

UNIVERSITY OF ZAMBIA

SCHOOL OF MEDICINE

DEPARTMENT OF PUBLIC HEALTH

**DISCLOSURE OF HIV STATUS TO ADOLESCENTS AGED 10-15
YEARS LIVING WITH HIV IN KAFUE DISTRICT OF LUSAKA
PROVINCE IN ZAMBIA**

MABLE MWEEMBA

**A dissertation submitted to the University of Zambia in partial fulfillment of the
award of the degree of Master of Public Health in Health Promotion**

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DECLARATION

I **Mable Mweemba** do hereby declare that this dissertation represents my own work and that it has never been submitted before for the award of a degree or any other qualification at this university or any other university.

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We, **Dr. H. Halwiindi** and **Mr. J. Zulu**, having read this dissertation are satisfied that this is the original work of the author under whose name it is being presented. We confirm that the work has been completed satisfactorily and is hereby ready for presentation to the examiners.

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DEDICATIONS

This dissertation is dedicated to my dear husband **Dr. Maurice Musheke** for the inspiration to aim higher in life as my role model and mentor, as well as my son **Lumba Musheke** and daughter **Malele Musheke** who endured my absence and divided attention due to this work. I also dedicate this to my family for the moral support, and friends who supported and encouraged me during the course of my studies.

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ABBREVIATIONS AND ACRONYMS

AIDS.....Acquired Immune Deficiency Syndrome

ART.....	Antiretroviral Therapy
CSO.....	Central Statistics Office
DRC.....	Democratic Republic of Congo
ERES.....	Excellence in Research Ethics and Science
HIV.....	Human Immuno Virus
MOH.....	Ministry of Health
MPH.....	Master of Public Health
NAC.....	National AIDS Council
SSA.....	Sub-Saharan Africa
UNAIDS.....	Joint United Nations Programme on HIV/AIDS
USA.....	United States of America
WHO.....	World Health Organization
ZDHS.....	Zambia Demographic and Health Survey

DEFINITIONS OF KEY TERMS

Adolescents: Young people aged between 10 and 19 years of age (WHO 2010). In this study, adolescents are young people aged between 10 and 15 years. Focus on this age group was chosen because they are considered as pediatrics in the clinics and still

being escorted to health facilities by their caregivers, hence made it possible to get their caregivers for the study without much trouble.

Caregiver: The caregiver is defined as a person who has lived with the child for not less than 6 months and participates in the child’s daily care and is the most knowledgeable about the child’s health. The caregiver could either be a biological parent or guardian acting as a surrogate parent to the child.

Pharmacy pick up: This is when the caregiver comes to pick up medication for the adolescent and occurs on or before date for routine medical review.

Clinical review: This is when a caregiver brings the adolescent for routine review by the clinician.

Disclosure of HIV status: This is when the adolescent has been told about his or her HIV infection and knows about the status and the name of the disease.

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Abstract

Background: Disclosure of HIV status by caregivers to adolescents is low. This affects access to HIV care and treatment by adolescents living with HIV. While studies have been done to understand disclosure patterns, limited knowledge exists on factors that facilitate and inhibit disclosure by caregivers to adolescents aged between 10 to 15 years in Kafue district. This study explored factors related to caregiver disclosure of HIV-positive status to adolescents under their care.

Methods: This was an exploratory health facility-based qualitative study. Data was collected through in-depth interviews with 30 caregivers of adolescents living with HIV and health care providers. Data was coded using NVIVO and analysed using latent content analysis approach.

Results: 17 out of 30 caregivers had informed the adolescents about their HIV status. Reasons for disclosing the HIV status included inquiries by adolescents about reasons for taking of medication, threats by adolescents not to take HIV medication, desire to promote treatment self-efficacy amongst adolescents, maintaining/sustaining future cordial relationships as well as facilitating adoption of safe sexual behaviour. Direct conversations between caregivers and adolescents as well as assisted disclosure at the health facility were the two strategies used. Factors that facilitated HIV disclosure were adolescents' knowledge of HIV and caregiver's knowledge of and experience with HIV programs. Factors that inhibited disclosure of HIV status included fear of psychological trauma by adolescents, perceived inability of adolescents to keep their HIV status confidential which could attract HIV stigmatisation for the family, and caregivers' fear of being blamed by the adolescents for the infection.

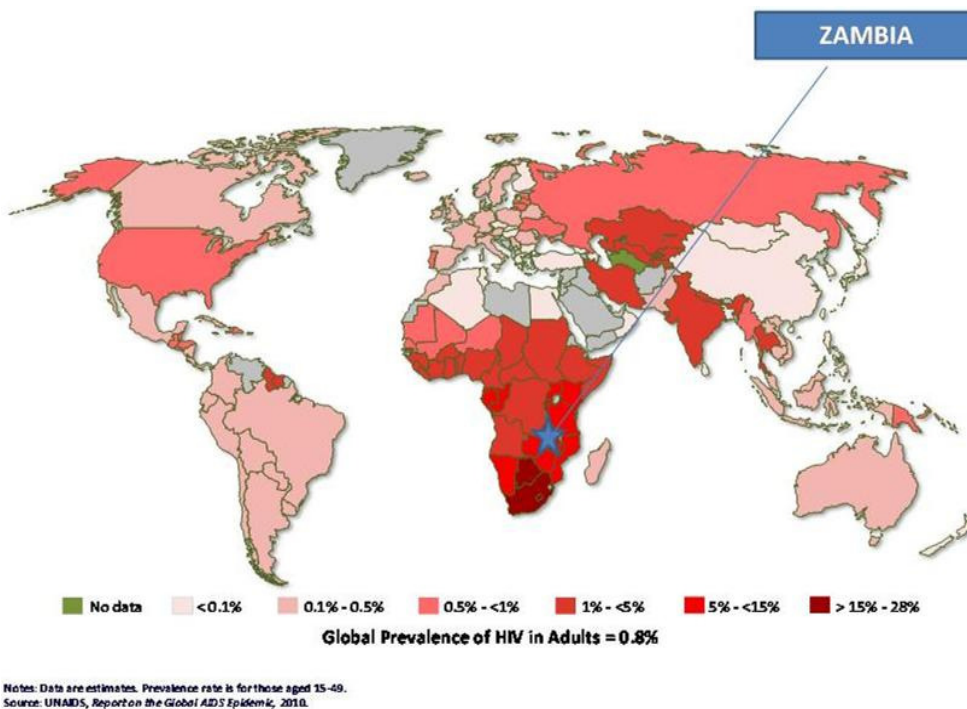
Conclusions: There is a need to improve disclosure skills of caregivers, promote assisted disclosure and establish adolescent-specific clinic days. Caregiver disclosure of their own HIV status is also crucial to ensure acceptance of HIV status by adolescents while efforts to address HIV stigma are still warranted.

CHAPTER ONE

1.0 Introduction

Since its first recognition as a disease in the early 1980s, the Human Immunodeficiency Virus (HIV) has spread throughout the world to the extent of it now being rated as the world's fourth most common cause of death. In 2010, there were an estimated 34 million people living with HIV, 2.7 million new infections, and 1.8 million AIDS-related deaths (UNAIDS 2010). The WHO African Region is the most affected where 1.9 million people acquired the virus in 2010. The estimated 1.2 million Africans who died of HIV-related illnesses in 2010 comprised 69% of the global total of 1.8 million deaths attributable to the epidemic (WHO 2010).

Figure 1: Global burden of HIV



Sub-Saharan Africa (SSA) remains the epicenter of the epidemic. Globally an

estimated 34 million people were living with HIV at the end of 2011, 69% of these in SSA (UNAIDS 2012); and an estimated 2.5 million adults and children became newly infected in 2011. This was despite the fall of new infections by more than 25% between 2001 and 2011 in 39 countries (UNAIDS 2012). Despite the low number of people getting infected, sub-Saharan Africa accounted for 71% of new infections in adults and children (UNAIDS 2012).

Zambia has an HIV prevalence rate of 14.3 % with approximately 1.5 million people living with HIV and AIDS and approximately 89,000 people estimated to be dying as a result of HIV annually (MoH, 2007). It is also projected that approximately, 123,000 people would have died from HIV by year 2014 (NAC, 2003), rendering a big number of children orphans. According to the 2007 Zambia Demographic and Health Survey (ZDHS), HIV prevalence among the youth aged from 15-24 years is about 7 percent (CSO 2009).

Despite the evolution of HIV into a mainstream, manageable illness, people living with HIV including adolescents continue to maintain secrecy surrounding their sero status (Chandra et al. 2003). Individuals who are aware of their HIV sero-status are frequently confronted with the important difficult decision of whether or not to disclose their status to others. The way each person experiences and copes with the illness is reflected in the choice of whether to disclose or not. This is a potentially critical decision that can lead to both positive and negative consequences. Several factors seem to influence this decision. These may include fear of discrimination, the possibility of verbal or physical abuse, anticipated disruption of relationships, concern about employment, and a desire to protect oneself and others emotionally (Chandra et al 2003).

1.1 Problem statement

There are 120,000 children living with HIV and 690,000 AIDS orphans in Zambia (UNAIDS, 2010). Of these children, 90% were infected perinatally, and the rest contracted HIV through blood transfusion, injections with contaminated needles, or early sexual debut or abuse (WHO, 2008).

Little is known about the factors that promote or hinder disclosure of HIV status to adolescents aged 10-15 years living with HIV/AIDS among caregivers in Zambia. Furthermore, there is paucity of data concerning disclosure of HIV in adolescents in Kafue district, yet this is critical to enhance better delivery of HIV treatment and care to adolescents living with HIV. Most adolescents are on antiretroviral treatment (ART) and yet they do not know their HIV status due to non-disclosure (Menon et al. 2007). Above all, these adolescents are growing into adulthood and are becoming sexually active hence the transmission of HIV continues and this becomes a public health concern (ZDHS, 2007). If the dream is to have an HIV free future generation, then the need to start early prevention interventions with adolescents living with HIV before they become sexually active is necessary.

1.2 Justification of the study

In view of the foregoing, this study sought to describe the proportion of adolescents who know their HIV status, the barriers that caregivers and parents face in informing adolescents their HIV status, factors that facilitate disclosure and the disclosure strategies used among caregivers in Kafue district. Lack of disclosure undermines efforts aimed at promoting HIV prevention as well as treatment adherence and other services for adolescents living with HIV. The study will contribute towards designing disclosure strategies for adolescents that will in turn help equip adolescents with knowledge on safer sexual practices and reproductive health in order to enhance HIV prevention. The study will also help strengthen youth friendly HIV prevention and treatment services.

1.3 Study objectives

1.3.1 Main objective

To explore factors related to caregiver disclosure or non-disclosure of HIV-positive status to adolescents under their care.

1.3.2 Specific objectives

1. To determine the proportion of caregivers who have disclosed HIV-positive status to the infected adolescents.
2. To explore caregivers' reasons for disclosure and non-disclosure of HIV status to adolescents living with HIV.
3. To identify strategies used by caregivers in disclosing HIV status to the infected adolescents.
4. To recommend measures aimed at improving caregiver disclosure of HIV status to the infected adolescents.

1.4 Research question

What are the factors related to caregiver disclosure or non-disclosure of HIV-positive status to the infected adolescents?

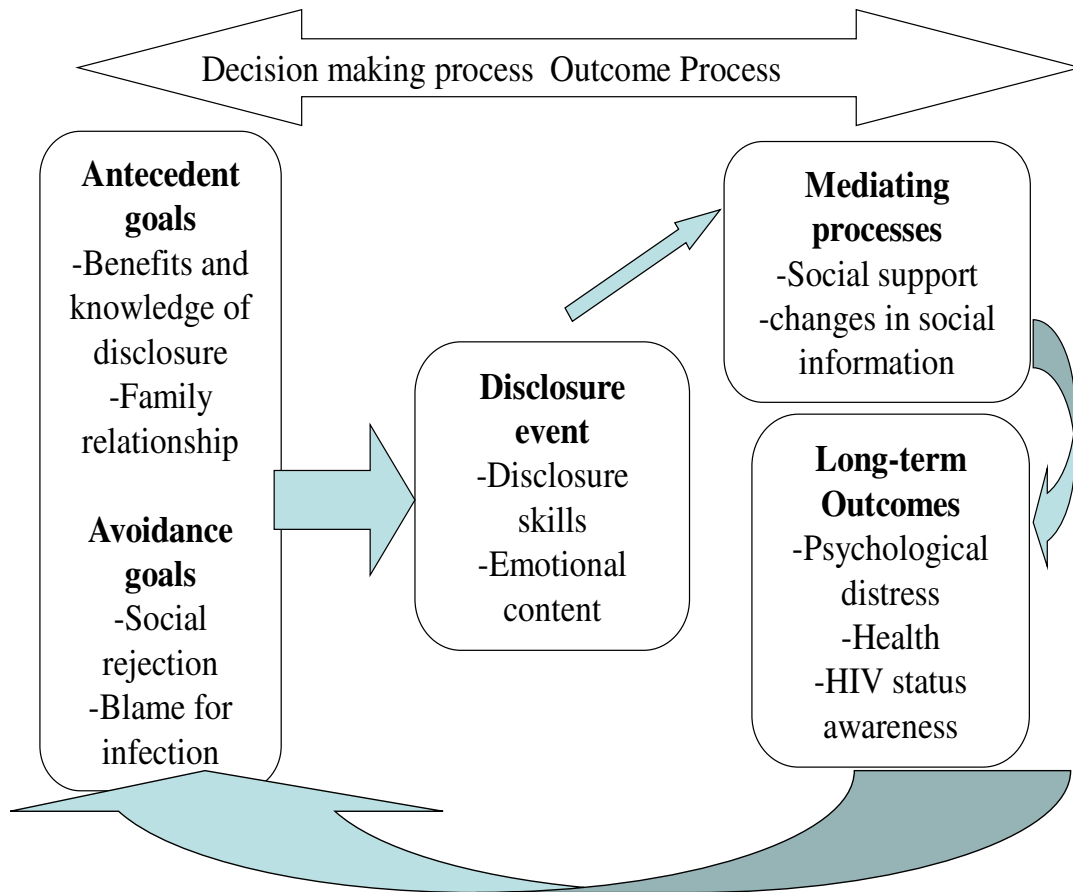
1.5 Conceptual framework of the HIV disclosure process to the adolescents living with HIV.

This is an illustration of the main issues highlighted in the literature concerning disclosure of HIV status to adolescents. This is a disclosure model developed by Chaudoir and Fisher which have been adapted for HIV disclosure on adolescents (Chaudoir and Fisher, 2010). Several factors associated with disclosure of HIV status to adolescent among caregivers identified are social and psychological determinants, blame for HIV infection, and knowledge about benefits of disclosure as well as caregiver disclosure skills. These factors affect the disclosure process of the HIV status to adolescents infected with the disease. Fear of blame for the infection or the social and psychological determinants may delay or hinder the caregivers to disclose the HIV status. Others may not have these fears but might just lack the knowledge about benefits of disclosure and skills on how to disclose.

The model illustrates how underlying reasons or factors that facilitate the decision

(decision making process) to be made on whether to disclose or not, and these could be perceived benefits of disclosure, fear of rejection or blame. This will lead to the next step which will be mainly dependent on disclosure skills as well as the emotional content of the involved parties. Following the disclosure event, there are definitely anticipated outcomes which could be positive (social support and changes in HIV knowledge, HIV status awareness and ultimately promoting health) or negative (psychological distress).

Figure 2: The HIV disclosure model –adapted from (Chaudoir & Fisher, 2010)



CHAPTER TWO

2.0 Literature review

2.1 Introduction

To facilitate better outcomes for HIV-positive adolescents and others, one must examine the factors that contribute to the decision to disclose, the process of disclosure and its impact on HIV-positive adolescents or individuals and others (Chandra et al. 2003). Several studies in various parts of the world have been conducted concerning disclosure of HIV status to adolescents living with HIV. This section of the thesis reviews the studies that have been conducted on disclosure of HIV status to adolescents. These studies took different approaches; some involved talking to the adolescents themselves while others involved caregivers or parents. Themes according to major issues surrounding disclosure of HIV status on infected adolescents have been generated. The main themes generated are knowledge about benefits of disclosure, social and psychological determinants and caregiver disclosure skills which are discussed in detail below.

2.2 Knowledge about benefits of disclosure

Vaz et al. (2008) found that youths are diagnosed with HIV infection at varying ages and age of diagnosis is not necessarily a good indication of the mode of HIV acquisition. A study conducted by Sarah et al. (2012) in the USA, demonstrated that women want to take a leading role in disclosing to their children and make the decision based on the child's ability to handle the information without being excessively worried or scared. They are protective of their children and gauge disclosure decisions based on perceived maturity and emotional stability. So they preferred to wait until the child was perceived to be mature enough to handle the news and be able to cope well emotionally and still be able to maintain confidentiality.

Immediate and long-term reactions provided more opportunities than negative repercussions. Children responded with gestures of comfort, acceptance and opportunities to discuss concerns. Thus, disclosure may provide children time to grieve, an opportunity to talk openly about the diagnosis and an opportunity for the mothers to clarify misconceptions children have regarding HIV. Disclosure also brought about opportunities for the mother to gain comfort, not rejection, from her child (Delany et al. 2008).

Another study done in south London by Waugh (2003), 'on parental views on disclosure diagnosis to their HIV positive children', found that in most cases, disclosure by caregivers or parents was partial, complete or not done at all. Complete parental disclosure refers to a situation in which both the parent or caregiver and child concur that the primary caregiver has told the child about his or her HIV status and drugs which prevent opportunistic infections and help prolong life. In this study, 29% of caregivers had explained to their child about the child's HIV infection and the relationship between their HIV disease and their medication.

Waugh (2003) further says partial disclosure refers to a situation in which the child is not fully aware of his or her HIV infection but is suspicious, asks the caregiver questions about the disease and the drug, and, in many cases, assumes that the drug is a cure. It was found that most parents or caregivers generally partially disclose information about the illness without naming it and delay full disclosure.

On the other hand, non-disclosure refers to a situation where the child is unaware of his or her infection. Fourteen, representing (33%) of the caregivers had not informed the adolescent of their HIV status, and they reported that the child did not suspect being HIV positive. Although many of these caregivers recognized improved adherence as a potential disclosure benefit, many were unable to disclose to their children. Children whose caregivers had never openly discussed their diagnosis but suspected their HIV status reported poor adherence (Waugh, 2003).

Workeabeba & Solomon (2012) and Arrive et al. (2012) conducted separate studies on disclosure in adolescents in Addis-Ababa, Ethiopia and West Africa, where it was found that disclosure of HIV status to children was low (16.3%) and (28.8 %) respectively. Biadgilign et al. (2011) found 17.4% disclosure rate in a study on factors associated with HIV/AIDS diagnostic disclosure in Ethiopia. In Ghana, Kallem et al. (2011) found a disclosure rate of 21%. This implies that parents or caregivers lacked knowledge about the benefits of disclosure and skills in telling the diagnosis to their children. It was also noted that health care providers were unsure as to how to approach disclosure in their setting.

2.3 Social and psychological determinants

Disclosure of HIV infection can lead to important social support that can mitigate the

negative effects that might occur. Conversely, hiding one's status may not only preclude HIV-related social support and its attendant benefits but may also have direct negative effects on disease progression for HIV positive individuals (Chandra et al. 2003). However, disclosure can also result in rejection, discrimination and stigma, making the decision to disclose a dilemma for individuals infected with HIV. Furthermore, the process of disclosure itself especially with adolescents may be inherently stressful, even in cases with positive outcomes (Chandra et al. 2003).

The most frequently given reason for delay in talking to their child about HIV was fear that the child may accidentally reveal their diagnosis, thereby simultaneously revealing maternal HIV status and exposing the family to potential stigmatization, discrimination and prejudice (Waugh, 2003).

Overall, it was observed that these children enjoyed a supportive and trusting relationship with their primary caregivers and became more responsible towards their illness and improved adherence to treatment (Waugh, 2003).

2.4 Caregiver disclosure skills

Little is known about disclosure of HIV status to adolescents as well as the associated effects. A qualitative study by Vaz et al. (2010) identified limited communication between caregivers and children, as well as the need for better support throughout the disclosure process. The improved adherence with HIV disclosure to the child suggests that full understanding of HIV medications is important in these children while on the other hand the child's age and sex was a notable and an important predictor towards disclosure of sero-status. One of the important factors found was that disclosure of HIV status helps the child to gain a better understanding about the need to adhere to the HIV treatment. Relatively few studies on this topic have been published from sub-Saharan Africa (Vaz et al. 2010).

The findings of Vaz et al. (2008) are comparable to those described in other settings. In Zambia, only 37.8% of 127 HIV infected adolescents aged between 11 and 15 years had been told of their HIV infection (Menon et al. 2007). Adult caregivers' decisions to disclose are influenced by their concerns around treatment adherence, the eminent onset of sexual activity of adolescents and their desire to protect their children and to protect others from becoming infected (Menon et al. 2007). Many

parents or caregivers as well as youths believed that youth's adherence to medication improved as a result of being told their HIV-positive status. Caregivers often approach disclosure as a process, contemplating disclosure and preparing for the moment, and providing their infected children with partial and or inaccurate information (Vaz et al. 2010).

CHAPTER THREE

3.0 Methodology

3.1 Study design

This was an exploratory health facility-based qualitative study which involved caregivers of adolescents living with HIV, who were enrolled in ART clinics in three selected health facilities in Kafue district. This study design was selected because it was suitable for identifying and eliciting in-depth insights into factors related to caregiver disclosure of HIV-positive status to the infected adolescents.

3.2 Study setting

The study was conducted in Kafue district of Lusaka province in Zambia. Kafue is located about 45 kilometres south of Lusaka. Kafue District was selected for convenience purposes. Kafue comprises of urban, peri-urban areas, and a large segment of the district being rural. The people in the district are involved in different kinds of livelihood activities although the majority are in the informal sector mainly involved in small scale farming, selling farm products in markets, fishing activities while others run small shops. There is a small portion of people in formal employment mainly government workers in various government departments. A few other people work as casual workers in some industries like Nitrogen Chemicals of Zambia, Kafue Steel Plant, Lee Yeast and a brewery.

Three health facilities were selected for the study because of being centres that provide antiretroviral services in Kafue district. These facilities are Nangongwe clinic, Estates clinic and Kafue district hospital.

3.3 Study population

The study population comprised of caregivers of adolescents who were enrolled in the ART clinics, regardless of whether they were on antiretroviral therapy or not. These were purposively recruited from the three health facilities of Kafue district (Kafue Estates clinic, Nangongwe clinic and Kafue district hospital) using clinical records. Lay HIV counsellors/peer educators or nurses directly involved in the provision of HIV care to adolescents in the selected paediatric clinics were also interviewed to get their views of caregivers' experiences of disclosure of HIV status to adolescents.

3.4 Sample size and sampling procedure

There were at least 60 adolescents in the HIV care program from the three selected facilities (approximat

variation sampling involves selection of study participants to reflect the diverse characteristics of the study participants, in this case the age of the adolescents, sex, length of time on treatment (if on medication) and relationship between adolescent and the caregiver. Thus young caregivers like brothers or sisters, old caregivers such as grandparents, uncles and aunties and actual parents helped generate in-depth unique insights and shared patterns that cut across cases. Caregivers whose adolescents knew their HIV status before they started providing care to them were excluded from the study because they would not have had the experience of having done the disclosure themselves or why they would not have done it yet.

The caregivers who were taking care of adolescents aged 10-15 years living with HIV and agreed to participate in the study by signing a written informed consent were enrolled for the study. All lay counsellors/ Peer educators and or nurses in ART facilities and those that were directly involved with adolescents under the paediatric ART clinic were enrolled in the study as key informants. In addition, six (6) key informants were interviewed (lay counselors/peer educators or nurses, 2 from each facility i.e. 1 lay Counsellor/peer educator and 1 nurse), thus having had at least 36 respondents.

3.5 Data collection

Data collection was done by the researcher who had experience in qualitative data collection. Face-to-face in-depth interviews were conducted with eligible research participants using an in-depth interview guide and a key informant interview guide. Key informant interviews were conducted in English while interviews with caregivers were conducted in English and Tonga, the local language widely spoken in the area. Interviews were recorded using a digital audio recorder. Where participants refused to have the interview recorded, detailed handwritten interview notes were taken and written in an interview notebook. Data collection was done concurrently at the three selected health facilities because the clinics have different days in which they attend to HIV-positive adolescents. Information collected included; disclosure status of the adolescents, age at disclosure and how caregivers informed adolescents about their HIV status or why they had not done so, as well as the general view of adolescent's disclosure and its processes from key informants.

Data collection and preliminary data analysis was a cyclical process: data collected informed ensuing interviews and data collection was concluded when no new information emerged, a stage called data saturation.

3.6 Data management and analysis

All recorded interviews were transcribed and translated verbatim, and were stored on a password protected computer with access only restricted to the researcher (MPH student). The transcripts were then shared with two supervisors for review and verification.

The interview transcripts were then entered into QSR NVIVO 10. Latent content analysis as put forward by Graneheim and Lundman (2004) was used to analyse and interpret the data. All interview transcripts constituted unit of analysis. Unit of analysis refers to all words and phrases of the interview transcripts. These were read several times to create an understanding of the whole data. The interview transcripts were then coded, and the codes were compared for similarities and differences by conducting within-and across-case analysis (Ayres et al. 2003). Similar codes were then grouped together to form categories and then themes were developed by interpreting the categories for their underlying meaning. The codes, categories and themes were separately reviewed by the two supervisors in order to enhance validity of the findings. By using this analytical strategy, I was able to generate experiences across caregivers that are still grounded in individual perspectives. Interview excerpts were then used to illustrate the themes.

3.7 Ethical considerations

The study was submitted to ERES CONVERGE for ethics clearance and the reference number is 2013-Aug-002

3.7.1 Respect for persons and confidentiality

Written informed consent was obtained from all study participants. To avoid involuntary disclosure of HIV status to the adolescents, the interviews were conducted in the absence of the adolescents. The interviews were conducted in private spaces

within the health facilities to ensure confidentiality. In order to ensure participants' confidentiality, no names or personal identifiers were included in the written questionnaires. Identification of an informant was only done through numerical codes.

3.7.2 Beneficence

There was no physical harm to the participants as the study did not involve administration of invasive medical instruments. The study may however, would have posed minimal psychological harm. I understand caregivers, especially biological parents ended up disclosing their own status in the process of the interview, and however, confidentiality was reassured. Counselling services were offered in view of the above as need arose.

The participants were not given any direct immediate benefits as they were being interviewed within the clinic environment and at the time that they brought the adolescents for medical attention.

3.7.3 Fairness

Everybody eligible was given an equal chance to participate or decline. Ethical clearance was sought from Excellence in Research Ethics and Science (ERES). Approval was also obtained from the Ministry of health Kafue District Health Office and health facility authorities.

3.8 Plan for disposal of research materials

All research materials containing participant responses will be destroyed after seven (7) years in line with ethical approval standards. The voice recordings were deleted immediately after transcription of the interviews.

CHAPTER FOUR

4.0 Findings of the study

4.1 Socio-demographic characteristics

The thirty (adolescents) whose guardians were interviewed were aged between 10-years and 15 years, and the majority of the adolescents were aged 11-years old (Table 1). The majority of them (20) were male and the rest (10) were female. All the

adolescents were on antiretroviral treatment.

Table 1. Age and sex of adolescents

Age of Adolescent	Male	Female	Total
10 years	5	1	6
11 years	8	3	11
12 years	2	0	2
13 years	2	2	4
14 years	2	3	5
15 years	1	1	2
Total	20	10	30

Half (15) of the caregivers interviewed were biological parents of the adolescents and thirteen (13) were relatives to the adolescents, and two guardians were foster parents (Table 2). Twenty-three (23 out of 30) of the caregivers were female.

Table 2. Characteristics of the caregivers of the adolescents

Type of caregiver		Sex	
		Female	Male
Biological parents	15	11	4
Foster parents	2	2	0
Relatives	13	10	3
Total	30	23	7

4.2 Caregiver knowledge of adolescents' HIV status

Almost half of the caregivers (14 out of 30) knew about the HIV positive status of the adolescents through taking them for HIV testing, themselves. The majority of the adolescents (14 in total) had been tested for HIV between 2 and 5 years ago; ten (10) had been tested for HIV less than 2 years ago (Table 3).

Table 3. Length of time since adolescent was tested for HIV

Years since testing for HIV	Number of adolescents
0-<2 years	10
2-<5Years	14

≥5 years	6
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4.3 Reasons adolescents were tested for HIV

Poor health: The most common reason why the adolescents were tested for HIV either when they were still young or during their adolescence stage was due to poor or declining health. The most common ailments mentioned were coughs, headache, diarrhoea, body weakness, rash, fever, swellings and sores on the body. This reason was mentioned by almost all caregivers as exemplified from the quotes below:

“You see, the problem was that it was too much on and off sickness, too much diarrhoea, malaria continuously, nearly every month he was unwell, so that is when I thought of bringing him here for testing.”(45-year old male caregiver)

“She used to have....a...you know it’s just a term I came across, opportunistic infections. She used to have rashes, cough, you know, she would have fever, you know it was off and on.” (42-year old female caregiver)

“I was looking at him; his health was not good, always sick, losing appetite and losing weight. He was developing sores in his head even on the mouth so many things and I didn’t like those symptoms I was seeing in him that is why I decided to bring him to have the test.” (35-year old female caregiver)

HIV-positive status of adolescents’ siblings: Caregivers were also motivated to test the adolescents because of the HIV-positive status of the adolescents’ siblings. One 37-year old female caregiver said:

“The young sibling was found HIV-positive, so for her I didn’t know that she could also be positive. I also noted that she was getting sick frequently; having

coughs and generally became unhealthy so that is when I decided to take her for an HIV test.”

HIV-positive status of the parents: Taking the adolescents for HIV testing was also prompted by the HIV-positive status of the parents. As two caregivers put it:

“Because I had tested myself after I lost my wife and so I thought of the child also.” (55-year old male caregiver)

“He used to be sick most of the times, so after I started medication I realized I had to test him as well and find out why he is often sick and yet his siblings are not.” (31-year old female caregiver)

Adolescent knowledge of their HIV-positive status: Slightly over half of the adolescents (17 out of 30) were aware of their HIV-positive status (Table 4). The male adolescents that did not know their HIV status were about twice the number of female adolescents (9 against 4) that did not know their HIV status. Equally, the number of males that knew their HIV-positive status was almost twice that of females (11 against 6).

Table 4. Number of adolescent who knew their HIV status by Age and Sex

Age of Adolescents	Know HIV status		Do not know HIV status		Total
	Male	Female	Male	Female	
10 years	2	0	3	1	6
11 years	5	1	3	2	11

12 years	2	0	0	0	2
13 years	1	1	1	1	4
14 years	1	3	1	0	5
15 years	0	1	1	0	2
Total	11	6	9	4	30

The reasons for informing them of their HIV-positive status were:

Adolescent inquiries about reasons for uptake of treatment: One of the recurring reasons why caregivers informed adolescents about their HIV status was due to persistent inquiries by the adolescents as to why they were on medication despite not being ‘sick’. The adolescents would ask how long they had to continue taking the drugs. On this basis, caregivers used this as a window of opportunity to inform adolescents about their HIV status. Two caregivers explained:

“The questions children ask us, is what forces disclosure to take place. Like my son has been asking when he will stop taking the medicine since we used to tell him that he is taking the drugs for the cough he used to have but now the cough is healed. So he wants to know why he has continued with the drug despite the cough being treated. It is such things.” (34-year old female caregiver)

“When am I going to stop taking the drug?” That is when I explained to him that this medicine you will drink forever. The medicine to cure this disease is not yet found and if you stop, you will start being sick the way you used to be before you started taking this drug” (45 year old male caregiver)

Threats by adolescents not to take HIV medication: Sometimes caregivers were forced to inform adolescents of their HIV status because of the threats by adolescents not to take medication. Therefore, in the quest to promote adherence to medication, caregivers informed adolescents of their HIV status. One 50-year old male caregiver

explained this in the following way:

“I told him when he developed a habit of refusing to take his medication; so when I came here they (clinic staff) told me that I have to disclose to the adolescent exactly why he is taking the drugs; he has to know the reason why.”

Another 37-year old female caregiver said, *“She asked me that, [“mummy so will I be taking these drugs through-out]? Because she doesn’t like drinking medicine, so I told her that there is no stopping. The same way I take every day, even you should take drugs daily till death. That is when I started explaining on drugs like I said earlier on.”*

Promote treatment self-efficacy amongst adolescents: Some caregivers also reported informing adolescents about their HIV status on the advice of health care providers in order to promote self-efficacy (ability to take medication independently) amongst the adolescents. As adolescents grow, there was a need for them to independently start going to the clinic to get medical attention instead of relying on caregivers who may not always be available. A 50-year old female caregiver explained:

“I disclosed because we were being advised to do so at the hospital. We were told to start disclosing because these children are growing up and soon they will become independent and will be going to the hospital alone and they will not be able to answer questions on their own.”

Similarly, disclosure of HIV status was aimed at promoting adherence to treatment. One caregiver narrated how an adolescent under her care improved adherence to treatment after being informed of the HIV status. She explained:

“The other reason was that he had started becoming problematic in taking medication because he had started telling me that he was tired of taking these drugs when he was no longer sick. Sometimes when I wasn’t around, he would not take his drugs. So after disclosing, he is no longer difficult in taking his medication.” (39-year old female caregiver)

Maintaining/sustaining future cordial relationship between adolescents and their caregivers: Informing adolescents of their HIV status earlier in their lives was reported as crucial in maintaining and sustaining cordial relationship between the caregivers and the adolescents once the adolescents grew up into adulthood. This was reported by most caregivers. One of them said:

“So here (at the health facility) I was told that I should disclose because when he grows up, he will hate you when you tell him at a very late stage or he will end up hearing it from the clinic accidentally and that will be hard as well, so it is better you disclose yourself.” (39-year old female caregiver)

Facilitate adoption of safe sexual behaviour: As adolescents grow into adulthood, they also become sexually active. Thus informing them of their HIV status is regarded as important to enable them adopt appropriate behaviour to avoid re-infection or infecting other people. One 34-year old female caregiver explained that adolescents were informed of their HIV status in order to;

“...avoid the children leading careless lives by infecting their friends or others or start having sexual activities with other people so they have to be told to avoid that.”

Receiving social support: Some caregivers also informed adolescents of their HIV status to facilitate access to social support beyond that provided by regular caregivers:

“In case of sickness and you are on drugs, children or people around you have to know so that they can remind you or give you drugs when you need them, so the child needs to know”. (39 year old female caregiver)

4.4 HIV disclosure strategies and process

The findings suggest that disclosure was an on-going process, which could be done either at home or at the health facility. It was not a one-off process; the adolescent had to be reminded and continued learning of their HIV-positive status till they reached a stage of full understanding of their HIV condition. As one health care provider put it:

“Because disclosure takes time, there are some children that you need to plan,

there are so many steps.”

Two disclosure strategies were used by the caregivers, namely direct conversation between the caregiver and the adolescent at home, and assisted disclosure at the health facility.

4.4.1 Direct conversation between caregiver and adolescent: Disclosure through direct conversation between the caregiver and the adolescent were often triggered by questions being asked by the latter about their sickness or medications they were taking every day, including when they felt not being sick. In most cases, the caregiver would disclose because they would want their adolescent to get the information about their HIV positive status from them and not from anyone else or the clinic.

The caregiver would disclose in the presence of some important family members as desired by the family. Two caregivers explained:

“We were together at home because he was asking that when am I going to stop taking the drugs? Even his mother was around, so we were the three of us.” (45- year old female caregiver)

“It is not malaria; this medicine you take is because you have a germ called HIV. So I have told you this but never tell your friends, do you understand? Then she said okay.” (50-year old female caregiver)

Direct conversations between the caregivers and the adolescents about their HIV status also involved caregivers disclosing their own HIV-positive status too. As two caregivers explained:

“Then I told him that I didn’t know that when he was born I was infected because all he knows is that am taking some drugs because am sick. So I told him that the drugs I take, is because I am also infected with a germ but it doesn’t kill if you follow instruction and keep taking medication.” (39-year old female caregiver)

“I sat with him because I explained my problem to him on why I was taking

medication which I have been doing now for the past 8 years or so. I told him this medication I am taking is because of this disease which you have also acquired from us the parents.” (55-year old male caregiver)

Mitigating possible negative reactions from the adolescents involved assurances of a positive future, including the possibility of an HIV cure. As one 39-year old female caregiver narrated:

“And for you [adolescent] since you are still young, maybe a cure will be found as you grow up. That is what I told him and went on to say that the problem I have is what you also have since I didn’t know about it the time you were born.”

4.4.2 Assisted disclosure at the health facility. On the other hand, some caregivers would fail to disclose and they would ask for help from health facility staff. This was achieved. This was done through counselling either during testing period or long after testing was done especially those that tested when they were still very young. Even at the health facility, disclosure was a process. In some cases, counselling could begin with the caregiver before being extended to the adolescent. Caregivers were being counselled in order to make them feel comfortable during disclosure to the adolescent. Thereafter, the counsellor would initiate the disclosure but allow the caregiver to say something concerning the HIV-positive status. This process is illustrated in the quotes below:

“It was the counsellor who started, and then I also came to make her understand that she got the infection from me because her late father and I are both infected.” (34-year old female caregiver)

“We were together during the test and counselling. When the results came out, the doctor asked me if he could go ahead and talk about the results so I said yes. So after the doctor talked about the results, she [adolescent] looked disturbed, so I also came in and talked about it as well because she has always been aware of my status too.” (34-year old female caregiver)

Some adolescents knew about their HIV status through health education at the health facility and also through their own knowledge about HIV and thereafter, inquired

from their caregivers. One 40-year old female caregiver explained:

“She was told here when they were educating them so when she got home she told the uncle and her auntie to tell her the truth because they never wanted to tell her.”

4.5 Factors supporting and shaping disclosure

4.5.1 Adolescent knowledge of HIV: Adolescent’s knowledge on HIV in most cases helped facilitate disclosure in that the adolescent would have learnt about HIV at school and then became inquisitive by asking guardians questions relating to HIV. The quote below exemplifies this point:

“Ok it was a bit easy because they had learnt at school and she had told me earlier on that they learnt about HIV at school. It is because the child had an idea after having learnt it at school.” (37-year old female caregiver)

4.5.2 Adolescent inquiries about medication: In most cases, some adolescents would just be inquisitive and ask questions surrounding the medications they take every day and their health as seen below.

“She used to ask me that “mummy you tell me to drink medicine every day, does it mean that I will never stop and will just be drinking every day?” so I told her that yes she will never stop and that is when I started explaining to her then she responded by saying they had actually learnt about it at school.” (41-year old female caregiver)

“One day when we were going to the clinic he asked me why he used to go there frequently even when he was not sick, so I told him that I will tell him properly when we get back home. When we got back home, that is when we sat him down with the father and started telling him.” (31-year old female caregiver)

4.5.3 Caregiver’s knowledge of and experience with HIV programs. For some caregivers, their knowledge on HIV and work experience in the HIV programs, either as formal or informal health care workers was useful in ensuring that they had the requisite skills and were comfortable to inform adolescents their HIV status. This was

particularly critical given the importance of disclosure on adherence to treatment and avoiding HIV transmission. As a health care provider explained:

“It is important, you know there are so many reasons, good adherence to treatment and to plan for their future and so it is important for them to know their status. Maybe that can prevent them from spreading the infection or being infected and they can also help other adolescents to know about this HIV by empowering others on how it is being spread and prevented.”

4.6 Reasons for non-disclosure of HIV status

4.6.1 Young age of adolescents: The common reason for non-disclosure was about age of the adolescents. Some caregivers that had not yet disclosed and even those that did partial disclosure described the young age of the adolescents as the underlying reasons for not informing them of their HIV status:

“I was waiting for a stage of maturity, not even the years, but a time when he would be able to grasp issues, or showing signs of maturity in mind.” (45-year old male caregiver)

“He is still young, am waiting for him to reach the age of 11...let me say 13 or 15 or so.” (35-year old Female caregiver)

4.6.2 Fear of negative reaction: Non-disclosure of HIV status was precipitated by fear that the adolescents would react negatively to their being HIV positive, including the danger of being violent towards their caregivers. As a health care provider put it:

“Okay it just depends on the adolescent themselves; some adolescents become furious and violent when they are told such that they can even beat up the caregiver. So some caregivers are scared of that; the reaction.”

4.6.3 Psychological trauma: There were also concerns that informing adolescents about their HIV status when they were not ready could result in some of them being psychologically traumatised, including the fear that they could commit suicide. One 50-year old male caregiver said:

“It is because some children would want to commit suicide due to unstable

emotions or short tempers; because they think they are already dead, so it is better when they are old enough to understand that it is not the end of life to HIV positive and they can even understand real life examples of people who have lived with HIV for a long time.”

4.6.4 Protecting own (caregiver) reputation: Some caregivers reported being reluctant to inform adolescents of their HIV status in order to protect their own reputation. This was particularly the case in instances where the adolescent had acquired HIV through mother-to-child transmission:

“May be they are scared of being embarrassed. In my own thinking maybe it is because they fear to be embarrassed, they fear that the child will say it is them who caused the child to be infected.”(Health care provider)

“To start with, a child differs from an adult; you find that wherever the child goes they tell people that the mother told them that they suffer from AIDS, so they take drugs, and that brings embarrassment to the family.” (35-year old female caregiver)

4.6.5 Fear of exposing adolescents to HIV stigma: One of the recurring reasons for not telling adolescents about their HIV-positive status was the fear of exposing them to stigma in the event that their peers came to know about their HIV status. A healthcare provider and caregiver put it this way:

“Others are scared that the child will disclose to the friends he plays with that he takes such drugs and then they will start laughing at him.” (Health care provider)

“When he is told from here, I will know what to say at home, because there are some of his friends that can start making mockery of his status so I would tell him that it is a secret for the two of us. Most of these children talk carelessly when they quarrel, they would say, you are already dead what can you tell us...such things.” (40-year old female caregiver)

4.6.6 Fear of blame: Fear of being blamed for causing HIV infection through mother-to-child transmission of HIV was another reason why some caregivers were reluctant to inform adolescents of their HIV status. This was expressed by both caregivers and healthcare providers:

“Hatred, fear, especially to parents, both parents who are alive, they fear.”

“They fear to be blamed, especially parents, they fear the child will be sick emotionally or psychologically.” (Health care provider)

4.6.7 Perceived inability by adolescents to keep their HIV status confidential.

Another reason for not informing adolescents their HIV status was the fear that they would not be able to keep their HIV status confidential. There was fear that this could trigger stigma and discrimination of the adolescent by the peers:

“Yes....at least where a child can keep a secret to themselves and not where they just go about saying they are HIV positive at school or where they go to play...It depends on maturity level of the child.” (56-year old female caregiver)

4.6.8 Lack of disclosure skills: Caregivers also acknowledge their lack of disclosure skills as the reason for not informing adolescents of their HIV status. The excerpt below from one of the caregivers clearly exemplifies this point:

“I don’t know...maybe it is not knowing or not getting proper guidance on how to go about it because imagine if you knew how to say it, it would even take 24 hours from the time you were told, you can just do it there and then. But it becomes...eh, how am I going to tell her? Where do I start from?” (42-year old female caregiver)

The lack of disclosure skills was confirmed by health care providers.

“Most of them answer that they don’t know what to tell the children, they don’t know what to say,” said one health care provider.

4.6.9 Negative attitude by some HIV counsellors. Even though caregivers reported being assisted by care providers to disclose HIV status to the adolescents, some

caregivers described some counsellors as ‘bad’, thus undermining efforts to seek help from them. As one 42-year old female caregiver narrated:

“You know sometimes there is that...eeh...I don’t know, people are not the same here, there are counsellors that you say counsellors, others are too good, they would counsel you, they would counsel the child, and even if it is not you getting everything that they are saying, at least you would get one or two things. But others, it’s like...eeh...the way they talk to you or the child, it is not....eeh....you know, not encouraging.”

CHAPTER FIVE

5.0 Discussion of the findings

This study explored factors related to caregiver disclosure or non-disclosure of HIV-positive status to adolescents under their care. In particular, the study sought to understand the proportion of caregivers who have disclosed HIV-positive status to the infected adolescents, the caregivers’ reasons for disclosure and non-disclosure of HIV status to adolescents living with HIV, and the strategies used by caregivers in disclosing HIV status to the infected adolescents. Open-ended in-depth interviews were conducted with guardians of the adolescents and health facility staff involved in the delivery of HIV treatment and care services.

Below, the findings are discussed around the following themes: proportion of adolescents aware of their HIV status is low; caregivers weigh the benefits of disclosure against the social-psychological dangers; disclosure is a process not a one

off event; Fear of blame undermines disclosure of HIV status; concerns about stigma and discrimination undermine disclosure of HIV status; and caregivers lack appropriate disclosure skills:

5.1 Proportion of adolescents aware of their HIV status is low: The study revealed that slightly over half of the adolescents were aware of their HIV status. This therefore means that most of the adolescents are growing up without knowing their HIV status. These findings corroborate the findings from a previous study conducted in Zambia in which only 37.8% of 127 HIV-infected adolescents aged between 11 and 15 years had been told of their HIV infection (Menon et al. 2007). However, findings of the disclosure rate are higher than those reported in other studies. In a study conducted in the Democratic Republic of Congo (DRC), only eight (8) out of 256 children, a rate of 3%, had been informed of their HIV status (Vaz et al. 2008) while a study in Uganda found a disclosure rate of 29% (Bikaako-Kajura et al., 2006). A study conducted in Ghana found a disclosure rate of 21% (Kallem et al., 2011) while a study conducted in Ethiopia found a disclosure rate of 16.3% (Abebe & Teferra 2012). The disclosure rate of this study is however lower than that of another study in Ethiopia (Biadgilign 2011).

Adolescent knowledge of their HIV status is critical for interventions to promote good health and reduce risky behaviour. Disclosure is particularly important given that some adolescents begin engaging in sexual activity early. According to the 2009 Zambia Sexual Behaviour Survey, the median age at first penetrative sex among young people aged 15-24 was 19.5 years for males and 17.5 years for females (CSO 2010). More so, adherence to treatment is crucial to ensure viral suppression. While reporting a high rate of adolescent adherence to antiretroviral treatment, a study conducted in Zambia has reported that lack of knowledge of HIV status is a risk to adherence to treatment amongst children living with HIV (Haberer et al. 2010).

5.2 Caregivers weigh the benefits of disclosure against the social and psychological dangers: The findings of this study also suggest that caregivers' decisions to disclose are influenced by their concerns around treatment adherence, the eminent onset of sexual activity of adolescents, and their desire to protect their children, and to protect others from being infected. The findings are consistent with the findings of Vaz et al. (2008) who reported the need to facilitate adherence to

treatment and to live a healthy lifestyle as underlying reasons for disclosure of HIV status.

However, disclosure of HIV status is undermined by fear that knowledge of HIV status would traumatize the child. Evidence elsewhere, however, shows that these fears are unwarranted. The study conducted in the United States of America by Santamaria et al. (2011) revealed that disclosure and timing of disclosure were not significantly associated with negative psychological functioning. Compared with children who had not been told their HIV status, children who knew their HIV status reported significantly less anxiety. These findings appear to contradict those of Vaz et al. (2008). In their study conducted in DRC, they found that whilst the youth did not feel angry or anxious upon learning their HIV status, they, however, reported feeling sad or heartbroken, worried, afraid and frightened.

What these findings suggest is that a blanket approach should not be used in implementing disclosure to adolescents. Instead, disclosure should be implemented taking into account the unique characteristics of the child, including the availability of social support and perceived level of stigma in the community. This is because encouraging disclosure in order to facilitate adherence to treatment may be achieved at the expense of adolescent-peer relationships, especially in an unsupportive and highly stigmatizing social environment.

5.3 Disclosure is a process not a one off event: This study found that disclosure is not a straightforward, linear process. It is not a one-off event, but a process heavily influenced by the social context, the perceived appropriate age for disclosure of HIV status, the perceived maturity level of the child to handle HIV information, and the role of health care providers in facilitating disclosure. It is also influenced by fears of backlash from the adolescents, the fear of exposing adolescents to psychological trauma, and the perceived level of stigma in the social context.

The findings of the disclosure process appear to contradict the four stages of disclosure put forward by Tasker (1992). These stages comprise, a) Secrecy stage, where parents want to keep all knowledge about the illness from the child; b) Exploratory stage, where they will begin to give some explanations to their child; c)

Readiness stage, when they give further information and prepare more fully; and lastly, the Disclosure stage, when the child is told the name of the virus (Tasker 1992).

5.4 Fear of blame undermines disclosure of HIV status: Because some of the adolescents may have contracted HIV through mother-to-child transmission, this study found that some caregivers were reluctant to inform adolescents of their HIV-positive status for fear of being blamed as the cause of the children having contracted HIV. While requiring statistical proof through other studies, these findings may suggest that caregivers who could have infected adolescents through mother-to-child transmission are unlikely to inform adolescents of their HIV-positive status. Our findings are similar to those of Vaz et al. (2008) who found that fear of being judged and blamed by the child dissuaded caregivers from telling adolescents their HIV-positive status.

5.5 Concerns about stigma and discrimination undermine disclosure of HIV status: The findings of the study also suggest that the fear of exposing adolescents to stigma and discrimination undermine efforts to tell them of their HIV-positive status. These findings are consistent with the findings of Vaz et al. (2008) who reported fear of discrimination, social rejection and isolation of the child as barriers to adolescent knowledge of their HIV status.

5.6 Caregivers lack appropriate disclosure skills: The findings also point to the challenges guardians encounter to disclose HIV status to the adolescents. These challenges include the when, the how, and what to inform adolescents about their status. This is further complicated by instances where caregivers are themselves HIV positive and fear of being blamed by the adolescents for infecting them with an incurable infection. These findings point to a need for closer rapport between service providers and the guardians to identify the best possible options and processes of disclosing HIV status to the adolescents.

This study suggests that barriers to disclosure of HIV status to adolescents are not mutually exclusive. They are interrelated and some may intersect and coalesce to undermine disclosure. For instance, while perception of young age of the adolescent

reduces motivation to inform the child of his/her HIV status, fears about stigma, sometimes influenced by guardians attempt to preserve their own social image, may undermine disclosure of HIV status to adolescents. Similarly, although lack of disclosure skills may undermine disclosure of HIV status to adolescents, concerns about young age of adolescents also dissuade caregivers from telling adolescents their HIV-positive status. Therefore, the inter-sectionality of these findings make one point saliently clear: there are many barriers to disclosure of HIV status to adolescents. These findings point to a need for a multi-pronged approach to addressing these barriers.

5.7 Limitations of the study

First, a more general limitation concerns the generalisability of the findings. This study was conducted in one setting with a small sample of respondents drawn from three (3) health facilities of Kafue district. It was exploratory, aimed at generating in-depth insights into factors undermining disclosure of HIV status to adolescents. The findings may therefore not be representative of other settings. Similar studies are therefore warranted in other settings for comparability of findings.

Second, this study did not explore when and how the adolescents became infected with HIV because of the potential difficult of validating this information as some adolescents were not living with their biological parents who could have shed light on this. Similarly, we did not systematically assess the HIV status of the caregivers in this study. However, spontaneous responses from the guardians revealed that some adolescents contracted HIV from their parents through mother-to-child transmission. Because some of the guardians in our study reported fear of being blamed as a reason for not telling adolescents their HIV status, future studies could explore the suspected modes of HIV transmission and how it impacted on disclosure rate and practices.

Third, the study did not explore the adolescents' level of cognitive development. Some studies have reported that neurological and cognitive function of perinatally-infected children is delayed and impaired as a result of HIV infection (Boivin et al.

1995; Smith et al. 2006). This study suggests that caregivers used their own lay assessment of the maturity of the child as a basis of disclosing HIV status to them.

Fourth, while the findings of this study suggest that disclosure of HIV status was done in order to ensure adherence to treatment, it was beyond the scope of this study to establish the relationship between disclosure of HIV status and adolescent adherence to treatment. Future studies should therefore explore this relationship.

Over and above, this study was exploratory, generating insights based on a small sample size in one setting. Other studies using larger sample sizes and quantitative research methods, and diversity of settings, are needed to determine the representativeness of these findings.

Notwithstanding the limitations, through maximum variation sampling of study participants, the strength of this study was the diversity of the guardians of the adolescents –biological parents, foster parents and other caregivers, as well as representation of the age categories of the adolescents. Therefore, the findings probably could be generalisable to similar settings in urban areas in the country and provide useful insights that can inform policy and practice to improve uptake disclosure of HIV status to adolescents.

CHAPTER SIX

6.0 Conclusions

This study explored the prevalence of and factors influencing disclosure of HIV status to adolescents living with HIV. Qualitative studies are useful in generating in-depth insights into such health behaviors. The findings suggest that disclosure rate is low, and it is mostly influenced by desire to enhance adherence to treatment and ensure adoption of safe sexual behaviour. However, improved level of disclosure is hampered by perceived young age of the adolescents; fear that knowledge of HIV status would traumatize the adolescent, fear of being blamed for HIV infection, and lack of disclosure skills. These findings underscore the need for in-depth, context-specific understanding of the hurdles to disclosure and the need to implement locally relevant, needs-based and beneficiary responsive intervention programmes to promote disclosure. This is because, as pediatric HIV scale-up continues, the low rates of disclosure may undermine the gains being scored in scaling-up access in resource-limited settings such as Zambia.

6.1 Recommendations

6.1.1. Improve disclosure skills of caregivers: Health education is key to enhancing the process of disclosure. More caregivers will only become free and courageous to disclose the HIV positive status to the infected adolescents if they are equipped with

the right and correct information on the disease and the disclosure process itself. This came out strongly from most caregivers interviewed. This was seen as the only way caregivers could be encouraged to disclose. Health talks as caregivers attend clinics are critical. The health talks should also include equipping caregivers about correct information about HIV.

6.1.2 Promote assisted disclosure: Health provider involvement in the disclosure process is vital. Counsellors should therefore be able to assess caregivers who cannot disclose and provide a platform for intervening to facilitate disclosure.

6.1.3 Establish adolescent-specific clinic days. Health facilities should explore possibilities of establishing adolescent-specific clinic days. This could allow adolescents to mingle with their friends. The situation of mixing adults and adolescents was not viewed as conducive for facilitating disclosure.

6.1.4 Age of disclosing HIV status to adolescents: There is no clear cut age for this. This is dependent on many factors such as HIV knowledge level of the adolescent, supportive mechanisms in place, growth/maturity level of the child (as some adolescents could be mature beyond their age). The official age of starting school (7 years) could also be used as the appropriate age for starting the disclosure process.

6.1.5 ‘Testing the waters’ through caregiver disclosure of their own status: Caregiver disclosure of their own HIV status is crucial to ensure acceptance of HIV by adolescents. This could be used as an opportunity to assess adolescent attitude towards HIV, which could in turn help establish whether adolescent would easily accept their own HIV status or not.

6.1.6 Disclosure should be a process, not a one-off event: Informing adolescents of their HIV status should not be undertaken as a one off-event. Instead, it should be treated as a process taking into account the unique characteristics of the adolescent such as temperament, how adolescent contracted HIV and social support mechanisms in place.

6.1.7 Efforts to address stigma still warranted: Stigma still remains a pervasive issue. Therefore, efforts to address stigma are still warranted. Sensitisation efforts should also target young people to ensure improved understanding of HIV.

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8.0 APPENDICES

Appendix 1: In-depth Interview Guide for Caregivers

ID No.....Interviewer.....Date of interview.....

Age of caregiver..... Sex of caregiver.....

Age of Adolescent..... Sex of Adolescent.....

1. What is your relationship with the adolescent?
2. How long have you known the adolescent?
3. Does the child go to school? (what grade are they doing or why not if not in school)
4. How long ago did the adolescent test HIV positive?
5. What prompted the adolescent to do the HIV test?
6. Is the adolescent on ART? (If yes for how long?)
7. Do caregivers in the community disclose to the adolescents their HIV status?
8. Has your adolescent been told of his/her HIV-positive status? (If yes, how long ago?)
9. And how did you go about disclosing HIV status to the adolescent?
10. What factors facilitate disclosure and why did you disclose (if disclosure was done?)
11. What factors hinder disclosure? (What are the reasons why disclosure is not done or have not been done?)
12. What is the importance of disclosure to the adolescent and to you as a caregiver?
13. What is the importance/advantage of disclosure to the community?

14. What is the disadvantage of disclosure?
15. At what age do you think disclosure should be done and why do you think so?
16. What do you think should be done to enhance the process of disclosure?

If there are no questions or concerns, we have now come to the end of our interview. Thank you very much for your time and your participation.

Appendix 2: Key Informant Interview Guide

ID No.....Interviewer.....Date of interview.....

Profession of interviewee.....Duration of service in clinic

1. What does your work involve?
2. Are you directly involved in attending to adolescents who are HIV positive?
3. How can you describe your experience in your involvement in attending to adolescents in your clinic concerning disclosure?
4. Do caregivers in the community disclose to the adolescents their HIV status?
5. How is the process of disclosure often done?
6. What factors facilitate disclosure?
7. What factors hinder disclosure? (What are the reasons why disclosure is not done?)
8. What is the importance of disclosure to the adolescent, their family and to you as a caregiver?
9. What is the importance of disclosure to the community?
10. What is the disadvantage of disclosure?
11. At what age do you think disclosure should be done and why do you think so?
12. What do you think should be done to enhance the process of disclosure?

If there are no questions or concerns, we have now come to the end of our interview. Thank you very much for your time and your participation.

Appendix 3a: Information Sheet - English

Disclosure of HIV status to adolescents aged 10-15 years living with HIV/AIDS among caregivers of Kafue district, Zambia

What the study is all about

My name is **Mable Mweemba**. I am a Master of Public Health (MPH) student at the University of Zambia-Ridgeway campus. I also work for the Ministry of health/ Mother Child and Community development based at Kafue district hospital. I am conducting a study in trying to understand how caregivers go about disclosing the HIV positive status to the infected adolescents in the district and also to identify the reasons for disclosure or non-disclosure by getting your experiences as caregivers. I will be interviewing caregivers like parents, guardians, foster parents as well as health workers in your clinic. Due to your involvement or experience with HIV positive adolescents under your care, I am asking for your participation in this study.

I also want you to know that your participation in this study is voluntary. You are free not to answer any questions that you are not comfortable with. You can also withdraw from the study at anytime without any consequences for doing so. The information you will provide will be strictly confidential and your identity will be protected and your names will not be used. I also want you to know that the interview will be tape recorded if that is alright with you. If you are not comfortable with that then I will write down what we will discuss.

In case of any emotional breakdown during the interview, counselling services will be offered to you by a counsellor. The interview will be conducted in a confidential manner and setting. There will also be no direct and immediate material and financial benefits to you. In general, this study will help contribute towards the improvement of

the disclosure process of HIV positive status to the adolescents who are infected with HIV in Kafue district of Zambia.

This study has been approved by the Excellence in Research Ethics and Science (ERES) and permission has also been obtained from Ministry of health/ Mother and child health, Kafue District Health Office and Facility authorities. Should you have any questions or want clarification about the study, contact me or the ERES Chairperson on the addresses below.

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Lusaka

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The chairperson

ERES CONVERGE IRB

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Mobile Phone: 0955 155633/4

Appendix 3b – Information Sheet – Tonga

Kuzubulula bulwazi bwakazunda ka HIV kubasikubusyi balaamyaka yakuzyalwa Kkumi kusikila ku Kkumi a Yosanwe akati kababalela mu Cooko ca Kafue mu Zambia

Mulumbe walwiiyo

Izina lyangu ndime **Mable Mweemba**. Ndili sicikolo wa Public Health okuya kucikolo cipati ca University ya Zambia. Kunze kwaboobo, ndilabeleka kucibbadela ca Kafue mumfulumende. Ndisoleke kuyandaula luzyibo alwiiyo mucibeela cakuzubulula na kwaambila basikubusyi baniini bajisi kazunda kabulwazi \bwasilileke na HIV mumubili wabo. Ndiyanda kuzyiba kuti ino bamazyali na basimalelo babana aaba babelesya nzila nzi kwaambila bana aaba kuti balijisi kazunda mumubili wabo. Kwamana boobo ndiyanda kuzyiba cakapa kuti babaambile bana na cipede kuti kabatana baambila ncinzi. Lwiiyo oolu luyakujana bumboni kuzwa kuli bamazyali abamwi balela bana batali bakuzyala kulimbabo pe, kufumbwa kuti mwana ngobalela uli mucibeela camyaka yaambwa kale alimwi bazulilwa mucooko ca Kafue. Aboobo nywebo mwasalwa nkaambo mulalela mwana upona akazunda, nkokuti mwalombwa kuti mutole lubazu mu lwiiyo oolu.

Mwelede kuzyiba kuti kutola lubazu mulwiiyo oolu nkwakuliyandila na kulyaaba, kuti kamutayandi inga mwaamba kutegwa twamuleka mwaunka kakutakwe abubi pe. Mulijisi nguzu zyakuleka akatikati kamubandi, na zyakutavwiila mibuzyo njomunga mwajana buyumu yumu ayalo. Alimwi ndilamusyomezya kuti zyoonse nzyotutibandike mumubandi wesu, kwiina kumbi nkomutikanzimviwe pe, zilasyaala akati kandiswe tobile. Tandikwe kubweza mazina eenu pe kunze ajwi lyenu litibikwe mukalimba aaka. Na tamuyandi kuti ndibelesye kalimba inga ndaulemba mubandi wesu mubbuku.

Cimwi ciindi kuti mwatalimvwa kabotu akati kamubandi wesu inga ndamutola kuliba kansula nakuba kubaita inga ndabaita kuti babandika andinywe kumugwsya kumvwa kabotu. Cimwi ncomweelede kusyiba ncakuti tamukwe kupegwa na kubbadelwa cili coonse. Bulumbu buyakujanika kumbele aamazuba twakuzyiba nzila zyuubauba ziyagwasya mukuzyibya bana mbotulele bapona akazunda ka HIV mucooko cesu ca Kafue.

Lwiiyo oolu lwakazumisigwa abalanga zyiiyo zinji zijatikizya Bantu. Aaka kabunga kaitwa kuti Excellence in Research Ethics and Science (ERES). Nguzu zyimbi ziyakapegwa akabunga kamfulumende kalanga malwazi abusilisi bwabantu abalangi bazibbadela mucooko ca Kafue. Kuti mwaba amazumbauzyo ayanda kusalasisigwa kuli ndinywe inga mwabuzya nokuba kulembela kuli basicuuno cipati kukabunga ka ERES nokuba lindime sikuyandaula bumboni mulwiiyo oolu. Nambala yakutumina ngu 0977160210 na 0955155633. Kwakulembela na kwakuunka nkooku;

Mable Mweemba

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The Chairperson

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Appendix 4a: Informed Consent Form - English

Dear participant,

The material in the information sheet and consent form has been read out and explained to me. I understand that taking part in the study is voluntary and that my privacy will be respected. All questions I had have been answered to my fulfilment. I choose to take part freely and voluntarily.

I has given consent to take part in the study.

Signature or (Thumbprint).....

Date.....

Witness.....

Signature or (thumbprint)

Date.....

Researcher Conducting Informed Consent
(Printed).....

Signature of Researcher:

Date:

Appendix 4b: Informed Consent Form - Tonga

Kuzumizigwa bumboni bwakubandika

Nomutola lubazu,

Ndazumina kuti ndapegwa mulumbe oonse kwiinda mukubala na kubalilwa. Aboobo ndazyiba lwiiyo oolu ncolusola kujana. Ndazyiba kuti mubandi wesu ngwamaseseke alimwi taunki kumbi pe, nkaambo tulambaula mubulemu kutali antangalala. Mibuzyo zyoonse njinda jisi yavwiila aboobo ndalisalila kuti nditole lubazu mulwiiyo oolu mukuyanda kwangu endike.

Mebo.....ndalyaaba kuti nditole lubazu muciiyo eeci.

Kusayina na kusimba cala.....

Buzuba kwasunu.....

Zina lya Kamboni.....

Kusayina na kusimba cala

Buzuba kwasunu.....

Zina lya sikubuzya.....

Kusayina.....

Buzuba kwasunu.....