Disclosure of HIV status by caregivers of HIV infected children at the University Teaching Hospital Pediatric ART Clinic.

BY

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LIST OF ABBREVIATIONS

AIDS - Acquired Immune Deficiency Syndrome
ARV - Anti retroviral
CSO - Central Statistical Office
FAO - Food and Agriculture Organization
HIV - Human Immunodeficiency Virus
HMIS - Health Management Information System
IEC - Information Education Communication.
MOH - Ministry of Health
NAC - National AIDS Council
NGOs - Non Governmental Organization
PMTCT - Prevention of Mother to Child Transmission
STIs - Sexually Transmitted Infections
UNAIDS - United Nations Programme on HIV/AIDS
WHO - World Health Organization
ZDHS - Zambia Demographic Health Survey
DECLARATION

I hereby declare that the work presented in this study for the degree of Bachelor of Science in Nursing has not been presented either wholly or in part for any other degree and is not being currently submitted for any other degree.

SIGNED..........................DATE..............08/06/11
(CANDIDATE)

APPROVED BY..........................DATE..............08/06/11
(SUPERVISING LECTURER)
STATEMENT

I Inambao Nalishebo hereby certify that this study is entirely the result of my own independent investigations. The various sources to which I am greatly indebted are clearly acknowledged in the text and in the references.

Signed: .................................................. Date: 08/06/11

(CANDIDATE)
DEDICATION

This study is dedicated to all HIV infected children who are innocently enduring the consequences of HIV infection without knowing what their condition is.

To my late daddy Mr. Maxwell Inambao who I would have loved to live to celebrate my achievement in the Nursing profession as he never thought I had such a calling.

To my mother Mrs. Elizabeth Mwangala Kabechani Inambao for her daily prayers and for putting up with my inability to visit her during her illness.

To my big brother Mr. M. Kamwi for laying down a foundation for my career.
ABSTRACT

HIV status disclosure to infected children by their caregivers is an important step in helping the children to cope with this life long condition. No matter how long caregivers want to conceal this information from the infected children, the children will one day come to learn about their condition either directly or indirectly.

The study sought to determine caregivers’ knowledge of HIV infection, knowledge of HIV status disclosure, their attitude towards HIV status disclosure and level of HIV status disclosure among caregivers of HIV infected children attending ART clinic at the University Teaching Hospital.

A descriptive cross sectional study design was used and an interview schedule was used to collect data from 50 caregivers. Data were analyzed using the Statistical Package for Social Sciences (SPSS) version 16. Findings revealed that all, 50(100%) respondents were knowledgeable about HIV infection. Majority of the respondents 38 (76%) were knowledgeable about HIV status disclosure. All the 50 (100%) respondents had positive attitude towards HIV status disclosure. Slightly over half of the respondents 27 (54%) had disclosed HIV status to their infected children, out of which 11 (22%) respondents only disclosed HIV status partially. However, the knowledge level and attitude of the respondents were not related to HIV status disclosure as disclosure was only 54%.

The major recommendations of the study are that there is need to develop disclosure guidelines for both health care providers and caregivers to help improve both the quantity and quality of HIV status disclosure to infected children. Counseling is an important aspect in nursing practice, therefore, all nursing staff require intensive training. Additionally, further research programmes on HIV status disclosure in paediatric HIV programmes need to be enhanced.
CHAPTER 1

1.0 INTRODUCTION

1.1 BACKGROUND INFORMATION

The epidemiology of Human Immune-deficiency (HIV)/ Acquired Immune Deficient Syndrome (AIDS) globally remains overwhelming and the leading cause of death with sub-Saharan Africa being the most affected. A Global summary report of HIV/AIDS epidemic as at 2007 showed a total number of 32.2 million people living with HIV of these 30.8 million were male, 15.4 million were female and 2.5 million were children under 15 years of age. The total number of people newly infected with HIV in 2007 was estimated at 2.5 million with adults being 2.1 million and children 420,000 (MOH, 2008). UNAIDS/WHO (2007) reported a total of 2.1 million deaths out of which adults were 1.7 million with deaths of children under 15 years being 330,000. According to UNAIDS (2007), the most hit country in the sub Sahara region is South Africa which is currently experiencing one of the most severe AIDS epidemics in the world. At the end of 2007, there were approximately 5.7 million people living with HIV in South Africa and almost 1,000 AIDS deaths occurring every day. Other low income countries such as Zambia, Botswana, Zimbabwe and Malawi have not been spared by this epidemic.

The first cases of AIDS were reported in Zambia in 1984. HIV and AIDS has since then become a fast-growing problem in the nation. In 2006, 98,000 Zambians had died because of AIDS, and there were approximately 710,000 children under the age of 15 in Zambia who had been orphaned by the death of one or both parents due to AIDS, (Ministry of Health, 2008). Overall HIV prevalence among pregnant women aged 15–39 years attending antenatal clinics in Zambia has remained at 19%-20% over the last years (CSO, 2007). According to the National Aids Council (NAC, 2009), the spectrum estimate for the adult (15-49 years) HIV prevalence in 2009 was 14.6 % with Lusaka province reporting a high HIV prevalence rate of 20% (NAC, 2009) among the reproductive age group thereby posing a higher risk of HIV transmission to infants.
Women constitute more than half of the Zambian population (CSO, 2007) and showing more women (18%) infected with HIV than men (13%). High infection rate among women may be attributed to traditional practices such as dry sex, polygamy as well as biological factors such as large surface area that disadvantage them. One infected man has the ability to infect more women because of the tendency to have multiple sexual partners besides some men in other sectors of the country being polygamous. Women are also believed to be engaging in sexual relations much earlier than men subjecting them to earlier contraction of HIV infections (CSO, 2007).

Women infected with the HIV virus are likely to transmit the infection to their babies. Approximately 39.5% of babies born from HIV positive mothers get infected with the virus, (NAC HIV/AIDS/STI/TB Intervention Strategic Plan 2002-2005). Mother to Child Transmission (MTCT) of HIV can occur during pregnancy (5-10%), delivery (10-20%), and breastfeeding (0-20%). More than 90% of HIV infections in children are the result of mother to child transmission of HIV. About 30-40% of the children born to HIV infected mothers will get infected with HIV if no interventions are instituted (MOH, 2008).

In order to curb Mother to Child Transmission of HIV (MTCT), the Prevention of Mother to Child Transmission of HIV (PMTCT) programme was initiated to offer primary prevention of paediatric HIV infection. The PMTCT activities include; (a) prevention of unintended pregnancies; (b) prevention of mother to child transmission through anti retroviral drug prophylaxis administration of Zidovudine from the 28th week of gestation and a single dose of Niverapine at the onset of labour (c) provision of care and (d) follow up psychosocial support (CSO, 2007).

New technology in HIV testing has made diagnosis of HIV infection in children easier. In 2008, the number of infants born to HIV-infected women who were tested for HIV within 12 months was 20,774 representing 32 per cent of the estimated 65,072 HIV infected pregnant women giving birth. The number of infants tested for HIV increased to 22,114 for the year 2009. This indicated a rise to 30 per cent based on an estimated 74,191 HIV infected pregnant women (MOH, 2009). Nine out of ten children infected with HIV are infected through their mother either during pregnancy, labour and delivery or breastfeeding (UNAIDS 2008).
However, not all the babies infected with HIV get the virus from their mothers. The other modes of transmission include blood transfusion with infected blood, defilement and sexual abuse. In Africa, Zambia inclusive, there is a wrong perception that having unprotected sex with a virgin, who are mostly children, would cure (commonly known as virgin cure) one from HIV/AIDS. This has contributed to an increase in sexual abuse. Hardly a day passes without a sexual abuse or defilement case being reported. Sexual abuse and defilement are posing serious threats since the abusers may not only transmit HIV but may also infect the virgins with sexually transmitted infections (STIs) that greatly facilitate the transmission of HIV. Efforts have been made to try and correct the “virgin cure” myth as shown in the picture below (AIDS Care, 2008).

**Figure 1.1**

*A road sign in Zambia confronting the “virgin AIDS cure myth”*

![Road sign](AIDS Care, 2008)

Since 1984 when HIV was first described in children, the epidemiology of pediatric AIDS has evolved significantly. In the US, as well as in other high resource settings, the introduction of widespread HIV counseling, testing, and treatment with Antiretroviral Treatment (ART) during pregnancy has led to a dramatic drop in the rate of perinatal transmission, as well as significantly improved morbidity and mortality. Many HIV-infected children who were not expected to survive childhood are entering adolescence and young adulthood. The prospect of a longer lifespan brings new challenges related to the impact of HIV infection on physical and
mental health, as well as on normative developmental processes such as growth, peer relationships, puberty, and sexuality (Wiener et al, 2007).

With increased survival, one of the greatest psychosocial challenges that caregivers of HIV-infected children face is disclosure of HIV serostatus to their infected children regardless of the mode of transmission. Disclosure is a process or act of making known the information of HIV status to a child who is HIV infected (MOH, 2008). Disclosure of HIV status to HIV infected children is done through counseling of either the child himself/herself or counseling of the parents/care givers to facilitate the dialogue and transmission of information.

In general, disclosure is geared to a child's level of cognitive development and psychosocial maturity. For most illnesses, young children receive simple explanations about the nature of their illness and what their responsibilities are in caring for themselves. 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 HIV, have exhibited better coping skills and fewer psychosocial problems when appropriately informed about the nature and consequences of their illness (American Academy of Pediatrics, 2009). Disclosure does 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 (American Academy of Pediatrics, 2009).

However, Children may inadvertently learn of the nature of their illness in a manner that is not supportive. If children find out their infection status from someone other than a parent, they may feel unable to confide in their caregiver or feel a need to conceal that they are aware of their diagnosis (American Academy of Pediatrics, 2009). Children who accidentally learn of their diagnosis may have a more difficult time adjusting to it. Some studies have shown 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 (New York State Department of Health AIDS Institute, 2009).
In Zambia, caregivers are being encouraged to disclose HIV serostatus to their HIV infected children. In addition, child counseling services have been introduced to enhance child counseling. Counseling of children is offered by specially trained personnel who have undergone child counseling training for a period of at least 6 weeks. Child counseling courses are offered by various organizations like Kara counseling, Chainama Hills College and University Teaching Hospital (UTH) Psychosocial Counseling unit. Child counseling courses are undertaken by both health providers and non health personnel. The course covers topics on child development, communication and psychological care. Counseling of children is dependant on the prevailing issues of concern to the child (MOH, 2006).

Pediatricians and nursing care staff serve as advocates for children in their care to their caregivers. This is achieved through information, education and communication (IEC) that is offered to caregivers of HIV infected children. For HIV infected adolescents, the health care professionals have an ethical obligation to provide counseling to respond to their needs and to ensure that they have an opportunity for examinations and counseling apart from their caregivers but young children require caregivers to play a major role in disclosure. Physicians and HIV/AIDS counselors provide full disclosure of HIV status to their adolescent patients and efforts are being made by health providers to encourage caregivers to disclose HIV status to their infected children.

HIV is a life long disease, as such, it is necessary that the affected children understand their health status for better participation. The Zambian Government has formulated a policy of providing free ART to adults and children alike (Kumar, 2005) and therefore, adherence to treatment in children is a sole responsibility of caregivers.

In the Ethical Handbook on HIV in Zambia, it states that in counseling for HIV infections in children, counselors should encourage care givers to share results with the children (Bush et al, 2006). This is more ideal, because caregivers are the closest individuals who interact and communicate with these children freely, thus facilitating understanding of their health status and adherence to treatment. Disclosure therefore, facilitates a smooth transition in the
grooming of the children to take over responsibility over their health matters as they grow into independent individuals.

Nondisclosure of HIV status to an infected child can result in a variety of problems, including anxiety, depression, phobias, and exclusion from peer support groups and medical camps (Lester et al, 2010). In Zambia, no study has been conducted on disclosure of HIV status to HIV infected children thereby reflecting no statistics on how much disclosure has been done.

1.2 STATEMENT OF THE PROBLEM

HIV in Zambia remains a burden to the nation with a prevalence rate of 14%. (UNAIDS/WHO, 2008). Zambia PMTCT HIV testing sites reflect reductions in HIV prevalence: 2005 recorded a prevalence of 20.3%, 2006 – 18.7% and a further reduction to 17.9% in 2008 (WHO, 09). In 2009, a total of 532, 484 women were tested for HIV during pregnancy, labor, delivery and post partum period (< 72 hours) and 74, 191 mothers (14%) were HIV positive (NAC, 2010). The high prevalence of HIV in pregnant mothers poses a higher risk of transmission to infants if preventive measures are not intensified early.

From January 2008 to June 2010, 35, 533 children were admitted to U.T.H pediatric department. Among these, 28,089 (79.1%) were children with unknown HIV status. 26,686 (95%) of these children received counseling and 99.8% were tested. Results showed that 5,698 (21.4%) of those were HIV positive. Children from 0-14 years actively receiving ARV treatment at U.T.H from 2008 were 1, 889, in 2009 they were 1,834 and 1, 737 in 2010 (UTH, HMIS, 2010).

Estimated deaths in children due to HIV have been decreasing from 11,404 in 2006 to 8,144 in 2008 and further decreased to 7,277 in 2009 (NAC Strategic Plan, 2006-2010). At UTH, mortality rates in children infected with HIV have showed a minimal decrease from 139 deaths in 2007 to 134 in 2008 followed by a remarkable decrease to 36 deaths in 2009 (UTH HMIS, 2010). However, the decrease in mortality implies that the burden and suffering of
children from HIV is increasing as they survive and grow into adulthood. Therefore, HIV status disclosure to these children is important because literature show that children who discuss HIV status with their caregivers have few behavioral problems: improved social functioning and school performance including adherence to medication (Oberdorfer, 2006). Adherence to treatment will therefore, reduce consequences of HIV opportunistic infections (OIs) which are common in children.

Pneumocystic Carinii Pneumonia (PCP) a common opportunistic infection accounts for 57% of AIDS defining conditions. The introduction of cotrimoxazole prophylaxis in children has contributed to the decline in the number of PCP cases at UTH reflecting 82 cases (2.8%) in 2006, 68 cases (1.6%) in 2007, 24 cases (0.7%) in 2008 and 11 cases (0.4%) in 2009 (UTH HMIS, 2009). Cryptosporidiosis is another opportunistic infection affecting the gastrointestinal tract characterized by compromised immunity. There has been a steady increase of cryptosporidiosis cases at the UTH from 195 cases (6.7%) in 2006, 365 cases (8.7%) in 2007, 278 cases (7.7%) in 2008 to 309 (9.9%) in 2009 (UTH HMIS, 2009). Mycobacterium tuberculosis has shown some fluctuations at the UTH from 109 cases (3.8%) in 2006, 177 cases (4.2%) in 2007, 36 cases (1.0%) in 2008 to 67 cases (2.1%) in 2009 (UTH HMIS, 2009). These infections can be drastically improved with adherence to ART. As stated earlier, children are more likely to adhere to ART regimen when they know their HIV serostatus.

There are few skilled counseling personnel with U.T.H pediatric department having only 4 child and 31 psychosocial counselors (Pediatric Nursing Officer, 2010). The low numbers of available child and psychosocial counselors in the Pediatrics department does not suffice to adequately prepare caregivers to address issues of HIV status disclosure to the high numbers of HIV infected children as reflected. The standard ratio of child counseling is 3 sessions per day (UTH Child sexual abuse center coordinator, 2010). The number of child counselors is still far below the ideal.

Non disclosure of HIV status to children fosters secrecy, and prevents the individual from assuming responsibility for their own health care and well-being. Non disclosure also places adolescents who are sexually active at risk for unknowingly exposing others to HIV (Lewis,
2007). In view of the above, the researcher is compelled to undertake a study to establish HIV status disclosure among caregivers of HIV infected children so that the findings will help the policy makers come up with policies or programs that will encourage caregivers to be disclosing HIV status to infected children.

1.3 ANALYSIS OF INFLUENCING FACTORS

1.3.1 Factors influencing HIV status disclosure by caregivers of HIV infected children.

Caregivers of HIV infected children are partners in the promotion of health in children. Various factors influence the process of HIV status disclosure to infected children.

1.3.1.1 socio-economic and cultural factors

The socio-economic and cultural factors include: age of the child, religious beliefs, cultural beliefs, stigma, anticipated child reaction etc. These factors may have impact on the caregivers’ ability to disclose HIV status to the infected children.

1.3.1.2 Socio- economic status

Caregivers with limited resources tend to have low self esteem to handle issues of disclosure as compared to individuals in medium or high socio-economic class. People with low socio-economic status may feel defeated to have chronic illnesses like HIV which are so demanding in terms of transportation expenses to access health services, nutrition etc. Such individuals would therefore require a lot of encouragement to undertake issues of disclosure because they tend to look up to health providers to do everything for them. Individuals in medium and high socio-economic class also stand an advantage of access to more information on HIV/AIDS through the media like news papers, radio, television and internet facilities which may empower them with adequate knowledge to undertake disclosure.
1.3.1.3 Age of the child

The age of the child may be a limiting factor. The caregiver may feel the child is too young or emotionally immature to understand disclosure issues concerning their HIV status. The caregiver may fear that the child will not understand when not to disclose to every other person because they lack cognitive and emotional ability to understand and maintain confidentiality (New York State Department of Health AIDS Institute, 2009). When children are old enough and have the cognitive and emotional ability to understand their condition, disclosure assists them to learn about their health and be able to participate in their care.

1.3.1.4 Stigma

Many caregivers with HIV infection have difficulty accepting the illness, either their own or their child’s, and struggle with whether or not to disclose the diagnosis of HIV infection to the child. The caregivers may be reluctant to disclose HIV status to their children for fear that the infected child will inappropriately disclose his/her HIV status, especially in families in which the diagnosis remains closely guarded. Failure to disclose may also be attributed to fear of stigma, rejection, and loss of support by the family/community. Pediatric HIV infection remains a highly stigmatized issue that is difficult to discuss with the infected child and others (New York State Department of Health AIDS Institute, 2009).

1.3.1.5 Anticipated Child’s Reaction

Caregiver may fear that the child’s reaction to knowledge of his/her HIV status will be very difficult to handle. The caregivers may therefore, desire to protect the child from worrying about his/her future. Caregivers also fear the possibility that the child’s burden of learning of his/her HIV status will lead to depression or other mental health issues. Caregivers may be reluctant to disclose to children who are emotionally unstable or who have poor coping skills. Caregivers regularly worried that their children may be infected, but most preferred to wait for emergence of symptoms before considering HIV tests, citing fear of children's emotional reaction are usually reluctant to make a disclosure (New York State Department of Health AIDS Institute, 2009).
1.3.1.6 Feelings of Quilt
Feelings of guilt and shame may prevent HIV-infected caregiver from making a disclosure to the infected child. Caregivers may take the blame for the infection of the child, especially the biological parents (New York State Department of Health AIDS Institute, 2009).

1.3.1.7 Family/social circumstances
Factors such as whether child is adopted or in foster care, whether there are other siblings, and if siblings are HIV-infected may affect the caregiver’s approach to disclosure (New York State Department of Health AIDS Institute, 2009). This is because caregivers of adopted children are likely to struggle to communicate HIV status information to infected children than biological parents. Caregivers also find it difficult to disclose the HIV status to a child when only one is affected in the family.

1.3.1.8 Types of support available
Types of support available to the child and family once disclosure occurs such as counseling and peer support groups may influence disclosure decisions. Lack of support to both the child and the caregiver may derail the disclosure process.

1.3.1.9 Cultural Beliefs
Cultural beliefs may influence caregivers’ ability to make HIV status disclosure to infected children. In the Zambian setting, issues of HIV are associated with sex issues which are traditionally regarded as taboo to be discussed with children thereby affecting disclosure of HIV status to infected children. The issues of unfaithfulness in marriage are so much pronounced on women who are found to be HIV infected than on men thus pronouncement of an HIV infected child points to the sexual behavior of the woman who directly transmits the infection to the child.
1.3.1.10 Religious Beliefs

The church also has a negative perception on the people who are HIV positive. The church demands for no sexual activities before marriage or outside marriage. This demand entails that believers who are found to be HIV positive could have been unfaithful regardless of how and when they got the infection. This perception makes it even more difficult for believers to talk about HIV in their families, let alone to the child who has always known the parents to be believers all his/her life.

1.3.2 HEALTH SERVICES FACTORS

Health service related factors refers to those factors that are directly related to the health service delivery and these include: counseling services, information given to caregivers on HIV infection, staffing as well as condition of the child.

1.3.2.1 Counseling Services

Adequately counseled caregivers are better able to handle disclosure process than those who may not have received the same. Counseling better equips caregivers and gives them confidence to better handle the situation. Inadequate counseling robes caregivers of the ability to handle disclosure.

1.3.2.2 Information on HIV

Inadequate information about HIV/AIDS to caregivers may limit their ability to disclose the HIV status information. This may lead to lack of understanding about the infection and confidence in the ability to handle the disclosure issue. However, caregivers who have adequate information on HIV tend to better handle disclosure issues.

1.3.2.3 Staffing

Shortage of manpower results in inability of the few available staff to provide effective and efficient services to the satisfaction of the clients. Staff who are stressed due to work overload become ineffective in their service delivery.
1.3.2.4 Clinical Condition of the Child

Caregivers tend to feel more comfortable to discuss HIV status with a child who is well than a child who is already clinically affected. This is because a child who is healthy though HIV infected may be able to withstand the impact of the diagnosis. Health providers may discourage attempts of HIV status disclosure to a child who is critically ill until condition of the child is stable enough (New York State Department of Health AIDS Institute, 2009).

1.3.3 Other Factors

Other factors influencing caregivers’ decision to disclose the child’s HIV status include parental communication style, parental illness, child’s rights, treatment adherence, child questions and provider pressures. Pediatric HIV disclosure represents a complex task for caregivers caring for the HIV-infected child, one in which the child’s development and the family’s community should be considered in the setting of a potentially stigmatizing infectious illness (Lester et al, 2010).
Figure 1.2: DIAGRAM OF PROBLEM ANALYSIS

Socio-economic and cultural factors

- Stigma
- HIV information
- Knowledge of HIV status disclosure
- Cultural beliefs
- Age of the child
- Family social circumstances
- Feelings of guilt
- Religious beliefs
- Attitude

Health service factors

- Counseling services
- Staffing
- Clinical condition of the child

Disclosure of HIV status by caregivers of HIV infected children

Types of support
1.4 THEORETICAL FRAMEWORK

A theoretical framework is a reference that provides a rationale for predictions about relationship among variables in the research study. It is the base for observations, definitions of concepts, research designs, interpretations and generalizations. The theoretical framework for research study presents the reasoning on which the purposes of the proposed study are based (Basavanthappa, 2006). This study will be guided by the Health Promotion Model. The model was proposed by Nola Pender in the year 1982 and revised in 1996 (Sakaida & Pender, 2005).

The model defined health as a positive dynamic state not merely the absence of disease. Health promotion is directed at increasing a client’s level of wellbeing. The health promotion model describes the multi dimensional nature of persons as they interact within their environment to pursue health. Health Promotion Model is a reliable indicator of health promotion. This study focuses on three areas of the model: (a) Individual characteristics and experiences; (b) Behavior-specific conditions (Cognitive-Perceptual Factors and Perceived benefits); and (c) Health behavior outcomes;

**Individual characteristics and experiences** state that each person has unique characteristics and experiences that affect subsequent actions. The individual characteristics include the demographic variables such as age of the child; education and socioeconomic status of the caregiver also have influence on HIV status disclosure. Personal psychological factors include variables such as self esteem, self motivation and personal competence of the caregiver in making disclosure.

**Behavior-specific conditions and affect** have important motivational significance and these include Cognitive-Perceptual Factors and Perceived benefits. Cognitive-perceptual factors are the “primary motivating mechanisms for acquisition and maintenance of health promoting behaviors”. These include importance of health and self efficacy in making choices about whether or not to make disclosure. Cognitive-Perceptual factors may be influenced by variables such as the caregiver’s knowledge of HIV infection and HIV status
disclosure. Perceived Barriers to Action are concerns anticipated, imagined or real blocks and personal costs of understanding need for HIV status disclosure to HIV infected children such as stigma and cultural beliefs. Perceived Benefits of action refer to anticipated positive attitude towards HIV disclosure by the caregiver (Sakraida & Pender, 2005).

Health promoting behavior is the endpoint or action outcome directed toward attaining positive health outcome such as optimal well-being, personal fulfillment, and productive living through disclosure of HIV status by the caregiver to an HIV infected child (Sakraida & Pender, 2005).

Figure 1.3
Diagram of Pender’s Health Promotion Model Framework

Adapted from Pender’s Health Promotion Model (Burns & Grove, 2009).
Figure 1.4

Diagram describing the relationship between the variables

Knowledge
Socio-economic status: influences access to information leading to increase in knowledge on HIV.
Knowledge influences attitude towards disclosure

Attitude
Influences attempts to acquire knowledge about HIV infection and HIV status disclosure.
Influenced by cultural beliefs, religious beliefs, available support,

Disclosure
Age of the child: encourages or limits decision for disclosure,
1.5 JUSTIFICATION

This study is aimed at establishing disclosure of HIV status to infected children. Disclosure of HIV status can help children understand their illness and may further a child’s willingness to adhere to his/her treatment regimen. Disclosure also prevents an accidental disclosure from occurring, such as when the child overhears the caregiver discussing the illness. Children who accidentally learn of their diagnosis may have a more difficult time adjusting to it.

Having no studies published on pediatric HIV status disclosure in Zambia, this study is hoped to assist policy makers to come up with guidelines for both health providers and caregivers on disclosure to help improve the services. The possible findings of this study will also help the policy makers to consider coming up with training programs for child/psychosocial counselors to offset the shortage of skilled personnel and thus improve on quality of services provided. This will in turn help caregivers of HIV infected children be equipped with knowledge and skill to competently disclose HIV status to the children. This, will thereby, assist the children learn to cope with their condition early in life by understanding the nature and consequences of their illness e.g. issues of sexuality as they mature and participation in their care.

1.6 RESEARCH OBJECTIVES

1.6.1 GENERAL OBJECTIVE

To determine HIV status disclosure to HIV infected children by caregivers.

1.6.2 SPECIFIC OBJECTIVES

1. To determine knowledge of HIV infection among caregivers of children living with HIV
2. To assess knowledge of HIV status disclosure by caregivers of children living with HIV
3. To establish the attitude of caregivers’ towards HIV status disclosure to children living with HIV.
4. To establish HIV status disclosure among caregivers of children living with HIV.
1.7 HYPOTHESES

A hypothesis is a statement of the predicted relationship between two or more variables in a research study (Basavanthappa, 2007). In this study, the working hypotheses are stated in alternative terms to determine the existence of relationships between the study variables by testing the hypotheses. The hypotheses are:

1. There is a relationship between disclosure of HIV status by caregivers of children living with HIV and knowledge of HIV infection
2. There is a relationship between disclosure of HIV status by caregivers of children living with HIV and knowledge of HIV status disclosure
3. There is a relationship between disclosure of HIV status by caregivers of children living with HIV and attitude towards HIV status disclosure.

1.8 CONCEPTUAL DEFINITIONS

**Conceptual definition** refers to the abstract or theoretical meaning of the concept being studied (Polit and Beck, 2008).

1.8.1 Knowledge of HIV infection: understanding of what HIV is, transmission and presentation (MOH, 2008).

1.8.2 Knowledge of HIV status disclosure: Ability to define and outline the process of HIV status disclosure (MOH, 2007).

1.8.3 Attitude towards disclosure: Feelings, beliefs and emotions about HIV status disclosure (MOH, 2007).

1.8.4 Disclosure of HIV status: The act of informing the concerned children of their HIV status (MOH, 2008).

1.8.5 HIV positive: State of being infected with the HIV virus (MOH, 2007)

1.8.6 Caregiver: A person who looks after a sick person at home (Oxford Advanced Learner’s Dictionary, 2005)

1.8.7 Child: A young human being who is not yet an adult (Oxford Advanced Learner’s Dictionary, 2005)
1.9 VARIABLES AND CUT OFF POINTS

A variable is an attribute or characteristic that can have more than one value such as height, weight and blood pressure (Basavantapa, 2007).

1.9.1 Types of variables

1.9.1.1 Dependent variable is the variable that changes as the independent variable is manipulated by the researcher; sometimes called the criterion variable (Basavantapa, 2007). The dependent variable in this study is disclosure of HIV status.

1.9.1.2 Independent variable: the variable that is purposely manipulated or changed by the researcher; also called the manipulated variable (Basavantapa, 2007). The independent variables in this study are: knowledge of HIV infection, knowledge of HIV status disclosure and attitude.
<table>
<thead>
<tr>
<th>NO</th>
<th>VARIABLE</th>
<th>INDICATOR</th>
<th>CUT OFF POINTS</th>
<th>QUESTIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Knowledge of HIV infection</td>
<td>Knowledgeable</td>
<td>Caregivers who scored 13-25 on HIV infection questions</td>
<td>14 - 17</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Not knowledgeable</td>
<td>Caregivers who scored 1-12 on HIV infection questions</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Knowledge of HIV status disclosure</td>
<td>Knowledgeable</td>
<td>Caregivers who scored 4-6 on knowledge questions</td>
<td>18 - 20</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Not knowledgeable</td>
<td>Caregivers who scored 0-3 on knowledge questions</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Attitude towards disclosure</td>
<td>Positive</td>
<td>Caregivers who scored 13-25 on attitude questions</td>
<td>21 - 25</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Negative</td>
<td>Parents who scored 5-12 on attitude questions</td>
<td></td>
</tr>
<tr>
<td>Disclosure of HIV status</td>
<td>Adequate disclosure</td>
<td>Communicated HIV status in full to the infected child (Scores - 2)</td>
<td>26 - 27</td>
<td></td>
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<tr>
<td>Inadequate disclosure</td>
<td>Communicated HIV status with partial information to the infected child (Scores – 1)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No disclosure</td>
<td>No communication about HIV status to the infected child (Scores – 0).</td>
<td></td>
<td></td>
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</tbody>
</table>
CHAPTER 2

2.0 LITERATURE REVIEW

2.1 INTRODUCTION

Literature review refers to an extensive, exhaustive and systematic examination of publications relevant to the research project (Basavanthappa, 2007). In this study, literature review provided a systematic review of pertinent studies related to HIV status disclosure by caregivers of children living with HIV. The review focused on caregivers’ knowledge of HIV infection, knowledge of HIV status disclosure, caregivers’ attitude towards HIV status disclosure and HIV status disclosure including relationships between the study variables. Literature was accessed through internet from published abstracts and articles of studies conducted on the subject. However, there was limited literature available on Children’s HIV status disclosure in Zambia.

2.2 Overview of HIV Infection in Children

The fastest growing group of children with HIV infection and related illnesses are infants who are being infected through perinatal, mother-to-child transmission. Transmission of the virus can take place when the virus carried by the mother crosses the placenta to the fetus during pregnancy; during labor and delivery when the infant is exposed to the mother's cervical secretions and blood; and through breast feeding (Lyons, 1990). In some instances, infection can be transmitted through infected blood products and child sexual abuse. With improved HIV testing technology, the determination of whether an infant born to an infected mother has been infected can be made as early as 6 weeks after birth using the Polymerase Chain Reaction (PCR) technique (MOH, 2008).

Formulation of pediatric antiretroviral drugs has greatly improved the livelihood of children worldwide. With access to treatment, many children with perinatally acquired HIV infection and AIDS are surviving to middle childhood and some to adolescence prompting need for HIV status disclosure (American Academy of Pediatrics, 2006).
Knowledge of HIV infection gives caregivers the ability to undertake HIV status disclosure with confidence. Knowledge requires caregiver’s access to HIV/AIDS information through various media and through the health care system i.e. through Information, Education and Communication (IEC).

Reuters Health Reports (2010), states that Health care providers at HIV clinics do not consistently provide information to HIV-positive patients about how to avoid transmitting the virus or about when patients should disclose their HIV status. From 839 HIV-positive patients who were interviewed, each of whom attended one of six public HIV clinics in California, approximately 29% of the participants indicated that no staff person at an HIV clinic had ever discussed "safer sex" practices with them. Half of the respondents reported that no one at a public health clinic had ever discussed disclosure of HIV status to sex partners. In addition, the researchers found that health care providers at such clinics were more likely to discuss safe sex and disclosure issues with black or Hispanic patients than with white patients. Providers were also more likely to discuss such information with women or heterosexual men than with men who have sex with men. According to the researchers, the results could indicate that some health care providers "mistakenly' believe that whites or gays are more educated about safe sex matters and 'do not need additional information'' or that some health care providers may "feel uncomfortable" discussing homosexual sex practices. Some public HIV clinics in California are "more successful than others in integrating prevention into the routine care of HIV patients," but the number of patients seen at a clinic is not related to how successful providers communicate such information, according to the study. The authors conclude that "providers should assess and overcome barriers to providing appropriate (HIV infection) messages to patients" (Reuters Health Report, 2010).

In another study conducted in Sweden on knowledge of HIV infection, almost all of the participants (45) knew that HIV can be transmitted through blood and sexual intercourse, but sixteen (16) also stated that HIV might be transmitted through kissing. In five (5) of the six
(6) couples in the study, one of the partners believed that HIV could be transmitted through kissing, while the other did not. Four (4) participants believed that the HIV virus could be transmitted through blood in swimming pools and/or in sauna. Adequate knowledge about HIV transmission did not seem to be associated with degree of disclosure (Asander, 2010). Some parents described how receiving information about their HIV status created a change in their parenting role. After the diagnosis they expressed a fear of transmitting the HIV virus to their children. Another mother explained: “I am a bit careful; she (the daughter) cannot be too close to me. She can be close and I can hug her. How can I explain? Sometimes she wants to use my towel but I do not allow her. She does not understand since before we used the same towel, but not any longer” (Asander, 2010).

Similar results were reported among HIV infected individuals in Canada who feared causal transmission within the family despite good basic knowledge on HIV (Dematteo et al, 2002). The study results reveals the significance for HIV education which should therefore, be a component of health education in every health facility. Lack of knowledge about HIV transmission stresses the importance of improved counseling.

In another development, studies were carried out by Asander et al at the units for HIV care at the Department of Infectious diseases at Karolinska University Hospital in Stockholm. A quantitative cross sectional study was performed among 47 HIV infected African parents who were guardians of children younger than 18. The semi – structured interviews centered around four main areas; demographic and medical issues, social network and disclosure, knowledge of HIV transmission and future planning for their children. Ecological system and social network theory were used to discuss results on participants’ social networks. Results showed that participants had basic knowledge of HIV transmission although a third thought that HIV could be transmitted through non scientifically verified ways and there were uncertainties about whom to inform about the HIV infection. Parents also expressed fear of transmitting the HIV virus through daily contacts. Health care personnel needed to pay attention to the HIV infected African parents cultural dilemmas and adopt medical information accordingly and repeat information about how the virus is and is not transmitted (Asander et al, 2004).
2.4 KNOWLEDGE OF HIV STATUS DISCLOSURE

Knowledge of HIV status disclosure refers to the caregivers understanding of what HIV status disclosure means and how to go about it. The caregivers’ understanding of the process of disclosure enables them to have adequate information they require to communicate the HIV result information to the child and to consider the child’s level of understanding. Disclosure of HIV status may require preparation of both the caregiver and the child to be disclosed to.

In a study by Murphy et al (2003), qualitative interviews with 47 mothers who had disclosed their HIV status to their children were conducted. The mothers described their preparation and the process of the disclosure event. They discussed any regrets they had about disclosing or the process of disclosing. They were also asked what advice they had for other HIV-positive mothers who were trying to determine whether to disclose their serostatus to their young children. Overall, the majority of the mothers (68%) did not regret disclosing their HIV status. However, regrets fell into five categories: preparation, timing, context, content, and outcomes of the disclosure event. Based on these findings, mothers who had not disclosed their serostatus to their children needed assistance with behavioral practice and support in order to prepare for the process of disclosure. Furthermore, follow-up support for the children may be beneficial.

In another development, a study was conducted by Oberdorfer et al (2006) at Chiang Mai University in Thailand whose aim was to identify the prevalence and patterns of disclosure of HIV/AIDS diagnosis to HIV-infected children. A cross-sectional study was conducted among 103 main care givers of HIV-infected children aged ≥6 years who received highly active antiretroviral therapy at Chiang Mai University and Sanpatong district hospitals, northern Thailand. From the 84.3% of caregivers who reported that the child did not know their diagnosis, had inaccurately explained to the child that he or she had some kind of disease such as allergy, lung, or liver disease, almost all (88.7%) agreed that they should tell the children their diagnosis in the future but half needed health-care providers to help them at the event. Results from the study showed that there is a need for the development of
disclosure guide-lines and models for health-care providers and care givers as there was a high rate of inaccurate disclosure and, in addition, care givers expressed their need for assistance from health-care providers for the future disclosure.

Another study was conducted in Stockholm at the Karolinska University Hospital on 47 HIV infected African parents. In depth interviews were performed and the interview guide included the participant’s experience in relation to the disclosure of HIV status. In the analysis process, conversional content analysis was used. Coping theory to discuss findings on disclosure about HIV status was used. Results revealed that the participants’ main reason to avoid being open about their HIV status was fear of being treated differently. Strategies they used were to omit the word HIV in conversations and to pretend to have other illnesses when communicating with their children. This was evident that participants lacked knowledge on how to go about disclosure thereby making efforts to avoid confrontations.

2.5 ATTITUDE OF CAREGIVERS TOWARDS HIV STATUS DISCLOSURE

The caregivers’ perception of HIV status disclosure to an infected child will influence their decision to disclose or not. Caregivers who look at HIV status disclosure to children to be important are motivated to undertake the process while those who don’t appreciate the importance may not be motivated. Attitude towards HIV status disclosure may be influenced by various factors which include the caregivers’ knowledge about HIV infection and the disclosure process.

In a study conducted in Kinshasa, Democratic Republic of Congo (DRC), among children aged 8 to 17 years to participate in pediatric HIV related operational research; semi-structured interviews were conducted with caregivers of children living with HIV. Several caregivers suggested that minors should never be told their HIV positive status when participating in HIV related research, regardless of their age. It was suggested that the word, “HIV” should not be included when first explaining HIV related research to children unaware of their HIV infection. However, within the context of treatment programmes,
disclosure of HIV status to children was supported by caregivers as a means to improve adherence to medication (Corneli et al, 2009).

Another study was conducted in Los Angeles to assess parental decision-making about illness disclosure to human immunodeficiency virus (HIV)-infected children. This was a cross-sectional study of 51 children with HIV infection based on caregiver interviews, child cognitive testing, clinical assessments and medical records. Only 43% of children had been told their HIV diagnosis. Results of the study showed Qualitative analysis of parental decision- making about illness disclosure varied by child developmental level. Factors influencing parental decision to disclose the child’s HIV status included parental communication style, parental illness, child’s rights, treatment adherence, child questions and provider pressures, whereas concerns about HIV stigma and potential emotional distress were most frequently identified as reasons for non-disclosure(Lester et al, 2010).

The study shows the complex of the task of Pediatric HIV status disclosure for caregivers of HIV-infected children. Most caregivers showed concerns about the child’s reaction and stigma which emerged as barriers to disclosure of HIV status to the children.

In another development, a study was conducted on fifty caregivers to determine their perception about disclosure of the diagnosis of HIV infection in children. Fifty caregivers were interviewed using a structured questionnaire. The questionnaire included questions about the disclosure status of HIV infection in children and perception about disclosure of status to infected children. Results revealed that only 7 out of the 50 children (14%) were aware of their HIV status while 43/50 (86%) were unaware. Only 6 percent children (3/50) were given factual information about the disease while 68% (34/50) were given no information. Majority of caregivers felt mid-teenage as the appropriate age for disclosing the HIV infection status and that the parents were the appropriate persons to reveal the infection status (21/50, 42%) (Arun et al 2009).
Disclosure of HIV status is the process of communicating HIV diagnosis to an infected child. Disclosing the diagnosis of human immunodeficiency virus (HIV) or AIDS to a child is a controversial and emotionally charged issue among both the health care communities and caregivers of these children. Since HIV was first described in children, the epidemiology of pediatric AIDS has evolved significantly. The introduction of widespread HIV counseling, testing, and treatment with Antiretroviral Treatment (ART) during pregnancy has led to a dramatic drop in the rate of perinatal transmission, as well as significantly improved morbidity and mortality. Many HIV-infected children who were not expected to survive childhood are entering adolescence and young adulthood. The prospect of a longer lifespan brings new challenges related to the impact of HIV infection on physical and mental health, as well as on normative developmental processes such as growth, peer relationships, puberty, and sexuality (Wiener et al, 2007).

Disclosure of HIV positive serostatus is an ongoing process that is gaining significant attention in HIV literature. Decisions of if, how, and when to disclose are intimately personal but have a considerable effect on the HIV infected child, families, communities, service-delivery systems and policy-making bodies. Effective HIV status disclosure to the child has been linked to (1) reductions in HIV transmission as the child grows, (2) adherence to medical regimens, (3) access to support services, (4) reductions in mental health symptoms and (5) effective adaptation to living with HIV (Rapid Response Service (2009). It is therefore, vital that service providers and researchers understand the intricacies of the process and the unique paths that individuals take to disclosure.

HIV status disclosure remains the most difficult task surrounding HIV infection amongst both adult and Children HIV infections. Hundley (2009), stated that one of the scariest things an HIV person will eventually have to deal with is disclosing their serostatus, whether it be to friends, family, co-workers, bosses, or a romantic interest. As antiretroviral therapy becomes more widely available in low-resource settings and children with HIV live for longer periods, disclosure of HIV diagnosis to infected children is becoming increasingly important. In

Disclosure presents unique challenges to healthcare workers and caregivers of children living with HIV that include controlling the flow of information about the child's HIV status to him/her and deciding on what is in his/her best interest. Decisions about when and how to disclose HIV status to a child need to consider the evolving capacity of children to understand about HIV infection and their socio-psychological readiness for learning their status.

A study conducted in Thailand explored the attitudes of caregivers towards HIV disclosure to HIV infected children. 41 caregivers that had not disclosed HIV diagnosis to their children were recruited and asked to complete a questionnaire. Results showed the children's median age was 7 years (ranges 2.8 to 13 yrs). Seventeen percent (17%) of caregivers were unsure whether the children were aware of their HIV status. Sixty-three (63%) and thirty seven (37%) intended to disclose and not disclose respectively (Apateerapong et al, 2006). The results showed attitude of caregivers towards HIV status disclosure to HIV positive children was negative.

In a study conducted in Thailand, only 2% of parents/caregivers tell their children of their HIV status (Apateerapong et al, 2006). In another development, a study conducted in Congo D.R on disclosure of HIV status to children revealed the following results: youths stated that they believed minors would want to know what they have been suffering from. Youths also expressed that once minors know their HIV-positive status, they can protect themselves, as well as not transmitting the infection to others. Additionally, interviews with youths revealed a strong link between disclosure and their reported adherence to medication regimens, as many youths who were interviewed were taking antiretroviral drugs or other HIV-related treatment. Many youths indicated that knowing their HIV status helped them to take their medicines regularly.

A 13 year-old girl who was interviewed stated that “Before, I was refusing to take my medicine, but since they announced to me that I was infected with that disease, I started
taking medicines without any problems.” Another 11 year-old girl said “It's in order to have it in my mind [knowing her HIV status], to know that I have to take medicines. This is because it might happen that mother forgets to give me the medicines or that she is absent from home, but I myself can check where they put the medicine bottle, if there are some tablets to be taken at that moment. I can take them all by myself.”

In another development, a cross-sectional study was conducted among 103 main care givers of HIV-infected children aged > or =6 years who received highly active antiretroviral therapy at Chiang Mai University and Sanpatong district hospitals, northern Thailand. The aim was to identify the prevalence and patterns of disclosure of HIV/AIDS diagnosis to HIV-infected children. Results of the study revealed that one-third (30.1%) of the children knew their HIV/AIDS status at an average age of 9.2 years. The care givers' understanding of 'knowing' did not always mean that the children were told the name of 'HIV' or 'AIDS'. Many of those care givers (84.3%) who reported that the child did not know their diagnosis had inaccurately explained to the child that he or she had some kind of disease such as allergy, lung, or liver disease. The most common reason for non-disclosure was the fear that disclosure might have negative psychological consequences to the child (53.4%). Almost all (88.7%) agreed that they should tell the children their diagnosis in the future but half needed health-care providers to help them at the event (Oberdorfer et al, 2006).

The above results shows there is a need for the development of disclosure guide-lines and models for health-care providers and care givers as there was a high rate of inaccurate disclosure and, in addition, caregivers expressed their need for assistance from health-care providers for the future disclosure.

2.7 Relationship among Knowledge of HIV infection, knowledge of HIV status disclosure, Attitude towards HIV status disclosure and HIV status disclosure

From the studies carried out, Reuters Health Report highlights the relationship between knowledge of HIV infection, disclosure information and a step for individuals to take up disclosure. Inconsistency of information given to clients influenced non disclosure of their HIV status.
In another development, Apateerapong et al (2006), carried out a study on 41 caregivers where he discovered that (17%) of caregivers were unsure whether the children were aware of their HIV status. Sixty-three (63%) and 37% intended to disclose and not disclose respectively giving an impression of poor attitude towards disclosure thus none of them had disclosed HIV status to their children.

Another study conducted in Los Angeles on caregivers of 5 HIV infected children revealed only 43% of the children had been told their HIV status. Reasons given by many caregivers for non disclosure were stigma and fear of children reactions. On the contrary, in a study conducted in Congo D.R, interviewed youths indicated that knowing their HIV status helped them to take their medicines regularly.

Disclosure of HIV status to HIV infected children is closely related to the caregiver’s knowledge of HIV infection and HIV status disclosure information. The caregiver’s knowledge influences their attitude towards HIV status disclosure to infected children. The studies conducted therefore, show that the caregivers’ knowledge, attitude and HIV status disclosure are interrelated.
2.8 CONCLUSION

Majority of HIV-infected children acquired the virus from their mothers, and ensuing parental guilt about transmission distinguishes this disease from other life-threatening pediatric illnesses like cancer. Furthermore, unlike disclosing a cancer diagnosis, disclosure of a child’s HIV diagnosis often leads to disclosure of other family secrets, including paternity, and parental history of sexual behavior and substance abuse. Thus, not only are caregivers’ decisions to disclose affected by their fears about the emotional consequences of disclosure for the child, but also their fears about the child’s anger towards the parent, and the potential social consequences associated with the child sharing the diagnosis with others (e.g. negative reactions from family, friends and school, lack of community support).

The public health risks of non-disclosure, including non-adherence to medications that may result in drug resistant strains of HIV combined with risky sexual behavior that may result in transmission of the virus as the children grows, add a sense of urgency to the issue of disclosing the HIV diagnosis to children living with HIV infection. Disclosure problem is not only a Zambian problem as studies carried out globally portray an unresolved challenge.

Considering that no study has been conducted on HIV status disclosure to HIV infected children in Zambia, this study is hoped to inspire policy makers to find ways of improving HIV status disclosure to children. It is also hoped that counseling trainings shall integrate child counseling programmes in order to fully equip health providers to adequately prepare caregivers for the disclosure responsibility.
CHAPTER THREE

3.0 RESEARCH METHODOLOGY

3.1 RESEARCH DESIGN

A research design is a plan, structures and strategy of investigations for answering the research question in the overall plan the researcher selects to carry out their study (Basavanthappa, 2006). It is the overall plan for obtaining answers to the research questions and for addressing factors described (Polit & Beck, 2006). It is a structural framework within which the study was implemented. The research design helped the researcher to make decisions about the methods used to address the research question and plan for the actual collection of data. The methodological decisions made by the researcher during this phase affected the integrity, interpretability and clinical utility of the results.

In this study, a non experimental, cross sectional descriptive study design was used. In a cross sectional study, the data collected defines or describes some phenomenon which sample may subject to ascertain change at a given point in time (Polit & Beck, 2007). A cross sectional study was used because it was less time consuming, less expensive and more manageable for the researcher as data could be collected at a single point in time. A descriptive study design is one in which data are collected, recorded and analyzed to define some group or phenomenon (Basavanthappa, 2007). This study described HIV status disclosure by caregivers of children living with HIV. A descriptive design helped to measure a precise measurement of phenomenon (HIV status disclosure) as it currently existed (Basavanthappa, 2007). A non experimental study is one where no manipulation of the independent variable is done (Polit & Beck, 2006). This study therefore, being descriptive, means that no manipulation and control of variables was applied.

3.2 RESEARCH SETTING

The research was conducted in Lusaka district, located in Lusaka Province which has a total population of about 2 million people with HIV prevalence of 21% (CSO, 2010). Lusaka was selected by the researcher to lessen the burden of costs as the researcher came from the same locality. Lusaka was also selected for its high prevalence of HIV(21%). The study was carried
out at the University Teaching Hospital (UTH), which is a third level referral hospital for the whole nation.

The respondents were captured through the Children’s Antiretro-viral therapy (ART) clinic which is situated within the pediatric department. Pediatrics is one of the major departments in UTH that caters for children from 0 – 14 years of age from within Lusaka health centers and from the rest of the country. The department offers consultation and out-patient services, in-patient services to the critically ill, laboratory services which include CD4 monitoring, radiology, pharmacy and counseling services. The U.T.H pediatric department caters for referrals from all health centers in Lusaka district including referrals from all around the nation because the hospital has no catchment population. The results obtained are therefore, representative of a cross section of Lusaka district.

3.3 STUDY POPULATION

A population is all the individuals or objects with common defining characteristics (Polit & Beck, 2006). Study population refers to a population with all the elements that meet certain criteria for the inclusion in a given universe (Burns & Grove, 2005). The study population in this research consisted of caregivers of HIV infected children accessing services at the University Teaching Hospital, Pediatric ART clinic.

3.3.1 TARGET POPULATION

Target population is the entire population in which the researcher is interested and to which he/she would like to generalize study results (Polit & Beck, 2006:510). In this study, the target population included care givers of HIV infected children who were accessing ART services from UTH Pediatric ART clinic.

3.3.2 ACCESSIBLE POPULATION

An accessible population is the portion of the target population to which the researcher has reasonable access (Burns & Grove, 2009). In this study, the accessible population were caregivers of HIV infected children who were attending ART clinic at U.T.H pediatric department during the data collection period.
3.4 SAMPLE SELECTION

Sample selection is the process of selecting a group of people, events, behaviors or other elements that are representative of the population being studied (Burns & Grove, 2009). It is a process of selecting a subset of a population in order to obtain information regarding phenomenon in a way that represents the entire population. The health facility and department were selected based on convenient sampling method.

3.4.1 UTH

The study was conveniently conducted at the University Teaching Hospital at the Pediatric department ART clinic. The researcher chose the site for its high numbers of subjects and proximity due to inadequate funding of the project.

3.4.2 Respondents

Probability sampling was used to select study respondents. Probability sampling is when sample elements are automatically selected by some scheme under which a particular sample of given size from a specified population has some known probability of being selected (Basvanthappa, 2007). It was characterized by the random selection of elements from the population of caregivers of HIV infected children. This type of sampling was chosen in this study to enable the researcher estimate the probability that each caregiver of an HIV infected child aged 6 to 14 years would be included in the sample. To give each member of the population an equal chance of selection into the sample, simple random sampling was used. Simple random sampling is a probability sampling procedure in which the required number of sampling units are selected at random from the population in such a manner that each population element has an equal chance (probability) of being selected for the sample (Basavanthappa, 2007). This technique was used because each respondent had equal chance to be selected and researcher could easily generalize the findings. It also reduces chances of researcher biasness. This was achieved through the use of the Fishbowl without replacement technique.

Fishbowl without replacement is a random sampling technique characterized by writing of each name or numbers from the sampling frame on a separate piece of paper, each slip of
paper was put into a container, the container was shaken and the numbers were selected until a required number according to the sample calculated was drawn. The slips drawn were equal to the desired sample and were not replaced (Polit & Beck, 2006). This technique had been chosen to avoid duplication of chances of selection of elements into the sample.

3.4.3 Inclusion Criteria

Inclusion sampling criteria are those characteristics that a subject element must possess to be part of the target population (Burns & Grove, 2009). Inclusion criteria in the study involved all caregivers of HIV infected children aged 6 to 14 years attending ART clinic at U.T.H Pediatric department because this was the age group eligible for disclosure.

3.4.4 Exclusion Criteria

Exclusion sampling criteria are those characteristics that can cause a person or element to be excluded from the target population (Burns & Grove, 2009). In the study, exclusion criteria included caregivers of HIV infected children who attended ART clinic and were below 6 years of age. This was because these caregivers were not the researcher’s target population.

3.5 SAMPLE SIZE

A sample is a subset of the total population. Sample size is the total number of study participants in a study (Polit & Beck, 2006). The sample size of the study was 50 subjects. The sample size was determined by the available resources: manpower, money and the limited time in which the study was to be carried out.

3.6 OPERATIONAL DEFINITIONS

Operational definition refers to the definition of the concept or variable in terms of procedures by which it should be measured (Polit & Beck, 2008).

1.9.1 Knowledge of HIV infection: Ability to give a definition of HIV, explain modes of transmission and presentation of HIV infection in children.

1.9.2 Knowledge of HIV status disclosure: Being able to define disclosure, outline the benefits of disclosure and explain patterns of disclosure.
1.9.3 Attitude towards disclosure: The caregiver’s views towards HIV status disclosure to the HIV infected child, views about the best person to make disclosure and the benefits of disclosure.

1.9.4 Disclosure of HIV status: refers to the care giver’s act of informing the child his/her HIV serostatus and knowing the extent of information given whether partial or full.

1.9.5 HIV positive: It refers to a child who has been found to carry HIV infection after an HIV test and results have been communicated to the caregiver.

1.9.6 Caregiver: A person who takes care of an HIV infected child and is aware of the child’s HIV status.

1.9.7 Child: Refers to an individual aged 6 – 14 years who has undergone an HIV test and is diagnosed to have HIV infection.

3.7 DATA COLLECTION TOOL

According to Polit & Beck (2006), “Data collection is the gathering of information to address a research problem. Data collection tools are instruments used to collect data needed to address research questions (Polit & Beck, 2008). In this study, a semi standardized interview schedule was used to collect data on disclosure of HIV status to HIV infected children by caregivers. Semi standardized interview schedule is an interview type or data collection tool where interviewers ask a number of specific questions with the freedom to probe (Polit & Beck, 2008). The tool contained both closed and open ended questions. This enabled the researcher to easily probe and capture adequate information for the study. Interview schedule was chosen to reduce non response rate resulting from a good relationship that was created between the interviewer and the respondents.

The interview schedule comprised of 5 sections. Section A: demographic data for both the caregiver and the child. This section contained questions on age of both the caregiver and the child, educational background of the caregiver, occupation and religion, educational background of the child and whether child was on antiretroviral treatment. B:– knowledge of HIV infection: Focused on the definition of HIV infection, modes of transmission and presentation of HIV infection in children, C:– knowledge of HIV status disclosure: Involved
definition of HIV status disclosure, benefits of HIV status disclosure and patterns of disclosure, D: attitude of caregivers towards HIV status disclosure: Established views on HIV status disclosure, best person to undertake disclosure, risks of HIV infection, child corporation with care, adherence to ART, and section E: HIV status disclosure: Established whether the caregiver had disclosed HIV status to the infected child, pattern of disclosure used, information given in partial disclosure and why disclosure was done. Respondent responses to questions on HIV infection knowledge, HIV status disclosure and attitude was analyzed and used to explain relationships between variables

3.7.1 Validity

Validity is the ability of the data gathering instrument to measure what it purports to measure (Basavanthappa, 2007). Validity concerns the soundness of the study’s evidence – that is whether the findings are cogent, convincing and well grounded. It is an important criterion for measuring and assessing the methods of measuring variables. There are four types of validity which includes; external and internal validity, construct validity and statistical conclusion.

3.7.1.1 External validity

This is the extent to which the findings of the research can be generalized to a large population or to a different social, economic and political setting (Polit & Beck, 2008). To ensure external validity in this study, the sample size encompassed caregivers of HIV infected children from different socio – economic, educational and religious backgrounds. The researcher also ensured questions were asked clearly with clarifications made where respondents were unsure.

3.7.1.2 Internal validity

This refers to the interpretation of findings within the study, experiment or data collected (Polit & Beck, 2008). Internal validity sought to establish the effect of the dependent variable due to the action of the independent variable or the possible effects of the extraneous variables. Internal validity in this study was achieved through carrying out a pilot study at UTH Pediatric department, wards AO4 and A08, using the same data collection tool that was
used in the main study. This included maintenance of the same questions for all participants to be involved. Additionally construct validity of the collected data was assessed by the supervisor of the researcher.

3.7.2 Reliability

Reliability is defined as the extent to which instrument yields the same results with repeated testing. It is concerned with consistency, accuracy, precision, stability, equivalence and homogeneity (Basavanthappa, 2006). According to Polit & Beck (2006), reliability refers to the accuracy and consistency of information obtained in a study. Reliability is often associated with the methods used to measure research variables. It is the consistence with which an instrument measures the attribute. An instrument is said to be reliable if its measures accurately reflect true scores. In this study, an interview schedule was used for data collection to establish disclosure of HIV status by care givers of HIV infected children. Reliability of the measuring instrument was determined through pre testing of the interview schedule instrument in the pilot study. The pretesting of the instrument enabled the researcher to identify problems with the administration and understanding of the questions by subjects. Identified problems were later clarified and corrected before the main study was conducted.

3.8 DATA COLLECTION TECHNIQUE

Burns & Grove (2009), defined data collection as “the gathering of information needed to address a research problem”. The researcher first begun by obtaining permission from the respondents to carry out the interview. The plan for data collection included self introduction, explaining the process of the interview and getting consent from respondents. Data was collected through face to face interview, which created an interaction between the interviewer and respondents. The interview was conducted in a private room at the children’s ART clinic to ensure anonymity and confidentiality in an attempt to win the respondents’ confidence and to get honesty responses. The interview process was characterized by the interviewer reading out questions to respondents and recording their responses. The technique was suitable for both the literate and the illiterate because questions and responses
could be verified there and then. Each interview ended by thanking the respondents for their corporation.

3.9 PILOT STUDY

Pilot study is the study carried out at the end of the planning phase of research, in order to explore and test the research elements. It is a small scale dress rehearsal that proceeds as if it were the actual study, except for the fact that the subjects who will participate in the actual study are not used (Basavanthappa, 2006). For this study, a pilot study was conducted in ward AO4 and A08. Interviews were conducted on (5) randomly selected (10% of 50 actual respondents = 5) caregivers who were not part of the main study. The pilot study gave the researcher the general overview of the likely responses to the actual study and also served as a means of testing the data collection instrument.

3.10 ETHICAL AND CULTURAL CONSIDERATIONS

Polit & Beck (2006), defined ethics as “a system of moral values that is concerned with the degree to which research procedures adhere to professional, legal and social obligations to the study participants.” Consideration of ethics and culture in research design ensures protection of human rights. Permission to carry out the study was obtained from the School of Medicine, Head of Department at Department of Nursing Sciences, University Teaching Hospital Management. Letters of permission were sent to entire relevant authorities e.g. Pediatric Head of Department, the Departmental Nursing Officer and Children’s ART clinic Sister in-charge which facilitated understanding with the authorities. The right of privacy was observed by obtaining direct consent for participation from the respondents and measures were taken to ensure confidentiality through provision of a private room. Explanation of the nature and purpose of the study was given to respondents before the interview. Anonymity was ensured through omission of names on the interview schedule. Information collected from respondents was treated with high level of confidentiality.
CHAPTER FOUR

4.0 DATA ANALYSIS AND PRESENTATION OF FINDINGS

4.1 DATA ANALYSIS

Data analysis is the systematic organization and synthesis of research data and the testing of research hypothesis using those data (Polit & Beck, 2006). The purpose of data analysis regardless of the type of data or the underlying research tradition is to organize, provide structure and elicit meaning from the data (Polit & Beck, 2006). Data collection involved both quantitative and qualitative information.

4.1.1 Quantitative Analysis

Quantitative analysis is the manipulation of numerical data through statistical procedures for the purpose of describing phenomena or assessing the magnitude and reliability of relationships among them (Basavanthappa, 2007). Collected data were sorted out, edited for completeness and consistence and later entered on Statistical Package for Social Sciences version 16.0 spreadsheet for data analysis. Frequency tables were then drawn to determine the frequencies followed by cross tabulations to show associations between the demographic and the study variables which helped in scrutiny of the study data. Chi-Square test was done to test the hypotheses and standard deviation to measure how the data was distributed.

4.1.2 Qualitative Analysis

Qualitative analysis is a labor intensive activity that requires creativity, conceptual sensitivity and sheer hard work (Polit & Beck, 2008). Qualitative data which were derived from open ended questions were analyzed through careful reading of the data, with an eye to intensifying underlying regularities, concepts and clusters of concepts. The concepts were derived from the characteristics of the responses, and then developed into themes that were used to categorize the content into meaningful groupings and coded. Coding is the process of transforming qualitative data into numerical symbols that can be computerized (Burns and Grove 2009). The data were finally entered on the spread sheet using SPSS version 16 followed by analysis to determine the variable frequencies and relationships among the variables through cross tabulations.
4.2 PRESENTATION OF FINDINGS

Presentation of findings involves display of the results of the data collected (Basavantappa, 2007). The findings of the study are presented using fourteen (14) frequency tables, three (3) graphs, six (8) cross tabulations and two (2) pie charts. Frequency tables give summary of the study results thus ensuring understanding of the findings by the reader. Pie charts are used for easy interpretation of findings. Cross tabulation of variables helps to show relationship between variables and therefore, helps the reader to draw meaningful inferences.

Data were divided into five (5) categories namely: Section A – caregiver demographic data; and demographic data for the child; Section B- knowledge of HIV infection, Section C - knowledge of HIV status disclosure, Section D - attitude towards HIV status disclosure ; Section E - HIV status disclosure Section F: Suggestions on how HIV status disclosure to children can be improved.
SECTION A

4.2.1: DEMOGRAPHIC DATA

The section comprises of two frequency tables presenting demographic data of caregivers and demographic data of children living with HIV.

Table 4.1
Caregivers Demographic Data (n = 50)

<table>
<thead>
<tr>
<th>Variables</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>12</td>
<td>24</td>
</tr>
<tr>
<td>Female</td>
<td>38</td>
<td>76</td>
</tr>
<tr>
<td>Total</td>
<td>50</td>
<td>100</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>24 - 30</td>
<td>13</td>
<td>26</td>
</tr>
<tr>
<td>31 - 37</td>
<td>13</td>
<td>26</td>
</tr>
<tr>
<td>38 - 44</td>
<td>14</td>
<td>28</td>
</tr>
<tr>
<td>45 - 51</td>
<td>4</td>
<td>8</td>
</tr>
<tr>
<td>52 years and above</td>
<td>6</td>
<td>12</td>
</tr>
<tr>
<td>Total</td>
<td>50</td>
<td>100</td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>33</td>
<td>66</td>
</tr>
<tr>
<td>Never married</td>
<td>4</td>
<td>8</td>
</tr>
<tr>
<td>Separated</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Widowed</td>
<td>12</td>
<td>24</td>
</tr>
<tr>
<td>Total</td>
<td>50</td>
<td>100</td>
</tr>
<tr>
<td><strong>Educational Level</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never been to school</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Primary school</td>
<td>15</td>
<td>30</td>
</tr>
<tr>
<td>Secondary school</td>
<td>23</td>
<td>46</td>
</tr>
<tr>
<td>Tertiary level</td>
<td>11</td>
<td>22</td>
</tr>
<tr>
<td>Total</td>
<td>50</td>
<td>100</td>
</tr>
<tr>
<td><strong>Residential Area</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low density area</td>
<td>12</td>
<td>24</td>
</tr>
<tr>
<td>Medium density area</td>
<td>11</td>
<td>22</td>
</tr>
<tr>
<td>High density area</td>
<td>27</td>
<td>54</td>
</tr>
<tr>
<td>Total</td>
<td>50</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 4.1 continues on next page
Table 4.1 continues

<table>
<thead>
<tr>
<th>Variables</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Religious Denomination</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>United church of Zambia</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>Seventh day Adventist church</td>
<td>4</td>
<td>8</td>
</tr>
<tr>
<td>Roman catholic</td>
<td>13</td>
<td>26</td>
</tr>
<tr>
<td>Pentecostal</td>
<td>14</td>
<td>28</td>
</tr>
<tr>
<td>None</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Other</td>
<td>14</td>
<td>28</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>50</strong></td>
<td><strong>100</strong></td>
</tr>
<tr>
<td><strong>Occupation</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>6</td>
<td>12</td>
</tr>
<tr>
<td>Formal employment</td>
<td>12</td>
<td>24</td>
</tr>
<tr>
<td>Informal employment</td>
<td>20</td>
<td>38</td>
</tr>
<tr>
<td>Housewife</td>
<td>12</td>
<td>24</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>50</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

Three quarters of respondents were females 38 (76%). Age ranged from 24 to 69 years with a mean of 38.20 and Std Deviation of 10.694. Two thirds 33 (66%) of respondents were married with 24% of widowed respondents. Slightly less than a half 23 (46%) of the respondents attained secondary education with only 1 (2%) who had never been to school. Over a quarter 27 (54%) came from high density area. Fourteen (28%) of the respondents came from Pentecostal churches with another 14 (28%) from others which comprised of Baptist, Salvation Army, Jehovah’s witness and Anglican churches.
### Table 4.2
Demographic data for the children (n = 50)

<table>
<thead>
<tr>
<th>Variables</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6 - 8</td>
<td>14</td>
<td>28</td>
</tr>
<tr>
<td>9 - 12</td>
<td>20</td>
<td>40</td>
</tr>
<tr>
<td>13 - 14</td>
<td>16</td>
<td>32</td>
</tr>
<tr>
<td>Total</td>
<td>50</td>
<td>100</td>
</tr>
<tr>
<td><strong>Relationship with the child</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Biological parent</td>
<td>36</td>
<td>72</td>
</tr>
<tr>
<td>Nephew</td>
<td>4</td>
<td>8</td>
</tr>
<tr>
<td>Niece</td>
<td>4</td>
<td>8</td>
</tr>
<tr>
<td>Grandparent</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>Other</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>Total</td>
<td>50</td>
<td>100</td>
</tr>
<tr>
<td><strong>If not biological child</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Both alive</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>Only one is alive</td>
<td>6</td>
<td>12</td>
</tr>
<tr>
<td>None is alive</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
<td>Total</td>
<td>14</td>
<td>28</td>
</tr>
<tr>
<td>System</td>
<td>36</td>
<td>72</td>
</tr>
<tr>
<td>Total</td>
<td>50</td>
<td>100</td>
</tr>
<tr>
<td><strong>Grade of child</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not in school</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Nursery</td>
<td>7</td>
<td>14</td>
</tr>
<tr>
<td>Lower primary</td>
<td>26</td>
<td>52</td>
</tr>
<tr>
<td>Upper primary</td>
<td>14</td>
<td>28</td>
</tr>
<tr>
<td>Secondary</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Total</td>
<td>50</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 4.2 continues on the next page
Table 4.2 continues

<table>
<thead>
<tr>
<th>Variables</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>How long have you known the child to have HIV infection?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 - 12 months</td>
<td>14</td>
<td>28</td>
</tr>
<tr>
<td>13 - 24 months</td>
<td>7</td>
<td>14</td>
</tr>
<tr>
<td>25 - 36 months</td>
<td>13</td>
<td>26</td>
</tr>
<tr>
<td>37 - 48 months</td>
<td>7</td>
<td>14</td>
</tr>
<tr>
<td>49 - 60 months</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
<td>61 - 72 months</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>108 months</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>50</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Is the child receiving ARV treatment?</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>46</td>
<td>92</td>
</tr>
<tr>
<td>No</td>
<td>4</td>
<td>8</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>50</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

The age of children ranged from 6 to 14 years with a mean of 10.08 years and Std Deviation of 2.423. More than half 36 (72%) of the children were brought to the clinic by their biological parents. Out of the 14 (28%) children brought by other caregivers, 5 had lost both parents. More than half 26 (52%) of the children were attending lower primary school with 2 children (4%) in secondary school. Duration of the caregivers’ knowledge of the children HIV infection ranged from 1 to 108 months. 14 children (28%) were known to have HIV infection in a period of 1 to 12 months. The mean period was 34.02 months and Std Deviation of 22.640. More than two thirds 46 (92%) of the children were on ARV drugs.
SECTION B

4.2.2 KNOWLEDGE OF HIV INFECTION

This section presents a table that highlights the distribution of study variables and also presents information on the caregivers’ knowledge of HIV infection in four tables; knowledge on definition of HIV; transmission of HIV; contraction of HIV and signs of HIV infection in children. There is one pie chart depicting Caregiver’s level of knowledge of HIV infection. Cross tabulations between knowledge of HIV infection and demographics were not done due to lack of variability in knowledge.

Table 4.3

Distribution of study variables (n = 50)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>Standard Deviation</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge of HIV infection</td>
<td>20.78</td>
<td>1.941</td>
<td>17 - 25</td>
</tr>
<tr>
<td>Knowledge of HIV status disclosure</td>
<td>4.43</td>
<td>1.225</td>
<td>1 - 6</td>
</tr>
<tr>
<td>Attitude</td>
<td>23.61</td>
<td>2.110</td>
<td>17 - 25</td>
</tr>
<tr>
<td>Disclosure</td>
<td>0.84</td>
<td>0.874</td>
<td>0 - 2</td>
</tr>
</tbody>
</table>

Knowledge of HIV infection levels ranged from 17 to 25 (Mean = 20.78; SD = 1.941). Knowledge of HIV status disclosure ranged from 1 to 6 (Mean = 4.43; SD = 1.225). Attitude ranged from 17 to 25 (Mean = 23.61; SD = 2.110). Disclosure ranged from 0 to 2 (Mean = 0.84; SD = 0.874).
Table 4.4 Respondent knowledge on definition of HIV (n = 50)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Correct</th>
<th>Incorrect</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>What is HIV?</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A virus that fights the immune system</td>
<td>42 (84%)</td>
<td>8 (16%)</td>
<td>50 (100%)</td>
</tr>
<tr>
<td>A virus that can be cured</td>
<td>47 (94%)</td>
<td>3 (6%)</td>
<td>50 (50%)</td>
</tr>
<tr>
<td>A disease that has no cure</td>
<td>46 (92%)</td>
<td>4 (8%)</td>
<td>50 (100%)</td>
</tr>
<tr>
<td>Infection that affects only adults</td>
<td>49 (98%)</td>
<td>1 (2%)</td>
<td>50 (100%)</td>
</tr>
<tr>
<td>Infection that affects adults and children</td>
<td>49 (98%)</td>
<td>1 (2%)</td>
<td>50 (100%)</td>
</tr>
<tr>
<td>A disease that comes through witchcraft</td>
<td>48 (96%)</td>
<td>2 (4%)</td>
<td>50 (100%)</td>
</tr>
</tbody>
</table>

About two thirds, 42 (84%) of the respondents were able to state that HIV is a virus that fights the immune system while 8(16%) were not able to correctly define HIV. The majority of respondents 47 (94%) correctly denied that HIV can be cured and 46(92%) observed that the disease has no cure. Almost every respondent 49(98%) correctly objected the statement that HIV affects only adults but that it affects both adults and children. Another 48 (96%), objected the notion that HIV comes through witchcraft.

Table 4.5 Respondent knowledge of transmission of HIV (n= 50)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Correct</th>
<th>Incorrect</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>How is HIV transmitted?</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Through mosquito bites</td>
<td>47 (94%)</td>
<td>3 (6%)</td>
<td>50 (100%)</td>
</tr>
<tr>
<td>Through sexual intercourse</td>
<td>50 (100%)</td>
<td>0 (0%)</td>
<td>50 (100%)</td>
</tr>
<tr>
<td>Through infected blood products</td>
<td>42 (84%)</td>
<td>8 (16%)</td>
<td>50 (100%)</td>
</tr>
<tr>
<td>Through contaminated needles and razor blades</td>
<td>49 (98%)</td>
<td>1 (2%)</td>
<td>50 (100%)</td>
</tr>
<tr>
<td>Through sharing of toilets</td>
<td>42 (84%)</td>
<td>8 (16%)</td>
<td>50 (100%)</td>
</tr>
<tr>
<td>Through mother to child</td>
<td>47 (94%)</td>
<td>3 (6%)</td>
<td>50 (100%)</td>
</tr>
</tbody>
</table>

Majority of the respondents 47(94%) objected that HIV can be transmitted through mosquito bites, 50 (100%) said HIV can be transmitted through sexual intercourse, 49(98%) stated HIV can be transmitted through contaminated needles and razor blades and 47(94%) said HIV can be transmitted through mother to child. However, 8(16%) of the respondents did not know that HIV
can be transmitted through blood products and another 8(16%) stated that HIV can be transmitted through sharing of toilets.

Table 4.6: Respondent knowledge of contraction of HIV (n = 50)

<table>
<thead>
<tr>
<th>Variables</th>
<th>Correct</th>
<th>Incorrect</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>How do children contract HIV infection?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Through sexual intercourse</td>
<td>39 (78%)</td>
<td>11 (22%)</td>
<td>50 (100%)</td>
</tr>
<tr>
<td>Through defilement</td>
<td>37 (74%)</td>
<td>13 (26%)</td>
<td>50 (100%)</td>
</tr>
<tr>
<td>From mother to child in uterus</td>
<td>22 (44%)</td>
<td>28 (56%)</td>
<td>50 (100%)</td>
</tr>
<tr>
<td>From mother to child during birth</td>
<td>44 (88%)</td>
<td>6 (12%)</td>
<td>50 (100%)</td>
</tr>
<tr>
<td>From mother to child through breast milk</td>
<td>46 (92%)</td>
<td>4 (8%)</td>
<td>50 (100%)</td>
</tr>
<tr>
<td>Through blood transfusion</td>
<td>31 (62%)</td>
<td>19 (38%)</td>
<td>50 (100%)</td>
</tr>
<tr>
<td>Through mosquito bites</td>
<td>46 (92%)</td>
<td>4 (8%)</td>
<td>50 (100%)</td>
</tr>
</tbody>
</table>

Over two thirds, 39 (78%) objected that children can contract HIV through sexual intercourse and 37 (74%) said children can contract HIV through defilement. More than half, 28 (56%) did not know that children can contract HIV from mother in the uterus and 19 (38%) did not know children can contract HIV through blood transfusion. The majority, 44 (88%) stated children can contract HIV from the mother during birth and 46 (92%) said through breast milk. More than two
Table 4.7: Respondent knowledge of signs of HIV infection in children (n = 50)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Correct</th>
<th>Incorrect</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>What are the signs of HIV infection in children?</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Slowed growth is a sign that would make you think a child could have HIV infection?</td>
<td>38 (76%)</td>
<td>12 (24%)</td>
<td>50 (100%)</td>
</tr>
<tr>
<td>Delayed mental development is a sign that would make you think a child could have HIV infection?</td>
<td>26 (52%)</td>
<td>24 (48%)</td>
<td>50 (100%)</td>
</tr>
<tr>
<td>Enlarged lymph nodes is a sign that would make you think a child could have HIV infection?</td>
<td>35 (70%)</td>
<td>15 (30%)</td>
<td>50 (100%)</td>
</tr>
<tr>
<td>Sickness on and off is a sign that would make you think a child could have HIV infection</td>
<td>50 (100%)</td>
<td>0 (0%)</td>
<td>50 (100%)</td>
</tr>
<tr>
<td>Inability to play is a sign that would make you think a child could have HIV infection</td>
<td>33 (66%)</td>
<td>17 (34%)</td>
<td>50 (100%)</td>
</tr>
<tr>
<td>Child growing tall and slim is a sign that would make you think a child could have HIV infection</td>
<td>39 (78%)</td>
<td>11 (22%)</td>
<td>50 (100%)</td>
</tr>
</tbody>
</table>

Almost a quarter, 12 (24%) did not know that slowed growth, almost half, 24 (48%) did not know that delayed mental development and 15(30%) did not know that enlarged lymph nodes are signs of HIV infection in children. All respondents 50 (100%) stated that sickness on and off is a sign of HIV infection in children. About one third, 17 (34%) of the respondents said inability to play and 11 (22%) said child growing tall and slim are signs of HIV infection in children.
Figure 4.1

Level of Knowledge of HIV infection (n = 50)

All the 50 (100%) respondents displayed high knowledge of HIV infection

SECTION C

4.2.3 KNOWLEDGE OF HIV STATUS DISCLOSURE

The section presents data on the caregiver’s knowledge of HIV status disclosure. There is one frequency table on questions to determine knowledge of HIV status disclosure covering: definition of HIV status disclosure, benefits of HIV status disclosure and patterns of HIV status disclosure. This is followed by a bar chart on knowledge level of HIV status disclosure. Finally, two cross tabulation tables on knowledge of HIV status disclosure and demographic variables are presented.
Table 4.8

Respondent knowledge of HIV status disclosure (n = 50)

<table>
<thead>
<tr>
<th>Variables</th>
<th>Correct</th>
<th>Incorrect</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>What is HIV status disclosure?</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HIV status disclosure is informing the child that they have HIV infection</td>
<td>29 (58%)</td>
<td>21 (42%)</td>
<td>50 (100%)</td>
</tr>
<tr>
<td><strong>What are the benefits of HIV status disclosure?</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Helps people understand the reality of living with HIV</td>
<td>36 (72%)</td>
<td>14 (28%)</td>
<td>50 (100%)</td>
</tr>
<tr>
<td>It challenges myths and misconceptions about who becomes infected with HIV</td>
<td>19 (38%)</td>
<td>31 (62%)</td>
<td>50 (100%)</td>
</tr>
<tr>
<td>It helps people to examine their risks of infection</td>
<td>45 (90%)</td>
<td>5 (10%)</td>
<td>50 (100%)</td>
</tr>
<tr>
<td>Improves adherence to treatment</td>
<td>50 (100%)</td>
<td>0 (0%)</td>
<td>50 (100%)</td>
</tr>
<tr>
<td><strong>What is the best pattern of HIV status disclosure to an infected child?</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Complete disclosure is the best pattern of HIV status disclosure</td>
<td>45 (90%)</td>
<td>5 (10%)</td>
<td>50 (100%)</td>
</tr>
</tbody>
</table>

Almost half of the respondents 21 (42%) did not know the definition of HIV status disclosure. Almost three quarters of respondents, 36 (72%) said disclosure helps people understand the reality of living with HIV. More than half, 31 (62%) did not know that disclosure challenges myths and misconceptions about who becomes infected with HIV. Majority, 45 (90%) said disclosure helps people examine their risks of HIV infection and all respondents, 50 (100%) said it improves adherence to treatment. More than two thirds, 45 (90%) of the respondents said complete disclosure was the best pattern of HIV status disclosure to infected children.
Figure 4.2

Respondent knowledge level of HIV status disclosure (n = 50)

Knowledge level of HIV status disclosure

About three quarters, 38 (76%) of the respondents were graded as knowledgeable of HIV status disclosure.

Table 4.9

Education Level in Relation to Knowledge of HIV Status Disclosure (n = 50)

<table>
<thead>
<tr>
<th>Knowledge of HIV status disclosure</th>
<th>Educational Level</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Never been to school</td>
<td>Primary School</td>
</tr>
<tr>
<td>Knowledgeable 4 - 6</td>
<td>0 (0%)</td>
<td>10 (67%)</td>
</tr>
<tr>
<td>Not knowledgeable 1 - 3</td>
<td>1 (100%)</td>
<td>5 (33%)</td>
</tr>
<tr>
<td>TOTAL</td>
<td>1 (100%)</td>
<td>15 (100%)</td>
</tr>
</tbody>
</table>

Majority of the respondents 10 (91%) with tertiary education were knowledgeable while the only person who did not have formal education 1 (100%) was not knowledgeable about HIV status disclosure.
Table 4.10
Gender in Relation to Knowledge Level of HIV Status Disclosure (n = 50)

<table>
<thead>
<tr>
<th>Knowledge of HIV status disclosure</th>
<th>Gender</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male</td>
<td>Female</td>
</tr>
<tr>
<td>Knowledgeable 4 – 6</td>
<td>12 (100%)</td>
<td>26 (68%)</td>
</tr>
<tr>
<td>Not knowledgeable 1 - 3</td>
<td>0 (0%)</td>
<td>12 (32%)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>12 (100%)</strong></td>
<td><strong>38 (100%)</strong></td>
</tr>
</tbody>
</table>

All the 12 (100%) males were knowledgeable where as 12 (32%) of the females were not knowledgeable.

SECTION D

4. 2.4: ATTITUDE TOWARDS DISCLOSURE

Section D describes data on the caregivers’ views towards HIV status disclosure to the infected children. Respondent’s attitude towards HIV status disclosure is presented in one frequency table and one graph showing respondent level of attitude. Cross tabulations of respondent attitude towards HIV status disclosure and demographics were not done due to lack of variability.
### Table 4.11

**Respondent’s attitude towards HIV status disclosure (n = 50)**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Neither agree nor disagree</th>
<th>Agree</th>
<th>Strongly agree</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV status disclosure to HIV infected children need to be encouraged</td>
<td>4 (8%)</td>
<td>4 (8%)</td>
<td>2 (4%)</td>
<td>8 (16%)</td>
<td>32 (64%)</td>
<td>50 (100%)</td>
</tr>
<tr>
<td>Caregiver is the best person to disclose HIV status to an infected child</td>
<td>2 (4%)</td>
<td>3 (6%)</td>
<td>1 (2%)</td>
<td>1 (2%)</td>
<td>43 (86%)</td>
<td>50 (100%)</td>
</tr>
<tr>
<td>HIV status disclosure helps an infected child examine the risk of HIV infection as they grow into adulthood</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td>3 (6%)</td>
<td>47 (94%)</td>
<td>50 (100%)</td>
</tr>
<tr>
<td>HIV status disclosure helps an infected child cooperate with care</td>
<td>0 (0%)</td>
<td>1 (2%)</td>
<td>1 (2%)</td>
<td>1 (2%)</td>
<td>47 (94%)</td>
<td>50 (100%)</td>
</tr>
<tr>
<td>HIV status disclosure helps an infected child adhere to antiretroviral treatment</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td>1 (2%)</td>
<td>1 (2%)</td>
<td>48 (96%)</td>
<td>50 (100%)</td>
</tr>
</tbody>
</table>

Almost two thirds, 32 (64%) of respondents strongly agreed that HIV status disclosure to HIV infected children need to be encouraged, 43 (86%) strongly agreed that Caregiver is the best person to disclose HIV status to an infected child and 47(94%) strongly agreed that HIV status disclosure helps an infected child examine their risk of HIV infection as they grow into adulthood. The majority 47 (94%) of respondents strongly agreed that HIV status disclosure helps an infected child cooperate with care and 48 (96%) strongly agreed that HIV status disclosure helps an infected child adhere to antiretroviral treatment.
All respondents, 50 (100%) displayed a positive attitude towards HIV status disclosure.

SECTION E

4.2.5 DISCLOSURE OF HIV STATUS

This section sought to determine how much disclosure has been done and the patterns of disclosure used. Findings are displayed in the frequency table below. The level of HIV status disclosure is further displayed in a pie chart that follows. The frequency tables also displays information given by respondents in partial disclosure and reasons respondents gave for disclosure. Cross tabulations of disclosure of HIV status and demographic variables are then presented.
Table 4.12: Disclosure of HIV status to the Child (n = 50)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have you disclosed HIV status to the concerned child?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>27</td>
<td>54</td>
</tr>
<tr>
<td>No</td>
<td>23</td>
<td>46</td>
</tr>
<tr>
<td>Total</td>
<td>50</td>
<td>100</td>
</tr>
<tr>
<td>What pattern of disclosure did you use?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Partial disclosure</td>
<td>11</td>
<td>22</td>
</tr>
<tr>
<td>Complete disclosure</td>
<td>16</td>
<td>32</td>
</tr>
<tr>
<td>Total</td>
<td>27</td>
<td>54</td>
</tr>
</tbody>
</table>

More than half, 27 (54%) respondents had disclosed HIV status to their HIV infected children out of which 11 (22%) only had partial disclosure.

Figure 4.4: Levels of HIV status disclosure

Slightly less than half, 23 (46%) of children were not communicated to about their HIV status, while 11 HIV infected children only had partial disclosure with 16 (32%) of the children having received complete disclosure.
More than half, 7 (64%) of children who received partial disclosure were told to take medicines for the rest of their life and 4 (36%) were told to take drugs daily because they were unwell.
Table 4.13
Reasons for disclosure of HIV status to the concerned children (n = 50)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>What were your reasons for disclosure of HIV status to the concerned child?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not disclosed to</td>
<td>23</td>
<td>46</td>
</tr>
<tr>
<td>Sickness on and off</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>To improve adherence to treatment</td>
<td>13</td>
<td>26</td>
</tr>
<tr>
<td>Child asked questions concerning their sickness</td>
<td>6</td>
<td>12</td>
</tr>
<tr>
<td>Wanted the child to know his/her HIV status</td>
<td>6</td>
<td>12</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>50</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

From the 27 HIV infected children who were disclosed to, only 2 (4%) of the children were disclosed to due to sickness on and off, 13 (26%) were informed in order to improve their adherence to treatment while and 6 (12%) were disclosed to because children asked questions concerning their sickness and another 12% wanted the children to know their HIV status.

Table 4.14
Marital Status in Relation to Disclosure (n = 50)

<table>
<thead>
<tr>
<th>Disclosure</th>
<th>Married</th>
<th>Never married</th>
<th>Separated</th>
<th>Widowed</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(52%)</td>
<td>(75%)</td>
<td>(0%)</td>
<td>(58%)</td>
<td><strong>27</strong> (54%)</td>
</tr>
<tr>
<td>Yes</td>
<td>17</td>
<td>3</td>
<td>0</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>16</td>
<td>1</td>
<td>1</td>
<td>5</td>
<td><strong>23</strong> (46%)</td>
</tr>
<tr>
<td>Total</td>
<td><strong>33</strong> (100%)</td>
<td><strong>4</strong> (100%)</td>
<td><strong>1</strong> (100%)</td>
<td><strong>12</strong> (100%)</td>
<td><strong>50</strong> (100%)</td>
</tr>
</tbody>
</table>

Three quarters, 3 (75%) of Respondents who never married (single parents) had disclosed HIV status to their HIV infected children where as the married and widowed respondents showed 52% and 58% respectively.
Table 4.15:
Religious Denominations in Relation to Disclosure (n = 50)

<table>
<thead>
<tr>
<th>Disclosure</th>
<th>Religious Denomination</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>UCZ</td>
<td>SDA</td>
<td>Roman Catholic</td>
<td>Pentecostal</td>
<td>None</td>
<td>Other</td>
</tr>
<tr>
<td>Yes</td>
<td>2 (67%)</td>
<td>3 (75%)</td>
<td>9 (69%)</td>
<td>5 (36%)</td>
<td>1 (50%)</td>
<td>7 (50%)</td>
</tr>
<tr>
<td>No</td>
<td>1 (33%)</td>
<td>1 (25%)</td>
<td>4 (31%)</td>
<td>9 (64%)</td>
<td>1 (50%)</td>
<td>7 (50%)</td>
</tr>
<tr>
<td>Total</td>
<td>3 (100%)</td>
<td>4 (100%)</td>
<td>13 (100%)</td>
<td>14 (100%)</td>
<td>2 (100%)</td>
<td>14 (100%)</td>
</tr>
</tbody>
</table>

Seventh day Adventist church respondents had 75% of disclosure followed by 69% from Roman Catholic respondents and 67% from the UCZ where as the Pentecostal churches had less than half, 36% of disclosure. * Other comprised of denominations like Baptist, Jehovah’s witness, Anglican and Reformed Church of Zambia who had 50% of disclosure.

Table 4.16: Child Age group in relation to disclosure

<table>
<thead>
<tr>
<th>Disclosed HIV Status</th>
<th>HIV Age Group</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>6 – 8 years</td>
<td>9 – 11 years</td>
</tr>
<tr>
<td>Yes</td>
<td>4 (29%)</td>
<td>12 (60%)</td>
</tr>
<tr>
<td>No</td>
<td>10 (71%)</td>
<td>8 (40%)</td>
</tr>
<tr>
<td>Total</td>
<td>14 (100%)</td>
<td>20 (100%)</td>
</tr>
</tbody>
</table>

Highest disclosure, 69% was observed from children aged 12 to 14 years followed by 60% from those aged 9 to 11 years while children aged 6 to 8 years only had 29% of disclosure.
Table 4.17

Child receiving ARV treatment in relation to disclosure (n = 50)

<table>
<thead>
<tr>
<th>HIV disclosed</th>
<th>Status</th>
<th>Child Receiving ARV treatment</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Yes (57%)</td>
<td>No (25%)</td>
</tr>
<tr>
<td>Yes</td>
<td></td>
<td>26</td>
<td>1</td>
</tr>
<tr>
<td>No</td>
<td></td>
<td>20 (43%)</td>
<td>3 (75%)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td></td>
<td><strong>46 (100%)</strong></td>
<td><strong>4 (100%)</strong></td>
</tr>
</tbody>
</table>

Out of the 46 children, who were receiving ARV treatment, 26 (57%) had disclosure of their HIV status while from the 4 who were not receiving ARV treatment, only 1 (25%) was disclosed to.

SECTION F

4.2.6 Relationship among knowledge of HIV infection, knowledge of HIV status disclosure, Attitude towards HIV status disclosure and disclosure

This section highlights the relationship that exists among the four main variables in the study: knowledge of HIV infection, knowledge of HIV status disclosure, attitude towards HIV status disclosure and disclosure. There is only one cross tabulation in this section: knowledge of HIV status disclosure in relation to disclosure because there was no significance between knowledge of HIV infection, attitude towards HIV infection disclosure and disclosure as 100% of respondents were rated knowledgeable as well as having positive attitude.
Table 4.18
Disclosure in relation to knowledge of HIV status disclosure (n = 50)

<table>
<thead>
<tr>
<th>Disclosed HIV status</th>
<th>Knowledge of HIV status disclosure</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Knowledgeable</td>
<td>Not knowledgeable</td>
</tr>
<tr>
<td>Yes</td>
<td>21 (55%)</td>
<td>6 (50%)</td>
</tr>
<tr>
<td>No</td>
<td>17 (45%)</td>
<td>6 (50%)</td>
</tr>
<tr>
<td>Total</td>
<td>38 (100%)</td>
<td>12 (100%)</td>
</tr>
</tbody>
</table>

P value 0.1

There was no significance difference between disclosure of HIV status and knowledge of HIV status disclosure (Chi square P value - 0.1). More than half, 21 (55%) of the respondents who were knowledgeable had disclosed HIV status to their children where as 6 (50%) of those who were not knowledgeable had disclosed HIV status to there children.
SECTION G

4.2.7 Respondent Suggestions

This section comprises suggestions presented in the frequency table below and were given by caregivers in an effort to improving disclosure to HIV infected children. The section also presents cross tabulation of the male and female suggestions and shows the distribution of the study variables.

Table 4.19

Respondent suggestions on how to improve disclosure to HIV infected children (n = 50)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Give suggestions on how to improve disclosure to HIV infected children</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No suggestion</td>
<td>8</td>
<td>16</td>
</tr>
<tr>
<td>Caregivers need to be helped with information on the process of disclosure</td>
<td>14</td>
<td>28</td>
</tr>
<tr>
<td>Need for consideration of age of the child</td>
<td>24</td>
<td>48</td>
</tr>
<tr>
<td>Need to inform children fully and truthfully about their HIV status</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>Need for follow up counseling for the children</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Total</td>
<td>60</td>
<td>100</td>
</tr>
</tbody>
</table>

Slightly less than half, 24 (48%) of the respondents suggested need to consider age of the children for disclosure to be effective while 14 (28%) of caregivers suggested need for guidance on information to be communicated and the process of disclosure. Only 3 (6%) of the respondents suggested need to inform children fully and truthfully about their HIV status and 1 (2%) suggested need for follow up counseling for the children.
CHAPTER FIVE

5.0 DISCUSSION OF FINDINGS AND IMPLICATIONS FOR THE HEALTH CARE SYSTEM.

5.1 Characteristics of the sample

The sample involved 50 caregivers who brought their children to the paediatric ART clinic at the University Teaching Hospital. The demographic characteristics which were relevant to the study were divided into two groups- demographic data for the caregivers and demographic data for the HIV infected children.

5.1.1 Caregivers

Demographic data for the caregivers included gender, age, marital status, educational level, area of residence, religious denomination and occupation. Table 4.1 findings showed that 38(76%) of the respondents who brought children to the ART clinic were females with only 12(24%) being males. This indicated that most caregivers taking care of sick children are females. This is in agreement with the report from Center for American Progress (2010), which states that women are more likely than men to care for children and elderly or disabled and sick family members. The study found that 69% of unpaid caregivers to older adults in the home are women. In the African setting, this can be attributed to the cultural beliefs that care giving is meant for females.

The age of respondents ranged from 24 – 69 years (Table 4.1). The age range 38-44 years had the highest number of respondents 14 (28%). The age group is a clear indication that the majority of respondents were still in the reproductive age group of 15 to 49 years. This finding is in agreement with 2007 ZDHS where the current age-specific fertility rate is 15-49 years.

About two thirds, 33 (66%) of the respondents were married with 12 (24%) of respondents being widowed and 4 (8%) had never been married (Table 4.1). This is in agreement with the 2007 CSO report where it was found that the median age for marriage in Zambia is at 19.1 years for women and 23.5 years for men since all the respondents spoken to in this study were over these median ages (24-69 years).
Almost all respondents 49 (98%) attained some level of formal education. Slightly less than half of the respondents 23 (46%) attained secondary level of education (Table 4.1). This finding is supported by the CSO (2007) report which states that 54.4% of women and 46.3% of men have attained at least primary school education.

Slightly more than half, 27 (54%) of the respondents were living in high density areas, 12 (24%) from low density while 11 (22%) came from medium density areas (Table 4.1). This is supported by CSO (2007) report which states that out of Zambia’s estimated population of 12million, more than 7.6 million people are still living in poverty.

Almost all respondents 48 (96%) were Christians with Pentecostal churches showing the largest figures of 14 (28%). This is demonstrated by majority of the respondents being protestants 35 (70%) while 13 (26%) were Catholics (Table 4.1). This finding is similar to the one in ZDHS (2007) where in a comparison of HIV prevalence by religion showed that HIV prevalence was high among protestants (15%), followed by Catholics (13%) and other religions (12%).

Less than half, 20 (40%) of the respondents were in informal employment, 12 (24%) were in formal employment while another 12 (24%) were housewives and the remaining 6 (12%) were unemployed (Table 4.1). This is similar to the findings in ZDHS (2007) in the percentage distribution of women and men aged 15-49 employed in the 12 months proceeding the survey by occupation which were professional/technical/managerial 12.4 and 11.3, clerical 4.2 and 1.9, sales and services 69.4 and 39.5, skilled manual 7.2 and 29.8, unskilled manual 0.1 and 1.2, and agriculture 6.7 and 13.3, respectively.

5.1.2 HIV infected children

Demographic data for the children included: age, relationship to the caregiver, grade of the child, duration of child HIV infection and whether child is receiving ARV treatment. Age of the children ranged from 6 to 14 years with the mean age of 10.8 years and standard deviation of 2.423. There were 20 (40%) of children aged 9 to 11 years, 16 (32%) children aged 12 to 14 years and 14 (28%) children aged 6 to 8 years (Table 4.2). This is supported by Wiener et al
(2007) who stated that many HIV-infected children who were not expected to survive childhood are entering adolescence and young adulthood.

Pertaining to respondent relationship with the child, table 4.2 revealed that 36 (72%) respondents were biological children, 4 (8%) nephews, 4 (8%) nieces, 3(6%) grand children with another 3 (6%) of either sister, brother or cousin. Out of the 14 (28%) children who were not brought to the clinic by their biological parents, 11 (22%) were orphaned with 5 (10%) being double orphans. The high number of orphans is supported by CSO (2007) report which states that 15% of children under age 18 are orphaned by the death of one or both parents with Zambia recording 17% single orphaned and 7% double orphaned children.

Only 1 (2%) child was not in school, where as 7 (14%) were in nursery, 26 (52%) in lower primary, 14 (28% in upper primary and 2 (4%) in secondary school. This finding is supported by the CSO, 2007 report which showed that only 6% of both male and female children aged 10 – 14 years had never attended school.

Results showed that 46 (92%) out of 50 children were receiving ARV treatment. This is in agreement with the UTH, HMIS (2010) report which revealed that 1, 737 children were receiving ARVs from the Paediatric ART clinic (Not published). The finding is contrary to the UNAIDS (2009) country report which states that Zambia only had 6,338 children on ART by the end of 2008 and a report by the World Health Organization at the International AIDS Conference conducted in Vienna, Los Angels where it was reported that treatment of HIV-positive children in the developing world grew by 28 percent in 2009, from 276,000 in 2008 to 365,000, but many children are still going untreated (Thomas, 2010).
5.2 DISCUSSION OF EACH VARIABLE

5.2.1 Knowledge of HIV Infection

Knowledge of HIV infection is key to ones’ action to undertake disclosure. In the study, all the 50 (100%) respondents were knowledgeable about HIV infection. In table 4.3, 42 (84%) of the respondents were able to state that HIV is a virus that fights the immune system. The finding is similar to the 2007 ZDHS report where the percentage of women and men who heard about HIV/AIDS in Lusaka Province was 100%.

Majority of the respondents 46 (92%) stated that HIV has no cure and 49 (98%) stated that it is infection that affects both adults and children. This is contrary to results from a study conducted among 1,420 South West Nigerian University undergraduate students in which 34.2% of the students believed AIDS could be cured by medical doctors (Odu & Akale, 2008).

Majority of the respondents, 48 (96%) denied that the disease can come through witchcraft. The finding is contrary to finding in studies by Yamba 1997, in Alter & Dyk (2008), where more than 25% of Zambian subjects ascribed STIs including HIV to witchcraft. The respondents argued that witchcraft is the reason for one man becoming infected and the other remaining uninfected when both men have had sexual contact with the same woman.

All the 50 (100%) respondents agreed that HIV can be transmitted through sexual intercourse. This agrees with findings in a study conducted by Odu and Akale (2008) in which 98.8% of Undergraduate University Nigerian students stated that HIV can be transmitted through unprotected sex.

Majority of respondents, 49 (98%) stated that HIV can be transmitted through contaminated needles and razor blades. However, notably is that out of 50 respondents, 8 (16%) didn’t know that HIV can be transmitted through blood products and 8 (16%) also believed that HIV can be transmitted through sharing of toilets (Table 4.5). The findings agrees with a study conducted in Nigeria by Odu and Akale, (2008), where 30.2% of undergraduate students did not know that one can get HIV through already used injection needles, 10% did not know HIV can be transmitted through blood products and 38.9% stated that one can contract HIV by
sharing a meal with an infected person. The findings are also in line with another study conducted in Sweden on knowledge of HIV infection where almost all the participants (45) knew that HIV can be transmitted through blood and sexual intercourse, but sixteen (16) also stated that HIV might be transmitted through kissing. Four participants also believed that HIV virus could be transmitted through blood in swimming pools and/or in sauna (Asander, 2010). In the two studies, adequate knowledge about HIV infection did not seem to be associated with degree of disclosure.

More than half, 28 (56%) of the respondents did not know that children can contract HIV from the mother in utero while 19 (38%) did not know that children can contract HIV through blood transfusion (Table 4.6). Similar results were obtained from a study by Odu and Akale (2008) in Nigeria where 37.3% of respondents did not know that a pregnant woman can transmit HIV infection to her unborn child.

In table 4.7, respondents were asked about signs of HIV infection in children and all 50 (100%) respondents stated of sickness on and off. Contrary, 24 (48%) of respondents did not know that delayed mental development is a sign of HIV infection in children and 17 (34%) of respondents considered inability to play as a sign of HIV infection in children. The findings slightly differed with findings from a study conducted in Malawi on 445 seropositive children. Features associated with HIV were determined as lymphadenopathy, hepatosplenomegally, oral Candida where any of these were present in the 74% of the HIV infected children. 28% of the HIV infected children were also associated with recurrent respiratory infection, recent out patient or hospital admission (Bunn et al, 2009).

### 5.2.2 Knowledge of HIV Status Disclosure

The study has revealed that 21 (42%) of the respondents did not know what HIV status disclosure is (Table 4.8). This is in agreement with a study by Murphy et al (2003), where qualitative interviews with 47 mothers who had disclosed their HIV status to their children were conducted. Overall, the majority of the mothers (68%) did not regret disclosing their HIV status but confessed the difficulties they faced with the context and content of the process.
Table 4.8 showed that the majority, 36 (72%) respondents considered helping people understand the reality of living with HIV as a benefit of disclosure. This agrees with Rapid Response Services (2009) who cited that HIV status disclosure helps individuals to effectively adapt to living with HIV.

Only 19 (38%) of the respondents agreed that challenging myths and misconceptions about who becomes infected with HIV is a benefit of disclosure. Helping people to examine their risks of HIV infection was considered a benefit of HIV status disclosure by 45 (90%) of the respondents (Table 4.8). The findings agree with a study conducted in Malawi by Bunn et al (2009) who established that benefits of HIV status disclosure include increased opportunities for instrumental and expressive social support, improved access to necessary medication and care as well as increased opportunities to plan for the future carefully and thoughtfully.

An overwhelming response was received from all (100%) of respondents who indicated that improving adherence to treatment is a benefit of HIV status disclosure. This is an indication that most disclosure to children is done mainly for the purpose of improving adherence to treatment. This is supported by a study by Lee & Johann-Liang (1999) who stated that the importance of disclosure relates directly to medication adherence, treatment compliance, sexual exploration, fears associated with premature death, and the child's developing autonomy.

Majority, 45 (90%) of respondents in table 4.9 considered complete disclosure as the best pattern of HIV status disclosure to children. This is contrary to a study conducted in New York where it was reported that a change in perspectives was taking place regarding the process of disclosure, whereby it may be approached as a gradual discussion process over the life of the child. A method of gradual and partial disclosure to the child with consistent support by a multi-disciplinary team of providers was reported to be a successful strategy for many children cared for at the New York Hospital-Cornell University Medical Center. Of 73 perinatally HIV-infected children who were 6 years of age or older, 41% had complete disclosure and another 19% were partially disclosed to. Continuous communication and negotiation among the members of the team, which included the parents and caregivers, were
considered vital to the gradual process leading to complete disclosure (Lee & Johann-Liang, 1999).

Figure 4.2 revealed that 38 (76%) of respondents were knowledgeable of HIV status disclosure where as 12 (24%) were found to be not knowledgeable. Levels of respondents’ knowledge may be attributed to little discussions over disclosure by health providers with caregivers due to shortage of manpower among counselors. The findings of the study is supported by a study conducted by Murphy et al (2003) in which mothers described their preparation and the process of the disclosure event in which results showed that 38% of mothers who had disclosed their HIV status to their children said they needed more knowledge and psychological support in order to prepare for the process of disclosure.

Figure 4.10 showed that the respondent educational level influenced their level of knowledge of HIV status disclosure. Respondents who attained tertiary education showed that 10 (91%) out of 11 were knowledgeable. Those who attained secondary education had 18 (78%) out of 23 who were knowledgeable while the primary school educational level revealed 10 (67%) out of 15 respondents were knowledgeable. All (100%) of respondents who had not been to school revealed that they were not knowledgeable. This clearly indicated that the better the education respondents attained, the better their knowledge level. This could be attributed to the level of understanding attained though education.

In table 4.11 showing gender in relation to knowledge of HIV status disclosure, study findings revealed that all males, 12 (100%) were knowledgeable of HIV status disclosure where as 12 (32%) of the females were not knowledgeable. This is in agreement with CSO’s statement that; in Zambia, more males are educated than females (CSO, 2007). This could be attributed to the fact that males have got better access to information through the media than females who are kept busy with house work and caring for the family. This disadvantages females who are the majority of caregivers. There is therefore, need to continue improving girl child education which will in turn empower them to be better caregivers.
5.2.3 Attitude Towards Disclosure

This section portrays the views of respondents towards HIV status disclosure. In table 4.12, respondents' attitude towards HIV status disclosure revealed that more than half 48(96%) of respondents strongly agreed that HIV status disclosure helps an infected child adhere to antiretroviral treatment. The finding is echoed by a study conducted on HIV infected youths in Congo D.R. Interviews with youths revealed a strong link between disclosure and their reported adherence to medication regimens. Many youths indicated that knowing their HIV status helped them to take their medicines regularly (Oberdorfer et al, 2006).

It was also revealed that 47 (94%) of respondents strongly agreed that HIV status disclosure helps an infected child examine their risk of HIV infection as they grow into adulthood and helps to corporate with care respectively. The finding agrees with a study conducted in Congo D.R on disclosure of HIV status to children. Interviewed youths expressed that once minors know their HIV-positive status, they can protect themselves, as well as not transmitting the infection to others (Oberdorfer et al, 2006).

All the respondents, 50 (100%) had a positive attitude towards HIV status disclosure. This is contrary to a study conducted in Thailand in which the attitude of caregivers towards HIV status disclosure to HIV infected children was explored. 41 caregivers that had not disclosed HIV diagnosis to their children were recruited and asked to complete a questionnaire. Results showed the children's median age was 7 years (ranges 2.8 to 13 yrs). Seventeen percent (17%) of caregivers were unsure whether the children were aware of their HIV status. Sixty-three (63%) and thirty seven (37%) intended to disclose and not disclose respectively (Apateerapong et al, 2006). In another study by Arun et al (2009), 86% of caregivers felt mid teenage was the appropriate age for disclosing the HIV infection status to infected children.

The findings showed that respondents who had disclosed and those who had not disclosed HIV status to their infected children both had positive attitude towards HIV status disclosure. The finding is contrary to results by Apateerapong et al (2006) where 37% of caregivers intended not to disclose HIV status to their HIV infected children.
The study results therefore, indicated that respondent’s positive attitude did not influence disclosure. The findings are contrary to the study conducted in Kinshasa, Democratic Republic of Congo (DRC) where within the context of treatment programs, disclosure of HIV status to children was supported by caregivers as a means to improve adherence to medication (Corneli et al, 2009). These findings as such, nullify the hypothesis which states that there is a relationship between HIV status disclosure by caregivers and attitude towards disclosure.

5.2.4 Disclosure of HIV Status

This section provides information on disclosure given by caregivers to their HIV infected children as determined in the sample. The study findings showed that 27 (54%) out of 50 respondents had disclosed the HIV status while 23 (46%) had not disclosed to the concerned children. The findings are similar to a study conducted on 77 perinatally HIV infected children aged 6 to 13 years. The majority of children in this study (70%) did not know their HIV status (Mellins et al, 2009).

It was also revealed that out of the 27 respondents who had disclosed HIV serostatus to the infected children, 11 (22%) of the children had only received partial disclosure. These results are similar to findings of a study by Kallem et al (2010) in a cross sectional study of 71 caregiver child dyads from the paediatric HIV/AIDS care programme at Korie-Bu Teaching Hospital in Accra, Ghana where the prevalence of disclosure among children aged 8 to 14 years of age was 21%.

Out of the 11 children that had received partial disclosure, 7 (14%) were told they were to take drugs daily for the rest of their lives while the remaining 4 (8%) were told to take drugs daily because they were unwell. The results are in agreement with a study conducted in Thailand where 75 caregivers of HIV-infected school children (aged 6 to 15 years), between November-December 2003, at the Chiangmai University and Sanpatong district hospitals, were interviewed using a semi-structured questionnaire. Up to 69% of children were reported not having known their HIV/AIDS status. Among the caregivers who reported having disclosed the status, more than half (61%) did not explain to the children about HIV/AIDS correctly (Oberdorfer et al 2004).
Two years later, similar results were obtained in another study conducted among 103 main care givers of HIV-infected children aged > or =6 years who received highly active antiretroviral therapy at Chiang Mai University and Sanpatong district hospitals, northern Thailand. Results revealed that one-third (30.1%) of the children knew their HIV/AIDS status at an average age of 9.2 years. The care givers' understanding of 'knowing' did not always mean that the children were told the name of 'HIV' or 'AIDS'. Many of those care givers (84.3%) who reported that the child did not know their diagnosis had inaccurately explained to the child that he or she had some kind of disease such as allergy, lung, or liver disease(Oberdorfer et al, 2006).

To improve adherence to treatment was the main reason for disclosure given by 13 (26%) of the respondents followed by 6 (12%) who stated reasons as being children asking questions concerning their sickness and the other 6 (12%) just wanted the children to know their HIV status. The remaining two stated their reasons for disclosure as being sickness of the children which was on and off. These findings are supported by a qualitative study which was conducted using focus groups and interviews with parents and guardians of HIV-infected children receiving ART in western Kenya. Data were collected from 120 parents and guardians caring for children 0–14 years (mean 6.8 years, SD- 6.4); 118 of 120 had not told the children they had HIV. Children's caregivers (parents and guardians) described their views on disclosure to children and to others, including how this information-sharing impacted pediatric ART adherence, children's well-being, and their social relationships. Caregivers believed that disclosure might have benefits such as improved ART adherence, especially for older children, and better engagement of a helping social network.

Three (3) (75%) out of 4 respondents who never married had disclosed followed by 7 (58%) out of 12 who were widowed. Only 17 (54%) out of the 33 married respondents made disclosure while 100% of the separated never disclosed. This is similar to issues of consent prior to operations which have proven delays related to consultations (Monahan et al, 2007). Additionally, the never married and widowed caregivers may be more close and open to their children as compared to their married counterparts who may have divided attention between the children and their partners.
Religious denomination in relation to disclosure in table 4.15 revealed that SDA church had the highest disclosure of 3 (75%) out of 4. This was followed by 9 (69%) out of 13 respondents. The lowest figure came from the Pentecostal churches which only had 36% of disclosure. High percentage of HIV status disclosure in SDA Church is attributed to lessons they undergo and church policies regarding HIV testing before marriage.

Child age group in relation to disclosure showed that 69% of disclosure was given to children aged 12 – 14, 60% to those aged 9 – 11 and only 29% to children aged 6 – 8. This is attributed to fears caregivers have that children below 9 years could be too young to understand issues of HIV. Caregivers might also be fearing that at this age, the children may not be able to keep confidentiality of their HIV status. The results are supported by the study conducted in Hyderabad, Nalgonda, and Krishna districts of Andhra Pradesh, and Bishnupur, Chandel, and Imphal East districts of Manipur in India. The research was exploratory in nature, and had used a mix of qualitative and quantitative methods. Respondents were caregivers of 7-14 years age groups who had been referred for HIV testing. A key finding related to age was that 10 years old or older was considered the appropriate age for disclosure by most parents (Vijay, 2009).

57 percent of children who were receiving ARV treatment were disclosed to and only 25% of children who were not on ARV treatment received disclosure. Children receiving ARV treatment was one criterion caregivers were using to disclose HIV status to the children. This could be attributed to the earlier caregivers’ reasons for disclosure which was stated to be improvement of adherence to treatment. This is supported by the Human Rights Watch research in Kenya which showed the disastrous effects of poor disclosure policies. Results showed that children who do not know they are HIV-positive may be less likely to take their medication regularly, which can lead to drug resistance and eventual death (Kippenberg, 2010). This is echoed by another study by Oberdorfer et al (2006), where results showed that when care givers were asked what they thought were advantages of disclosing the HIV/AIDS status to children, they reported that after knowing their status the children might adhere to HAART and look after themselves well (78.2%), be more relaxed (15.6%) and know the facts about their illness (6.2%).
5.3 Relationship among Knowledge of HIV Infection, Knowledge Of HIV Status Disclosure, Attitude Towards HIV Status Disclosure and HIV Status Disclosure

This section discusses the relationship existing among the four study variables which are: knowledge of HIV infection, knowledge of HIV status disclosure, attitude towards HIV status disclosure and disclosure.

A Chi-square test was conducted between knowledge of HIV status disclosure and HIV status disclosure which revealed no significant difference between the two with a P-value of 0.1. Table 4.3 gives a distribution of the study variables showing the following values; Knowledge of HIV infection ranged from 17 to 25 scores with the mean score of 20.78. Findings demonstrated a high knowledge level. The demonstrated high (100%) levels of knowledge of HIV infection did not influence HIV status disclosure evidenced by 23 (46%) respondents who were rated as knowledgeable but did not disclose HIV status to their infected children. Findings of the study agrees with results from a study conducted by FAO in Uganda (2010) to assess knowledge, attitudes and practice about HIV/AIDS. To assess peoples' knowledge of HIV/AIDS, study respondents were first asked whether they knew any person in their community who had AIDS, and if they had taken care of PLHA. Overall, 92.7% of the respondents had ever known a person who had AIDS in their community, while 74.8% reported to have ever taken care of a relative or household member who had HIV/AIDS. Over a half of the respondents (56.6%) had ever taken care of two or more persons with HIV/AIDS. Results revealed that, despite high knowledge about HIV, remarriages were still taking place as reported by almost a fifth (19.2%) of the respondents. A tenth of the sample (10.5%) reported sharing of skin cutting or piercing instruments as a practice that lead to the spread of HIV/AIDS. This was much related to traditional healing practices where a single razor blade can be used on several patients to administer local medicine. Other socio-cultural practices mentioned to contribute to the spread of HIV/AIDS were polygamy (9.6%) and alcoholism (6.7%). Respondent knowledge was therefore, not related to their practice. Similarly, the assumption that knowledge of HIV infection influences the caregivers’ ability to disclose HIV
status to their infected children is therefore, contrary to study findings. Reasons for non influence could be that the actual information on disclosure is not included. The findings, therefore, rejects the hypothesis that there is a relationship between disclosure of HIV status and knowledge of HIV infection.

About two thirds, 38(76%) of respondents were rated knowledgeable and 12(24%) were rated not knowledgeable of HIV status disclosure. More than half, 21(55%) of respondents who were rated knowledgeable and half, 6(50%) of those rated not knowledgeable had disclosed HIV status to their infected children. The study finding is contrary to study findings by FAO where several respondents and key informants knew the various ways of preventing and controlling the spread of HIV/AIDS. The study revealed the issue was not lack of knowledge on how to prevent HIV infection, but rather behavioral change. Findings showed 46.0% of all respondents reported that condom use would prevent HIV infection, but only 15.3% had ever used it in their life. The study finding therefore, makes us fail to reject the hypothesis that there is a relationship between knowledge of HIV status disclosure and disclosure.

Score range on attitude towards HIV status disclosure was 17 to 25 with a mean of 23.61 indicating a positive attitude towards HIV status disclosure by all respondents (100%). Despite positive attitude from all respondents, only 54% of the caregivers disclosed HIV status to their infected children. In this study, findings demonstrated that positive attitude did not influence HIV status disclosure thereby, rejecting the hypothesis which stated that there is a relationship between attitude towards HIV status disclosure and disclosure.

5.4. IMPLICATIONS TO THE HEALTH CARE SYSTEM

Lack of disclosure of HIV status to infected children leads to secrecy of information, where caregivers and health providers fail to discuss issues freely in the presence of the affected child. When information is not communicated adequately, there is usually misinterpretations and misunderstandings. This may also result into suspicions and speculations by the child which may result into mistrust of the health care system. None disclosure may also result into poor adherence of the child to treatment which in turn will result into appearance of opportunistic infections thus increasing chances of frequent admissions to the hospital thereby
increasing workload and expenditure. The hospital therefore, needs to put up measures that will help improve HIV status disclosure to infected children e.g. increasing number of trained child counselors and prepare caregivers adequately for disclosure.

5.4.1 Nursing Practice

Nursing practice has responsibilities in disclosure of HIV status. This is because it is difficult for caregivers on their own to undertake disclosure. In the study findings on attitude, 43 (86%) of the respondents strongly agreed that caregivers are the best individuals to disclose HIV status to an infected child. It is therefore the responsibility of health providers especially nurses who are in constant contact with these clients to ensure that caregivers are equipped with knowledge and skill that will enable them handle disclosure as well as preparing caregivers for the process of disclosure.

Disclosure may also be influenced by inadequacy of counseling of care providers. It is imperative that health providers should be equally tackling issues of disclosure. Counseling of the caregiver should therefore be an ongoing process throughout their encounter with health providers. On respondent suggestions, the study revealed that 14 (28%) of respondents would want caregivers to be helped on the process of disclosure. The study also revealed that level of respondents on HIV status disclosure was good but 24% of the respondents were not knowledgeable. Moreover, nurses ought to be friendlier to allow caregivers ask questions where they are not sure for clarifications.

5.4.2 The Hospital Administration

- The finding that knowledge of HIV status disclosure influences HIV status disclosure requires that awareness campaigns be carried out to sensitize the community on this important matter.

- Considering the high numbers of HIV infected children whose HIV status has not been disclosed, 23 (46%), there is a great need to increase the number of psychosocial and child counselors in the department. The hospital need to also consider sponsoring nurses for these short courses because currently nurses sponsor themselves to undertake the counseling
courses. This in turn limits the number of nurses who may desire to do counseling due to limited resources. Increasing the number of counselors will not only improve the quality of counseling but also reduce the burn out on the available counselors. The hospital need to therefore allocate more counselors to the pediatric ART clinic.

5.4.3 Nursing Education

The issue of counseling remains very important in HIV care, therefore, there is need to improve counseling services country wide why, how does your study imply this?. This can only be achieved through a deliberate move of incorporating counseling in the nursing curriculum to equip all the nursing staff with knowledge and skill as they qualify to go into the field. The measure will not only offset the shortage of counselors but will improve the quality of counseling services provided. It will also shove off the burden of self sponsorship by nurses.

5.4.4 Nursing Research

Disclosure of HIV status to infected children is key to improving HIV care as well as to reducing transmission of HIV. No study has been carried out in Zambia on disclosure of HIV status to infected children and the findings of this study revealed that only 32% of children received complete disclosure with 22% having received partial disclosure while the remaining 46% had not been disclosed to. This research finding needs to be an eye opener to the policy makers to find a way of improving disclosure in the pediatric HIV care programmes. There is therefore, need to carry out more research on a wider scale which will assist determine the extent of pediatric HIV disclosure in Zambia.

5.5 RECOMMENDATIONS

The purpose of the study was to determine how much HIV status disclosure exists in pediatric HIV with focus on the caregiver’s knowledge and attitude. Considering that the study has revealed 100% of respondent knowledge of HIV infection and positive attitude towards disclosure regardless of whether disclosure has been done or not, the researcher wishes to make recommendations to key offices in an attempt to improve pediatric disclosure.
5.5.1 To the Ministry of Health

- Ministry of Health as a policy making body needs to consider improving nursing staffing in health institutions so as to avert shortages which will in turn improve health services to HIV infected children. Counseling having become an important aspect in nursing requires that the ministry sponsor programs where all nursing staff can be trained in the skill to improve the quality of counseling services.

- The study revealed that caregivers require assistance on the process of disclosure. The ministry needs to consider development of disclosure guides for both the health providers and for the caregivers. This will assist the two parties be confident in handling issues of disclosure as evidenced by knowledgeable respondents with positive attitudes who were not able to disclose HIV status to the children.

- The Ministry also needs to support research programmes in disclosure of HIV status within the paediatric HIV programmes that will help improve the successes of pediatric HIV care.

- The Ministry needs to carry out sensitization campaigns on disclosure of HIV status to the communities.

5.5.2 To the General Nursing Council

- The general Nursing council needs to consider incorporation of counseling skills in the General Nursing curriculum so that nurses can qualify already equipped to reduce on need for such courses after qualification.

5.5.3 To the Hospital Management

- The hospital should support nurses who want to undertake counseling by sponsoring them as it used to be before. This will not only improve counseling services but will also motivate the staff who will in turn provide quality services to the satisfaction of clients.

- Management should also encourage and support staffs who want to undertake research in various areas including paediatric HIV in order to improve quality of health care services including disclosure to HIV infected children.
Disclosure of the diagnosis to an HIV-infected child should be individualized to include the child’s cognitive ability, developmental stage, clinical status, and social circumstances.

Caregivers of an HIV-infected child should be counseled by a knowledgeable health care professional about disclosure to the child of their infection status. This counseling may need to be repeated throughout the course of the child's illness.

5.5.4 Recommendations for further study

Despite significant advances in HIV treatment and care, children continue to be born with HIV infection, and disclosure of HIV infection to children remains a pertinent issue.

There is need for further studies to be conducted on paediatric HIV status disclosure on a larger scale in order to determine how much disclosure exists because the sample of this study can not be representative to the larger population.

A longitudinal study is critical for understanding the processes of disclosure in children.

There is need to determine reasons for non disclosure by caregivers who have not yet made disclosure to their HIV infected children in the subsequent studies.

5.6 DISSEMINATION OF FINDINGS

A number of copies will be printed and distributed to the following areas:

- The Department of Nursing Sciences of the University of Zambia for the upcoming students who would like to undertake a similar study to use for referencing.

- Ministry of Health who are the sponsors of the researcher and the project. This will enable the Ministry being the policy maker, to use the research findings to formulate policies and come up with programmes that will improve HIV status disclosure in the paediatric HIV care.

- The University of Zambia, School of Medicine Library to keep record of the study in order to help students with literature review.
The University Teaching Hospital who will use the findings to improve HIV status disclosure in the paediatric HIV care.

At the University Teaching Hospital paediatric department, where the research was conducted, the researcher will organize a one day meeting to disseminate the findings. This will help the counselors to work on their short comings in counseling thus improve the services. A research summary will also be given to the Paediatric Head of Department.

5.7 LIMITATION OF THE STUDY

The data collection tool did not have information to find out reasons for non disclosure of HIV status from respondents who had not disclosed HIV status to their children which could have assisted to discover the barriers to disclosure.

The data collection tool did not have information to find out the HIV status of caregivers which in some way could have assisted them to disclose HIV status to the children.

It was quite difficult for me to access literature pertaining to this study as limited studies have been conducted on the same with none carried out within Zambia.
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APPENDIX I

THE UNIVERSITY OF ZAMBIA

SCHOOL OF MEDICINE

DEPARTMENT OF NURSING SCIENCES

INTERVIEW SCHEDULE

STUDY TITLE: DISCLOSURE OF HIV STATUS BY CAREGIVERS OF HIV INFECTED CHILDREN AT THE UNIVERSITY TEACHING HOSPITAL.

DATE OF INTERVIEW: ____________________________________________________________

PLACE OF INTERVIEW: __________________________________________________________

NAME OF INTERVIEWER: _________________________________________________________

SERIAL NUMBER [ ]

INSTRUCTIONS TO INTERVIEWER

1. Introduce yourself to the interviewee.
2. Explain the purpose of the interview.
3. Get written consent from the interviewee.
4. Assure the interviewee of confidentiality and anonymity.
5. Do not write the name of the respondent on the schedule to ensure anonymity
6. For open ended questions, write responses in spaces provided.
7. For closed ended questions, tick in boxes provided.
8. Thank the respondent at the end of each interview.
SECTION A: DEMOGRAPHIC DATA

1. Caregiver Demographic Data

   1. Gender
      a. Male
      b. Female

   2. How old were you on your last birthday? ................. years

   3. What is your marital status?
      a. Married
      b. Never married
      c. Separated
      d. Divorced
      e. Widowed

   4. What is your educational level?
      a. Never been to school
      b. Primary school
      c. Secondary school
      d. Tertiary level

   5. Where do you live?
      a. Low density area
      b. Medium density area
      c. High density area
      d. Other (specify) ............................................
6. What religious denomination do you belong to?
   a. United Church of Zambia
   b. Seventh Day Adventist Church
   c. Roman Catholic
   d. Pentecostal
   e. None
   f. Other (Specify)

7. What is your occupation?
   a. None
   b. Formal employment
   c. Informal employment
   d. Housewife
   e. Other (Specify)

II. Child Demographic Data

8. How old is the child? years

9. What is your relationship with the child?
   a. Biological parent
   b. Nephew
   c. Niece
   d. Grandparent
   e. Other (Specify)

10. If not biological child, are the parents alive?
   a. Yes, both are alive
   b. Only one is alive
   c. None is alive
11. In what grade is the child? ..............................................

12. How long have you known the child to have HIV infection?
...............months/ years

13. Is the child receiving ARV treatment?
   a. Yes
      { }
   b. No
      { }

SECTION B: KNOWLEDGE OF HIV INFECTION

14. What is HIV? (Tick all correct responses)
   a. A virus that fights the immune system
      { }
   b. A disease that can be cured
      { }
   c. A disease that has no cure
      { }
   d. Infection that affects only adults
      { }
   e. Infection that affects adults and children
      { }
   f. A disease that comes through witchcraft
      { }

15. How is HIV transmitted (Tick all correct responses)
   a. Through mosquito bites
      { }
   b. Through sexual intercourse
      { }
   c. Through infected blood products
      { }
   d. Through contaminated needles and razor blades
      { }
   e. Through sharing of toilets
      { }
   f. Through mother to child
      { }
16. How do children contract HIV infection? (Tick all correct responses)

a. through sexual intercourse  

b. through Defilement  

c. from the mother to child in uterus  

d. from the mother to child during birth  

e. from the mother to child through breast milk  

f. through blood transfusion  

g. Through mosquito bites  


17. What are the signs that would make you think a child could have HIV infection? (Tick all correct answers)

a. Slowed growth  

b. Delayed mental development  

c. Enlarged lymph nodes  

d. Sickness on and off  

e. Inability to play  

f. Child growing tall and slim  


SECTION C: KNOWLEDGE OF HIV STATUS DISCLOSURE

18. What is HIV status disclosure?
   a. Informing the child that they have HIV infection?
   b. Informing the child that they have AIDS?
   c. Informing the child that they are sick?
   d. Informing the child that they will take ARVs for life?

19. What are the benefits of disclosure? (Tick all correct answers)
   a. Helps people understand the reality of living with HIV
   b. It challenges myths and misconceptions about who becomes infected with HIV.
   c. It helps people to examine their risks of infection
   d. Improves adherence to treatment

20. What is the best pattern of HIV status disclosure to an HIV infected child?
   a. Partial disclosure where only part of the HIV status information is communicated to the infected child.
   b. Complete / Full disclosure where all the HIV status information is communicated to the infected child.
   c. Telling the child they have some infection without disclosing the nature of the infection.
   d. Delayed disclosure where HIV status is not communicated until the child falls sick.
SECTION D: ATTITUDE TOWARDS DISCLOSURE

21. HIV status disclosure to HIV infected children need to be encouraged?
   a. Strongly agree { }
   b. Agree { }
   c. Neither agree nor disagree { }
   d. Disagree { }
   e. Strongly disagree { }

22. Caregiver is the best person to disclose HIV status to an infected child
   a. Strongly agree { }
   b. Agree { }
   c. Neither agree nor disagree { }
   d. Disagree { }
   e. Strongly disagree { }

23. HIV status disclosure helps an infected child examine the risk of HIV infection as they grow into adulthood.
   a. Strongly agree { }
   b. Agree { }
   c. Neither agree nor disagree { }
   d. Disagree { }
   e. Strongly disagree { }
24. HIV status disclosure helps an infected child cooperate with care
   
   a. Strongly agree
      { } 
   b. Agree
      { } 
   c. Neither agree nor disagree
      { } 
   d. Disagree
      { } 
   e. Strongly disagree
      { } 

25. HIV disclosure helps an infected child adhere to antiretroviral treatment

   a. Strongly agree
      { } 
   b. Agree
      { } 
   c. Neither agree nor disagree
      { } 
   d. Disagree
      { } 
   e. Strongly disagree
      { } 

SECTION E: DISCLOSURE OF HIV STATUS

26. Have you disclosed the HIV serostatus to the infected child?

   a. Yes
      { } 
   b. No
      { } 

27. If yes to question 26 above, what pattern of disclosure did you use when

   you disclosed the HIV serostatus to the infected child?

   a. Partial disclosure
      { } 
   b. Complete disclosure
      { }
28. If partial disclosure, what information was the child given? ........................................
.................................................................................................................................
.................................................................................................................................
.................................................................................................................................

29. What led to disclosure of HIV status to the concerned child?
.................................................................................................................................
.................................................................................................................................
.................................................................................................................................

30. Please give suggestions on how disclosure of HIV serostatus to infected children can be improved?
.................................................................................................................................
.................................................................................................................................
.................................................................................................................................

Thank you for your cooperation in answering the questions
APPENDIX II

CONSENT FORM

My name is Inambao Nalishebo, a final year Bachelor of Science in Nursing student at the University of Zambia, School of Medicine, Department of Nursing Sciences. I am required to undertake a research project as partial fulfillment of this program. My research topic is “HIV status disclosure by caregivers of HIV infected children”.

The purpose of the study is to establish HIV status disclosure among caregivers of HIV infected children. Your participation in the study is voluntary, you are free to refuse to participate or withdraw from the study at any point without your child suffering any denial of care. You will be asked questions concerning disclosure of HIV status to your child. Your name will not be written on the interview schedule and the information you will give will be treated with confidentiality.

Your participation in the study will not benefit you in terms of financial or material gains. However, the information that you will provide will be used to come up with programmes that will facilitate strengthening HIV/AIDS programmes for children. If you agree to take part in the study please sign below.

I........................................................................................................understand the essence of this study and I am ready to participate in the study.

Signature/ thumb print of participant..............................................................................................................

Date: ........................................................................

Signature of interviewer....................................................
The University of Zambia  
School of Medicine  
Department of Nursing Sciences  
P.O. Box 50110  
LUSAKA

17th November, 2010

The Senior Medical Superintendent  
University Teaching Hospital  
P/B RW 1X  
LUSAKA.

u.f.s. The Head of Department,  
Department of Nursing Sciences,  
P.O. Box 50110,  
LUSAKA

Dear Sir,

RE: PERMISSION TO CONDUCT A RESEARCH PROJECT

I am a fourth year Bachelor of Science in Nursing student at the School of Medicine, University of Zambia. In partial fulfillment for the award of the degree, I am required to undertake a research project. My topic is "Disclosure of HIV status by caregivers of HIV infected children".

I write to request your office for permission to conduct research at your institution. Pilot study will be conducted on a minimum of five caregivers of HIV infected children aged 6 -14 years on wards AO4 & A08 from 22nd to 24th November and the main study on fifty caregivers of HIV infected children at the Pediatric ART clinic from 25th November to 9th December, 2010. Attached is a copy of my research proposal. In case of need for further details and clarifications, please contact my supervisor, Dr. P. Mweemba, at the Department of Nursing Sciences. Your favorable consideration of my request will be highly appreciated.

Yours faithfully,

Inambao Nalishebo (4th year student BSc N)
## APPENDIX IV - WORK SCHEDULE

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## APPENDIX VI

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BUDGET JUSTIFICATION

The budget for this proposal has been divided into four parts namely; stationary, personal costs and secretarial services. This is so because the sections highlighted in the budget are cardinal for the research to be carried out successfully.

Stationary

The reams of paper will be used for printing and photocopying the research proposal, interview schedule, research report and letters for permission. The other stationary include the scientific calculator which will be used during analysis of data. Other items are required for routine data collection. The flip chart will be used for drawing up the data master sheet as well as during dissemination of information. Markers, pens, pencils erasers will be used during collection and processing of data. The memory stick will be used for storage of data.

Secretarial Services

Secretarial services will be used for typing, printing and photocopying the research proposal and the research report with the appendices as well as binding of the final research report.

Personnel

Since the research will be conducted in Lusaka, the researcher will require accommodation during the data collection period. The researcher will be paid lunch allowance as data collection may last the whole day. 10% of the budget is intended to cover up for unforeseen costs, other circumstances and inflation.