothesis was thus accepted (Table 2).

#### **4.8: Status Disclosure and Caseness Well-being**

The SDQ instrument can also be classified into caseness; i.e. normal, borderline, and abnormal cases. The five subscales earlier discussed can further be rated into case symptoms being experienced by the participant at each of those levels between the disclosed and the undisclosed group; i.e. emotional symptoms, conduct problems, hyperactivity, peer relationship problems and pro social behaviours.

Table 3 below shows the description of caseness with regard to status disclosure.

**Case emotional symptoms:** Disclosed group had 44.2% normal, borderline 0% and abnormal 7.1% cases, undisclosed group was represented by 31.4% normal, 5.7% borderline and 18.6% abnormal cases.

**Case conduct symptoms:** Disclosed group 40% were normal, 7.1% borderline and 4.2% abnormal cases, undisclosed group had 31.4% normal, 5.7% borderline and 11.4% abnormal cases.

**Case hyperactivity symptoms:** Disclosed group showed 28.5% normal, 15.7% borderline and 7.1% abnormal cases, undisclosed group 18.5% were normal, 12.8% borderline and 71.1% cases were abnormal.

**Case peer problems symptoms:** Disclosed group, 12.8% normal, 30% borderline and 8.5% abnormal cases, undisclosed group indicated 4.2% normal, 18.5% borderline and 25.7% abnormal cases.

**Case pro social symptoms:** Disclosed group, 44.2% normal, 5.7% borderline and 1.4% abnormal cases, undisclosed group indicated 37.1% normal, 2.8% borderline and 8.5% abnormal cases.

Amongst the disclosed participants: almost all of them recorded more normal cases; i.e. emotional, pro social and conduct cases with more borderline cases on case peer problems. The undisclosed group on the other hand recorded more borderline and abnormal cases on hyperactivity symptoms and case conduct with little evidence of normal peer interaction.

A Chi square test was conducted to determine if there was a significant difference between the two status groups. The same table 3 above shows the results at alpha 0.05. The association between the two variables was found to be significant at 2 levels as follows: case emotional symptoms (13.9% vs. 23.5%,  $\chi^2=6.1$ ,  $p = 0.049$ ); case peer problems symptoms ( $\chi^2 = 10.8$ ,  $p = .004$ ). The results indicated that there were fewer participants in the disclosed group with extreme scores in the borderline emotional difficulties, but it was observed more abnormal cases of participants amongst the undisclosed group. There was also no significant relationship on case conduct problems symptoms; ( $\chi^2 = 3.0$ ,  $p = .218$ ), case hyper activity symptoms; ( $\chi^2 = 4.5$ ,  $p = .105$ ) and case pro social symptoms ( $\chi^2 = 4.6$ ,  $p = .099$ ). Implying that those who had their status not yet disclosed to them experienced more conduct problems with extreme cases of hyper activity problems amongst the participants. Pro social scores recorded more normal cases of participants amongst the disclosed.

**Table 3: Status Disclosure and Caseness Well-being**

| Caseness Well-being           |            | Status known<br>n=36 (%=51.4) | Status unknown<br>n=34 (%=48.5) | $\chi^2$            | p value |
|-------------------------------|------------|-------------------------------|---------------------------------|---------------------|---------|
| case emotional symptoms       | Normal     | 31 (44.2%)                    | 22 (31.4%)                      | 6.169 <sup>a</sup>  | .046*   |
|                               | Borderline | 0 (0%)                        | 4 (5.7%)                        |                     |         |
|                               | Abnormal   | 5 (7.1%)                      | 8 (11.4%)                       |                     |         |
| case conduct problem symptoms | Normal     | 28 (40%)                      | 22 (31.4%)                      | 3.049 <sup>a</sup>  | .218    |
|                               | Borderline | 5 (7.1%)                      | 4 (5.7%)                        |                     |         |
|                               | Abnormal   | 3 (4.2%)                      | 8 (11.4%)                       |                     |         |
| case hyper activity symptoms  | Normal     | 20 (28.5%)                    | 13 (18.5%)                      | 4.514 <sup>a</sup>  | .105    |
|                               | Borderline | 11 (15.7%)                    | 9 (12.8%)                       |                     |         |
|                               | Abnormal   | 5 (7.1%)                      | 12 (17.2%)                      |                     |         |
| case peer problems symptoms   | Normal     | 9 (12.8%)                     | 3 (4.2%)                        | 10.834 <sup>a</sup> | .004*   |
|                               | Borderline | 21 (30%)                      | 13 (18.5%)                      |                     |         |
|                               | Abnormal   | 6 (8.5%)                      | 18 (25.7%)                      |                     |         |
| case pro-social symptoms      | Normal     | 31 (44.2%)                    | 26 (37.1%)                      | 4.623 <sup>a</sup>  | .099    |
|                               | Borderline | 4 (5.7%)                      | 2 (2.8%)                        |                     |         |
|                               | Abnormal   | 1 (1.4%)                      | 6 (8.5%)                        |                     |         |

\*Significant at 0.05 level

#### 4.9: Status Disclosure and Perceived Social Support

Table 4 below describes the total perceived social support from friends and family for both status groups. The mean ranks of the two status groups were compared. As can be observed in the table, the undisclosed group had slightly higher mean ranks as compared to the disclosed group. The Mann Whitney U test was performed to determine if the differences in the mean ranks of the two status groups with regard to total perceived social support were significant at alpha 0.05. The results were  $Z = -0.795$ ;  $p = 0.427$ .

These results showed no significant difference between the two status groups. It can therefore be concluded that there is no difference in total perceived social support between the

disclosed and the undisclosed status groups. Meaning that social support whether available or not did not have any effect on the psychological well-being of both status groups hence rejecting the second hypothesis.

**Table 4: Perceived Social Support and Status Disclosure**

| Case items (N=70)              | Mean Rank                  |                              | Test results |        |
|--------------------------------|----------------------------|------------------------------|--------------|--------|
|                                | Disclosed status<br>(n=36) | Undisclosed Status<br>(n=34) | Z            | pvalue |
| Total Perceived Social Support | 33.75                      | 37.35                        | -0.795       | 0.427  |

**4.10: Social Support and Psychological Well-being**

Following the above findings, further analysis was carried out to determine the significant relationship between social status and the psychological well-being of participants. A correlations coefficient analysis was conducted to determine the relationship of social support on the psychological well-being. The test showed that though there was a weak negative correlation between psychological well-being and social support as evidenced by the results:  $r = -0.48$ ,  $p = 0.696$ , the relationship was not significant.

## Chapter 5: Discussion

This chapter represents a discussion of the findings of the study. I.e. The relationship between adolescents' HIV positive status disclosure and their psychological well-being. The chapter further discusses effects of disclosure and total perceived social support with regard to their psychological well-being.

### 5.1. Status Disclosure

Evidence from this study has been found to be consistent with most other researchers who have indicated an association between status disclosure and psychological well-being. For example, Kalleem (2011) indicates that adolescents who know their HIV positive status tend to have less chance of getting depression and anxiety disorders. In contrast, only a handful of studies show that there is no relationship between disclosure and lowering the general well-being. In another cross-sectional study conducted in New York City demonstrated that Youths (n = 196, mean age 12.7 years) with disclosed HIV status were significantly less anxious than those who had not been told but there were no other differences in psychological functioning. This needs to be verified though in the African settings as the caregivers' fear for negative psychosocial outcomes is a common barrier to disclose as discussed previously (Kinyanda 2009). The exact diagnosis and prognosis of the disease are less important in early discussions with young children. As children mature, they should be fully informed of the nature and consequences of their illness and encouraged to actively participate in their own medical care. Children with a variety of chronic diseases, including those with cancer, have exhibited better coping skills and fewer psychosocial problems when appropriately informed about the nature and consequences of their illness (Slavin L A et al. 1982). Another interesting dimension was observed by Kellam (2011) where he posits that disclosure should not only take into consideration the child's age, maturity, and the complexity of family dynamics, but the clinical context as well. In critically ill children, issues of dying rather than disclosure may be more appropriate to address.

It is however important to also assess the coping mechanism of the child as one thinks of talking about a more sensitive topic as death. Much as it could be important to talk about dying at one time or another, this is the area that we avoid and never want to talk about even when things are obvious and probably the dying person even wants to talk about it. People keep hoping that even when one is critically ill, they may just have a bit of hope that they may get better. Talking about death can be quite stressful and depressing for others while

others could actually be prepared for a peaceful death. One should also critically consider the stages of grief before the issue of dying is even mentioned. In other words, it is important to find out if the person is undergoing any of these stages of grief, (i.e. denial, anger, bargaining, depression or are they in acceptance). Then one can choose whether this topic is appropriate or not. But ultimately disclosure of infection status plays a major role especially if complemented with social support. In addition to other important factors such as need for treatment, care and support, further expose the need for disclosure of infection status to adolescents. Disclosure of infection status helps improve the psychological well-being and other aspects of life of adolescents as evidenced by findings of this research.

## **5.2: Status disclosure and Caregiver**

It can be noted from the findings that most adolescents lived with other relatives other than their parents. Much as parental care is primary and critical for a healthy well-being, things are not so for most of these adolescents. One possible explanation of this picture could be that most parents have either died or are not able to care for their own children due to illness or other circumstances. Ideally biological parents try to do their best to be there for their children, but it might not be possible all the time. Of course we are not ignoring the fact that some caregivers who are not biological parents may at times even be better care givers, they may be able to provide a more conducive and enabling environment than the biological parents; socially and psychologically. Economical issues may not be so key as long as basic needs are provided and the child is helped to accept whatever situation, are happy and content. However, the fact still remains that biological parents play an important role and are ideally best care givers when all is in place.

Having also noted that most adolescents with undisclosed HIV status perceived above average total social support and yet scored high on psychological symptoms could actually be explained by the picture just observed above. It can additionally be assumed that most of them are not directly in the care of their own parents they turn to show problematic symptoms at different levels. Adolescents may have attitudinal factors influencing their perception and behaviors, they may think that anything that is done to or for them is not good enough; “just because they are not my parents” syndrome. Hence problematic symptoms in some areas.

A Chi square was run to find out whether the type of care giver the respondents had, had any influence on HIV status disclosure to them. The results indicated no association between type

of care giver and HIV status disclosure. It was observed that the type of caregiver one had had no significant effect on status disclosure.

Kallerm (2009) however argues that in some instances, there are low rates of disclosure of HIV infection status to children and adolescents. This may be partly due to lack of guidelines for assisting caregivers on making the decisions about disclosure in resource limited settings. He pointed out another issue that makes disclosure most difficult for caregivers as not knowing when and how to talk about HIV to their children, caregivers lack skills on how to disclose HIV infection to their children and adolescents.

Pediatric Child Health (2006) reports findings of a cross-sectional survey involving 172 parents/caregivers of HIV-infected school-age children who had follow-up at the Pediatric Infectious Disease Clinic of the Yekatit 12 Hospital, Addis Ababa. Only 16.3% of HIV-infected schoolchildren knew their diagnosis. He further states that the child's age was the main predictor of disclosure (OR: -0.25; 95% CI: -0.35, -0.09;  $p < 0.05$ ). The main reason for nondisclosure was fear of negative emotional consequences for the child. More than half of the parent/caregivers agreed that they need to tell the children their diagnosis, but 86% reported that they needed health care providers to help them at the event.

It can be seen clearly from literature above that the need for disclosure is acknowledged by most caregivers except there are mixed feelings among them that lead to indecisiveness or low status disclosure. In fact it is possible that despite revealing no significant relationship between status disclosure and type of caregiver in this study, the caregivers may want to disclose the status to their children, but children might not know this. The major challenge still remains, "not having necessary skills on how, what and when to disclose," hence the revelation of the findings. Therefore, caregivers need to be provided with the necessary knowledge and skills on how to disclose and look after children of both statuses in knowledge.

### **5.3: Emotional Well-being**

The results on case emotional well-being were expected; they revealed a significant relationship between emotional well-being and status disclosure. These findings are consistent with Salovey et al. (2000) who asserts that, adolescents with disclosed status tend to have positive emotions and beliefs; this is likely to enhance their physical and psychological health, as expected being in a good mood will cause refreshed mind to relieve some of the

stresses. Laughing is said to have a good deal of influence on reducing or forgetting about the hassles of daily life and additionally, strong social support is necessary to help succeed in achieving these traits of overall physical well-being.

From this revelation one can assume that since their HIV positive status has been disclosed to them, adolescents have also undergone adequate counseling which has and is still helping them cope positively with the infection status; as a result they learn to be careful with life generally bearing in mind that they are vulnerable, and knowing that if depression for example sets in and are careless generally, their health in general may be affected negatively. This may lead to constant ill health which may further hinder them from enjoying their adolescent life with peers freely and in full. Hence with support of counseling and other services they are able to enjoy good emotional well-being. It is also possible that other factors like the economical issues may play a part. On the contrary Muisi et al. (2001) reports that, emotional and behavioral disorders have been described in Africa throughout adolescence; among 82 Ugandan HIV-infected adolescents, 98% were orphans, 51% reported psychological distress and 17% attempted suicide.

Ragan, (2006) on the other hand reports that, adolescents could develop some kinds of sensitive feelings, which may impact on their health if they do not get adequate social attention from others. They may become involved in an unfortunate situation that makes them feel overwhelmed or awkward. The adolescent is still developing, could easily experience some strain to their emotion if no help is immediately available. Anxiety and depression are two main psychological disorders that often can be seen among the adolescents (Ragan, 2006).

#### **5.4: Conduct Problems**

This study showed no significant relationship between status disclosure and case conduct problems as evidenced by the Man Whitney U test results. This result indicates no significant relationship in conduct problem symptoms. Meaning that, whether the respondent had their status disclosed to them or not, this had no effect on their conduct. The American Academy of Pediatrics (1999) reveal quite an interesting picture though that children who are able to discuss their illness with adults have fewer behavior problems and have improved social functioning, school performance, and adherence to medications. However, other studies have shown an increase in behavior problems and stress levels after disclosure. Developmentally appropriate and truthful explanations of the illness, validation of the child's concerns about

the disease, clarifications of misconceptions, and ongoing support are the cornerstones for promoting a positive adjustment to living with HIV infection (American Academy of Pediatrics, 1999).

Lesch (2007) asserts that, poor adjustment to a chronic illness can be a barrier to adherence and may cause conflict between the child, the caregiver, and the healthcare team. Collaboration among providers and caregivers helps to ensure that a plan is in place to provide support to the child who learns about his or her HIV status.

### **5.5: Peer Support**

Though the study shows no significance relationship between status disclosure and social support; Stice et al. (2004) asserts that beside family support, peer support also is very important factor for adolescents. Children can expect a lot from their friends. Peer support can be considered as an alternate method of getting social support if the adolescents receive inadequate attention from their parents. This social support method is not as reliable as family support because young children could easily withdraw from their own friends if they become depressed. Another problem arises in this area, when the depressed adolescents isolate themselves from friends. This would prevent those suffering adolescents from getting any form of care and social support at all (Stice et al. 2004).

### **5.6: Status Disclosure and Psychological well-being**

The results that were obtained from the Mann- Whitney U test which were testing status disclosure and psychological well-being showed a very strong significant relationship between status disclosure and psychological well-being, but at the same time indicated no significant relationship with total perceived social support. These test results are in agreement with some scholars who have done similar research and have observed similar characteristics in results. That HIV status disclosure is important for a better psychological well-being. Consistent with the above findings, a significant relationship between status disclosure and the psychological well-being was observed by Lipson (1994) who adds that children who know their HIV status have higher self-esteem than infected children who are unaware of their status. Parents who have disclosed the status to their children experience less depression than those who do not. He also says that disclosure should not only take into consideration the child's age, maturity, and the complexity of family dynamics, but the clinical context as well (Lipson, 1994). Wiener et al. (2007) also reveals that adolescents had come to terms with

their diagnosis by 6 months post-disclosure. Importantly, parents who disclosed the HIV status to their children experienced less depression and considered disclosure as having an overall positive effect on themselves and their families. Kallem (2011), attest to the fact that conditions of disclosure vary according to settings. In Abidjan, relatives were encouraged to conduct the disclosure while the medico-social staffs were more involved in the other countries (Oberdorfer, 2006). In Nigeria, most of the disclosure was conducted by family, preferably the mother, at home. In Ghana, it was also mostly conducted by caregivers, but among those who had not disclosed, one-third wanted to defer to the health workers. Similarly, in Ethiopia, 60% of 193 caregivers interviewed thought that the doctor was responsible for disclosure and in Thailand, 50% of the interviewed caregivers reported the need of assistance from health workers (Oberdorfer, 2006).

Based on the theoretical framework adopted for this study, it states that when people are faced with stressful situations such as HIV status disclosure to adolescents. They may find themselves in one of the two positions discussed depending on their coping resources adopted. From the results above, this theory is consistent with disclosure having positive outcomes on the psychological well-being of adolescents who may have adopted the attentive confrontative coping strategy. This suggestion could be possible because those with known status may have been distressed at the beginning but later adopted much more positive attitudes which enhanced a better psychological well-being in them. It is also possible that because those with disclosed status adopt a positive attitude towards their condition, they also applied the concept suggested earlier, i.e. between assimilative and accommodative coping. The former aiming at an alteration of the environment to oneself, and the latter aiming at an alteration of oneself to the environment (Brandtstädter, 1992). They may have been trying to put more effort in trying either to alter the environmental factors to oneself according to prevailing circumstances (status disclosure and psychological well-being) or they endeavored to alter themselves to suit the demands of the environment in relation to their health. This in addition to social support enhanced their psychological well-being.

### **5.7: Status Disclosure and Perceived Social Support**

Contrary to studies that have reported positive outcomes between status disclosure and social support on the psychological well-being, the findings of this study found no significant relationship between HIV status disclosure and perceived social support on the psychological well-being. Interestingly also, the result of the total perceived social support and disclosure

showed no significant relationship between status disclosure and type caregiver or social support the adolescent had on the psychological well-being. This further suggests no difference in psychological well-being whether social support is available or not. Few scholars have equally found no difference in the psychological well-being of people despite the unavailability of social support.

On the face of it, social support appears to be an important factor in the process of and post disclosure; contrary to the findings of this study. Most findings show that disclosure with social support contributes even to a better psychological well-being. For example, UNAIDS (2003) has shown that if a high level of social support becomes available to everyone, it will benefit their overall health in the long run. The importance of social support applies to everyone in our society, ranging from young childhood through older adulthood. UNAIDS, (2003) adds that providers of social support can be anyone in society who brings the positive environment and reinforcement to the individuals, especially from their family members. The higher average score it gets means the better social support the person has in their life, thus reducing their chance of developing any negative outcome in their health.

For adolescents, family support is the most important element in their lives. As part of their growth experience, adolescents usually expect a lot of things from their parents. Inadequate support from the parents will likely increase the chance of getting depression among adolescents who get into unfortunate situation with their parents. This occurs because adolescents usually become confused when they expect to get plenty of help and positive reinforcement from their parents, but it does not happen (Stice et al. 2004).

Social support is one of the most important factors in predicting the physical health and well-being of everyone, ranging from childhood through older adults. The absence of social support shows some disadvantage among the impacted individuals. In most cases, it can predict the deterioration of physical and mental health among the victims. The initial social support given is also a determining factor in successfully overcoming life stress (Ogden, 2000). This is true because even from the information from the primary source which were the medical staff and the coordinator from centre of excellence, mentioned that some adolescents suffered isolation and deterioration in physical health because they were not accepted at home due to their infection status. In fact it was even mentioned that some even moved from home because of lack of social support and started staying with fellow HIV positive adolescents in similar situations.

In this regard the findings of this study are not consistent with the literature but to some extent it is with the information on the ground. The findings instead suggested that there was no significant relationship between HIV infection status disclosure and social support with regard to psychological well-being. Santamaria et al. (1991) also adds that, the presence of social support significantly predicts the individual's ability to cope with stress. Knowing that they are valued by others is an important psychological factor in helping them to forget the negative aspects of their lives, and thinking more positively about their environment. UNAIDS (2004) states that, social support not only helps improve a person's well-being, it affects the immune system as well. Thus, it is also a major factor in preventing negative symptoms such as depression and anxiety from developing.

### **5.8: Perceived Social Support and Psychological Well-being**

Analysis which was carried out to determine the association between status disclosure and social status on the psychological well-being of participants, showed a weak negative correlation between the psychological well-being and social support. The relationship was not significant. The findings here are also not consistent with most findings which indicate a relationship between social support and psychological well-being.

For example Uchino et al. (1996) asserts that, receiving social support is very essential for adolescents to become successful with themselves and achieve a satisfactory level at school. The level of social support also has been found to be related to a lower rate of disease and early death. The familial support is a psychological enhancement to help the individual reduce their stress. These findings are somewhat weak and further studies need to be done to gather more specific information about the influence of social support on physical health.

The social support theory by Ogden et al. (2000), used for this study portrays contrary views to the findings of this study. He predicted that increased social support contributes to positive health outcomes and that there is a link between social support and health status (Ogden 2000). He further reported in one of his studies that social support influences or mediates stress-link through the stress buffering hypothesis, for example, through the presence of other people Ogden (2000). This is an ideal situation according to Ogden, but it did not seem to apply in the case of adolescents in this study. It was instead observed that it did matter whether social support was available or not as this had no effect on their psychological well-being.

One can of course assume that, probably counseling played a mediating role or as a buffer to their stress, but interaction from friends and family is much more close, longer and intense as compared to counseling. Counseling could be a form of support, but it only takes a session at a time, no matter how long the sessions take, it can never match the length of time clients spend with the family and friends, which if this family is able to provide adequate support, it is expected that it would improve their psychological well-being. Reality from this study showed different views.

### **5.9: Conclusion**

The final part of the report presents the conclusion, implications and recommendations. Adolescents being a sensitive group of youths are active generally including in the area of reproductive health. They are vulnerable and at risk of STIs including HIV through mother to child transmission of HIV (MTCT). Most of them are not even aware of their HIV positive infection status and so are denied access to care and support from relevant disciplines. The findings of this study are consistent with findings that indicate the need for disclosure of HIV infection to the adolescents at the earliest possible time to enhance the psychological well-being and accessibility to care and support including counseling services. Social support is necessary, but the findings of this study show no significance with regard to the psychological well-being. HIV status disclosure remains key in promoting psychological well-being with or without social support. It is possible for affected adolescents to use their natural coping resources to cope with their knowledge of status.

### **5.10: Implications**

Disclosure of HIV positive status is a complex, difficult and very personal matter. Disclosure entails communication about a potentially life threatening, stigmatized and transmissible illness. Choices people make about this are not only personal but vary across different age groups, in different situations and contexts, and may change with time, depending on one's experiences. Disclosure may have lifelong implications since more people are living longer, and often asymptotically, with HIV.

Disclosure can provide psychological benefits for adolescents who are also on ART; they may experience increased intimacy with friends, family members' reaffirmation of their sense of self. Many disclosed adolescents may find that it reduces anxiety about transmission; and

sex practices amongst themselves can also be delayed in the process because they understand its value and their needs as a result of status disclosure to them. Kellarm (2006) asserts that HIV-positive children who were told their HIV status in one of the recent studies were significantly less anxious compared to children who were not told. Children who knew their HIV status longer were also more likely to self-disclose to potential future sexual partners.

Disclosure can sometimes result in rejection, discrimination or violence. Disclosing to certain persons also can be more of a burden than a benefit. This study has however revealed more benefits in disclosure than burdens.

### **5.11: Limitation of the Study**

- Data collection was limited to one location; centre of excellence at UTH, this restriction in location makes generalization of the findings to the rest of the country challenging.
- Since the research work was self sponsored, finances were challenging therefore affecting the response rate of participants in the process.
- The small number of the sample size had a limiting factor of the statistical analysis and the level of generalization again comes into play.

### **5.12: Recommendations**

The study makes the following recommendations:

- 1) There is need for adolescents to have their HIV positive results disclosed to them for a better psychological well-being at the earliest convenient time.
- 2) There is need to also do a study that will determine the best age for disclosure.
- 3) There is need for continuous and child friendly counseling services throughout care irrespective of status (disclosed or undisclosed).
- 4) There is also need to determine if there are any variations in the counseling services provided for the disclosed group and the undisclosed group and their effect on adolescents.

## References

- American Academy of Pediatrics Committee on Pediatric AIDS. (1999). *Disclosure of illness status to children and adolescents with HIV infection*. *Pediatrics*. **103**.
- American Academy of Pediatrics Committee on Pediatric AIDS. *Disclosure of illness status to children and adolescents with HIV infection*. *Pediatrics*. . January;103(1):
- American Academy of Pediatrics. Confidentiality in adolescent health care. *AAP News*. April 1989:9
- American Academy of Pediatrics, Committee on Bioethics (1995) *Informed consent, parental permission, and assent in pediatric practice*. *Pediatrics*. **95**:314–317.
- Bal, S., Crombez, G., Van, Oost, P., et al. (2003). *The role of social support in well-being and coping with self-reported stressful events in adolescents*. *Child Abuse Negl.* ;**27**:1377–1395.]
- Berk, D.R., Falkovitz-Halpern. M.,S, Hill, D.W, et al. (2005); *Temporal trends in early clinical manifestations of perinatal HIV infection in a population-based cohort*. *JAMA*. **293**(18):2221–2231.
- Berman, S.,M, Hein, K., (1999) Adolescent and STDs. In: Holmes KK, editor. *Sexually Transmitted Diseases*. New York: McGraw Hill; 129–42.
- Butler, A, M.,et al .(ND). *Children and Adolescents with HIV Infection Impact of Disclosure of HIV Infection on Health-Related Quality of Life Among*
- Centers for Disease Control and Prevention(2006). *Table 14. Reported AIDS cases and annual rates (per 100,000), by area of residence and age category, cumulative through 2004—United States*”. [accessed 7 April available at
- Cohen, S., Gottlieb, B., Underwood, L. (2000). *Social relationships and health*. In: Cohen, S., Underwood, L., Gottlieb, B.,. *Measuring and Intervening in Social Support*. Oxford University Press; New York.
- Cranston, .R.I.,et al . (1984). *Intuition, critical evaluation and ethical principles: The foundation for ethical decisions in counseling psychology*. *Counseling Psychologist.*;**12** (3):43–55.
- Durkheim, E., . (1951). *Suicide*. Free. Press; New York.
- Dubler, N. (2005). *Conflict and consensus at the end of life*. *Hastings Center Special Report.*;**(35)**:S19–S25.

- Futterman, D., Chabon, B., Hoffman, N., (2000) *HIV and AIDS in adolescents. Pediatric Clinics of North America*; **47**:171-87.
- Goodman, R. and Scot, S. (1999). *Comparing the strength and difficulties questionnaire and the child behavioral Checklist: Is small Beautiful?* Journal of Abnormal Child psychology **36**: 675 – 678.
- Henry, J., Kaiser Family Foundation. (2000). *National Survey of Teens on HIV/AIDS*. Menlo Park, CA: The Foundation.
- Holt R, Court P, Vedhara K, et al. (1998). *The role of disclosure in coping with HIV infection. AIDS Care*. 1998;10:49–60.
- Kallem S, Renner L, Ghebremichael M, Paintsil E (2011) Prevalence and Pattern of Disclosure of HIV Status in HIV-Infected Children in Ghana. *AIDS Behav* 15: 1121–1127
- Klitzman, R. M. D. et al. (N.D). *Ethical Issues Concerning Disclosures of HIV Diagnoses to Perinatally Infected Children and Adolescents* Columbia University, New York,.
- Lesch A, Swartz L, Kagee A, et al. Paediatric HIV/AIDS disclosure: Towards a developmental and process-oriented approach, *AIDS Care* 2007;19:811-816.
- Lipson M, (1994) *Disclosure of diagnosis to children with human immunodeficiency virus or acquired immunodeficiency syndrome. J DevBehavPediatr. 15:S61–S65.*
- Menon A, Glazebrook C, Campaign, Ngoma M. (2007) Mental and Disclosure of HIV status in Zambian Adolescents with HIV infection: Implications for Peer – Support Programmes. *Acquir Immune Defic Syndr*
- Michaels, D., and Levine, J.C. (1992) *Estimates of the number of motherless youth orphaned by AIDS in the United States. JAMA.*: **286(24)**:3456-3461.
- Miller *Encyclopedia and dictionary of medicine, nursing and Allied Health*, seventh edition .(2003). Saunders an imprint of Elsevier inc.
- Musisi S, Kinyanda E (2009) Emotional and behavioural disorders in HIV seropositive adolescents in urban Uganda. *East Afr Med J* 86: 16–24.
- Naswa, S. & Marfatia, Y.S. (2010). *Adolescent HIV/AIDS: Issues and challenges*. Indian J Sex Transm downloaded from
- Nehring W, Lashley F, Malm K. (2000). *Disclosing the diagnosis of pediatric HIV infection: Mothers' views. J SocPediatr Nurse*
- Oberdorfer P, Puthanakit T, Louthrenoo O, Charmsil C, Sirisanthana V, et al. (2006) Disclosure of HIV/AIDS diagnosis to HIV-infected children in Thailand. *J Paediatr Child Health* 42: 283–288.

- Ogden, J. (2000). *Health Psychology*. Buckingham; Open University Press
- Patterson D. and Christine .L. C (2004) *Promoting successful transition from pediatric to adult-oriented health care. EP Mag. , pp. 56-60.*
- Pettifor, . A. et al . (2005). *Young people's sexual health in South Africa: HIV prevalence and sexual behaviors from a nationally representative household survey.*
- Riekert KA, Wiener L, and Battles HB (1999). *Prediction of psychological distress in school-age children with HIV. Children's Health Care. .*
- Rotheram-Borus MJ, Murphy DA, Miller S, et al. (1997). An intervention for adolescents whose parents are living with AIDS. *Clinical Child Psychological Psychiatry.*
- SANAC .(2010). [The national HIV counseling and testing campaign'](#)
- Santamaria . E .K. et al . (1991) . *Psychosocial implications of HIV serostatus disclosure to youth with perinatally acquired HIV.* New York ;psychiatric institute press.
- Sarason, I.G, Levine, H.M, Basham, R.B. (1983). *Assessing social support: The Social Support Questionnaire. J Pers Social Psychological.*
- Slavin LA, O'Malley JE, Koocher GP, Foster DJ. (1982). *Communication of the cancer diagnosis to pediatric patients: impact in long term adjustment. Am J Psychiatry. 139:179–183*
- Statistics South Africa (2008, October), ['Mortality and causes of death in South Africa, 2006: Findings from death notification'](#)
- Symister, P., Friend, R., .( 2003). *The influence of social support and problematic support on optimism and depression in chronic illness: A prospective study evaluating self-esteem as a mediator.* Health Psychology. ;**22**:123–129.
- Tolsdorf C. (1976). *Social networks, support and coping: An exploratory study.* Fam Process. ;**15**: 407–417.
- Turner, B.J., McKee, L. Pantell, R.H, et al.(1996) *Health care of children and adults with acquired immunodeficiency syndrome.* Arch Pediatr Adolesc Med. **150**: 615–622.
- UNICEF, UNAIDS, UNESCO, UNFPA, ILO, WHO, The World Bank. (2011). *Opportunity in crisis: Preventing HIV from early adolescence to young adulthood*
- UNAIDS (2011) Global HIV response. Available from: Kinyanda E (2009)
- UNAIDS (2010) 'UNAIDS report on the global AIDS epidemic'
- UNAIDS (2008), ['2008 Report on the Global AIDS epidemic'](#)

UNAIDS (2004) *Report on the Global AIDS Epidemic*. Down loaded from <http://www.unaids.org/bangkok2004/report.html>.

UNAIDS (2000). *Opening up the HIV/AIDS epidemic: guidance on encouraging beneficial disclosure, ethical partner counseling & appropriate use of HIV case-reporting*. Geneva, Joint United Nations Down loaded from (<http://www.ijstd.org/article.asp>)

UNAIDS ( 2004) *Report on the Global AIDS Epidemic*. Down loaded from: <http://www.unaids.org/bangkok2004/report.html>.

UNGASS (2010, 31st March) '[South Africa UNGASS Country Progress Report](#)'

V. H. W.H, Paradise LV. (1979). *Ethics in counseling and psychotherapy: Perspectives in issues and decision-making*.

White House Office of National AIDS Policy. (2002). *Youth and HIV/AIDS 2000: A New American Agenda*. Washington, DC:

Wiener, L., Mellins, C.A, Marhefka S, Battles, H.B. (2007). *Disclosure of an HIV diagnosis to children: history, current research, and future directions*. *Journal of Developmental Behavior Pediatrics*: **28**. ( 2 ): 155 – 166.

World Health Organization. (2004). *Global report on HIV and AIDS*.



## Appendices

### Appendix I

#### Questionnaire for Participants

HellenNg'ongaChipeta is a student at the University of Zambia undertaking her research in partial fulfillment of the Masters Degree in Child and Adolescent Psychology.

You are kindly requested to fill in this Questionnaire as honestly as possible. This information will be confidential and purely for academic purpose and will not use it in any way to discredit your name.

#### DEMOGRAPHIC DATA

1. Gender

a). Male ..... Female .....

2). Age .....

3). Area of residence .....

4).What grade are you doing .....

5). Who do you live with?.....

a). Mother and Father

b). Mother only

c). Father only

d). Aunt and Uncle

e). Aunt only

f). Uncle only

g). Brother

h). Sister

i). Other (please specify)

6). What is your religion?.....

7). Occupation and work activities of caregiver .....

8).What activities do you do home?

a). Before you come to school .....

- b). After school .....
- 9). How often do you do these activities .....
- 10). How long are these activities .....

**Appendix II**

**Strength and difficulty questionnaire**

For each item please tick the box for not true, somewhat true, or certainly true. It would help us if you answered all items as best you can even if you are not absolutely certain. Please give your answers on the basis of how things have been for you over the last six months.

Your number.....

Male / Female

Date of birth.....

|     |  | Not<br>True | somewhat<br>True | certainly<br>True |
|-----|--|-------------|------------------|-------------------|
| 1.  | I try to be nice to other people. I care about their feelings  |             |                  |                   |
| 2.  | I am restless, I cannot stay still for long                    |             |                  |                   |
| 3.  | I get a lot of headaches, stomach – aches or sickness          |             |                  |                   |
| 4.  | I usually share with others, e.g. CDs, games, food             |             |                  |                   |
| 5.  | I get very angry and usually lose my temper                    |             |                  |                   |
| 6.  | I would rather be alone than being with friends of my age      |             |                  |                   |
| 7.  | I usually do as I am told                                      |             |                  |                   |
| 8.  | I worry a lot  |             |                  |                   |
| 9.  | I am helpful if someone is hurt, upset or feeling ill.         |             |                  |                   |
| 10. | I am constantly fidgeting or squirming                         |             |                  |                   |
| 11. | I have one good friend or more                                 |             |                  |                   |
| 12. | I fight a lot. I can make other people do what I want          |             |                  |                   |
| 13. | I am often unhappy, depressed or tearful                       |             |                  |                   |
| 14. | Other people my age generally like me                          |             |                  |                   |
| 15. | I am easily distracted, I find it difficult to concentrate     |             |                  |                   |
| 16. | I am nervous in new situations, I easily lose confidence       |             |                  |                   |
| 17. | I am kind to younger children                                  |             |                  |                   |
| 18. | I am often accused of cheating                                 |             |                  |                   |
| 19. | Other children or young people pick on me or bully me          |             |                  |                   |
| 20. | I often offer to help others ( parents, Teachers, Children )   |             |                  |                   |
| 21. | I think before I do things                                     |             |                  |                   |
| 22. | I take things that are not mine from home, school or elsewhere |             |                  |                   |
| 23. | I get along better with adults than with people of my age      |             |                  |                   |
| 24. | I have many fears, I am easily scared                          |             |                  |                   |
| 25. | I finish the work I am doing. My attention is good             |             |                  |                   |

Your signature.....

Today's date.....

Thank you very much for your help Robert Goodman, 2000

## Appendix III

### Social Support Questionnaire

#### Social Support Scale

Directions:

The statements which follow refer to feelings and experience which occur to most people at one item or another in their relationships with friends and family. For each statement there are three possible answers: Yes, No, Don't Know. Please make a cross on the answer you choose for each item. Use the simple rating scale below –

Yes = Y          No = N          Don't Know = D

Friends social support scale (Pss – fr)

|     |  |   |   |   |
|-----|--|---|---|---|
| 1.  | My friends give me the moral support I need  | Y | N | D |
| 2.  | Most other people are closer to their friends  | Y | N | D |
| 3.  | My friends enjoy hearing about what I think  | Y | N | D |
| 4.  | Certain friends come to me when they have problems or need advice  | Y | N | D |
| 5.  | I rely on my friends for emotional support   | Y | N | D |
| 6.  | If I felt one or more of my friends were upset with me, I'd just keep it to myself                       | Y | N | D |
| 7.  | I don't feel part of my friend's group.  | Y | N | D |
| 8.  | There is a friend I could go to if I were just feeling down, without feeling funny about it later        | Y | N | D |
| 9.  | My friends and I are very open about what we think about things  | Y | N | D |
| 10. | My friends are sensitive to my personal needs  | Y | N | D |
| 11. | My friends comes to me for emotional support   | Y | N | D |
| 12. | My friends are good at helping me solve problems   | Y | N | D |
| 13. | I have a deep sharing relationship with a number of friends  | Y | N | D |
| 14. | My friends get good ideas about how to do or make things from me   | Y | N | D |
| 15. | When I confide in friends, it makes me feel uncomfortable  | Y | N | D |
| 16. | My friends like my company.  | Y | N | D |
| 17. | I think that my friends feel that I'm good at helping them solve problems                                | Y | N | D |
| 18. | I don't have a relationship with a friend that is as intimate as other peoples relationship with friends | Y | N | D |
| 19. | I've recently gotten a good idea about how to do something from a friend                                 | Y | N | D |
| 20. | I wish my friends were much different  | Y | N | D |

## Appendix IV

UNZAREC FORM

1a



### THE UNIVERSITY OF ZAMBIA

#### DIRECTORATE OF RESEARCH AND GRADUATE STUDIES

Telephone: 290258/

P O Box 32379

Fax: +260-1-290258/253937

Lusaka, Zambia

E-mail drgs@unza.zm

---

#### HUMANITIES AND SOCIAL SCIENCES RESEARCH ETHICS COMMITTEE

#### PARTICIPANT INFORMATION SHEET

##### **PURPOSE OF THE STUDY:**

To find out if knowledge of health condition can have an effect on the psychological well-being in young people in the age group of 11 to 15 year olds.

##### **DESCRIPTION OF THE STUDY AND YOUR INVOLVEMENT:.**

The study will look at the psychological well-being of children aged between 11 to 15 years old and are receiving care at UTH centre of excellence. You have been chosen because this age group has special needs that need special care and social support as this helps improve the state of the mind. You will be asked to take part in the study by filling in the questionnaire containing information provided for you. You will not be required to put down your name but we will ask for some information about your friends, family and general health. It will about 30 minutes to fill in the questionnaire.

##### **CONFIDENTIALITY:**

The information is confidential. The research will not identify you individually and no one other than the researcher will know what you have said. You will not be writing your name on the questionnaire and your name will not be recorded by the researcher. The researcher will make sure that all information given is not known by any other person, all elements that can identify with you will not be included on the questionnaire, i.e. no addresses or phone numbers, the researcher will identify you by numbers assigned to you and no one else will know these numbers. The information you will give will also be kept safely were no one else will get to see or hear the answers you have given other than the researcher.

**VOLUNTARY PARTICIPATION AND WITHDRAWAL:**

You are not going to be forced to participate in the study; it is up to you whether you take part. If you do not take part it will not affect the medical care or any other benefit. If you do take part you can withdraw from the study at any time, again with no penalty and without having to give a reason.

**RISKS AND BENEFITS:**

There is no direct benefit that you may get from this study, but by being part of this study, you will help other parents and staff at the centre to know how to help other children of the same age. We hope the results from the study will help programs at the centre to improve the quality of life of adolescents with chronic conditions that are in need of care and support and to meet the social and medical needs of other adolescents. The researcher will give you and your parent / caregiver transport refund of K100, 000 for both of you and drinks will be provided for you. Those that might be stressed will be referred for management by the relevant staff.

**WHO CAN I ASK IF I HAVE ANY QUESTIONS?**

If you would like to ask any questions about the research then you can contact

**1). Principal Investigator**

Hellen Ng'onga Chipeta

University of Zambia University of Zambia

Psychology Department

Cell # 0979 464096.....0977 – 846116

**2) Supervisor**

Dr. J. Anitha Menon

Psychology Department

3). Research Ethics Office, Ridgeway campus,

University of Zambia,

Tel: 250753.

Thank you for reading this.

# INFORMED CONSENT

The participant should complete the whole of this sheet himself/herself

**Tick what is necessary**

- Have you read & understood the information sheet? YES/NO
- Have you had opportunity to ask questions & discuss the study? YES/NO
- Have all the questions been answered satisfactorily? YES/NO
- Have you received enough information about the study? YES/NO
- Who have you spoken to Dr/Mrs/Ms .....
- Do you understand that you are free to withdraw from the study
- at any time YES/NO
- without having to give a reason YES/NO
- without affecting your future medical care YES/NO
- Do you agree to take part in the study? YES/NO

If you agree to take part in the study, please sign below:

Signature.....

Name (In block capitals).....

Date.....

(participant)

I have explained the study to the above participant and he/she has indicated his/her willingness to participate.

Signature.....

Name (In block capitals).....

Date.....

(researcher)



**THE UNIVERSITY OF ZAMBIA**

**DIRECTORATE OF RESEARCH AND GRADUATE STUDIES**

Telephone: 290258/

P O Box 32379

Fax: +260-1-290258/253937

Lusaka, Zambia

E-mail drgs@unza.zm

**HUMANITIES AND SOCIAL SCIENCES RESEARCH ETHICS COMMITTEE**

**PARENTS/ CAREGIVER INFORMATION SHEET**

**TITLE OF RESEARCH:**

Impact of HIV Status Disclosure on the Psychological Well-being of HIV Positive Adolescents.

**PURPOSE OF THE STUDY:**

To find out if knowledge of health condition can have an effect on the psychological well-being.

**DESCRIPTION OF THE STUDY AND YOUR CHILD'S INVOLVEMENT:.**

The study will look at the psychological well-being of children between the age of 11 to 15 years old. These have been chosen because this age group has special needs that require special care and social support as this helps improve the state of the mind. Children will be asked to take part in the study by filling in the questionnaire provided for them. They will be given information about the study but without any mention of HIV and AIDS unless you feel it is okay for the researcher to mention this. They will not be required to put down their name but will find questions about their relationships with their friends and family and about how they cope generally with life and health. This will only take about 30 minutes.

**CONFIDENTIALITY:**

The researcher will make sure all information is confidential. The research will not identify with your children individually and no one other than the researcher will know what they have said. They will not be writing their name on the questionnaire and their names will not be recorded by the researcher. The researcher will make sure that all information given is not known by any other person, all elements that can identify with your child will not be included on the questionnaire, i.e. no addresses or phone numbers, the researcher will identify your children by numbers assigned to them and no one else will know these numbers. The information they will give will also be kept safely were no one else will get to see or hear the answers they will have given other than the researcher.

**VOLUNTARY PARTICIPATION AND WITHDRAWAL:**

The child will not be forced to participate in the study. It is up to you and him/ her whether they can take part. If they do not take part it will not affect the medical care or any other benefit. If they do take part they can withdraw from the study at any time they feel like, again with no effect on the services they receive at the centre, no penalty and without having to give a reason.

**RISKS AND BENEFITS:**

There is no direct benefit that your children may get from this study, but by being part of this study, they will help other parents and staff at the centre to know how to help other children of the same age. We hope the results from the study will help programs at the centre to improve the quality of life of adolescents with chronic conditions that are in need of care and support and to meet the social and medical needs of other adolescents. The researcher will give you and your child transport refund of KR10 each, drinks will be provided for you as well. Those that might be stressed will be referred for management by the relevant staff.

**WHO CAN I ASK IF I HAVE ANY QUESTIONS?**

If you would like to ask any questions about the research then you can contact

**1). Principal Investigator**

Hellen Ng'onga Chipeta  
University of Zambia  
Psychology Department

**Supervisor**

Dr. J. Anitha Menon

Psychology Department

Cell # 0979 464096.....0977 - 8461 16

**3). Research Ethics Office, Ridgeway campus,**

University of Zambia,

Tel: 250753.

Thank you for reading this.

# INFORMED CONSENT

The parent /caregiver should complete the whole of this sheet.

**Tick what is necessary**

- Have you read & understood the information sheet? YES/NO
- Have you had opportunity to ask questions & discuss the study? YES/NO
- Have all the questions been answered satisfactorily? YES/NO
- Have you received enough information about the study? YES/NO
- Who have you spoken to Dr/Mrs/Ms .....
- Do you understand that your child is free to withdraw from the study
- at any time YES/NO
- without having to give a reason YES/NO
- without affecting his / her future medical care YES/NO
- Do you allow your child to take part in the study? YES/NO

If you agree to allow your child take part in the study, please sign below:

Signature.....

Name (In block capitals).....

Date.....

(Parent)

I have explained the study to the above parent and he/she has indicated his/her willingness to allow their child to participate.

Signature.....

Name (In block capitals).....

Date.....

(Researcher)