FACTORS AFFECTING PARENTAL DISCLOSURE OF HIV STATUS TO HIV-POSITIVE CHILDREN AND ADOLESCENTS

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FACTORs AFFECTING PARENTAL DISCLOSURE OF HIV STATUS TO HIV-POSITIVE CHILDREN AND ADOLESCENTS

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Declaration

This dissertation is the original work of Sylvia Kanse. It has been prepared in accordance with the guidelines of MPH dissertation of the University of Zambia. This dissertation has not been submitted elsewhere for a degree at this University or any other university.

Signature: ........................................ Date................................................

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Dedication

To my husband, Christopher, who’s been highly supportive throughout the pursuit of this degree. You have provided moral, spiritual and material support. I couldn’t have managed this without you. I love you. You are a true blessing to me.

To my parents, Christine and Edmond Kansembe, thanks for believing in me and inspiring me to reach great heights from a very young age. Thanks for your immeasurable contribution to my life and aspirations.

To my children, Chishimba and Kangwa, it’s true that treasures of life do come in small packages. You are the best children ever!

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Abstract

Disclosing the diagnosis of HIV or AIDS to a child is a controversial and emotionally-charged issue among health workers, parents and caregivers of these children.

195 parents and guardians were enlisted for this cross-sectional and exploratory study. A survey questionnaire and one to one in-depth interviews were used to collect the data. Data was analysed using SPSS version 17 and modified grounded theory.

We found that HIV status disclosure was very low and stood at 32.3%. The pattern of disclosure was such that n=32 (51%) opted for full disclosure whereas n=31 (49%) opted for partial disclosure. The opting for full disclosure of the child’s HIV status were higher the age groups of children 6 to 10 and over 10 years (that is when the child was older than five years) and age was statistically significant for those less than five years children (p = 0.000). The proportions for full disclosure were not high among parents or guardians who had biological or other children and this did not reach the significance level (p = 0.489). The level of education had no clear association with parent’s desire to disclose the child status (p = 0.544). Risks of disclosure outweighed benefits of disclosure factors for disclosure. The quality of counselling was good. The following is recommend:

- There is need for parents or guardians of HIV-infected children and adolescents to be counselled before HIV status disclosure is done to the child/adolescent and to be provided with ongoing help and support during and after the difficult and distressing task of disclosing the diagnosis to these children.
- Parental and child factors both need to be considered regarding disclosure of HIV status to the child.
- Parents or guardians of HIV-infected children and adolescents need to be empowered to believe they have the best knowledge of themselves and their family and will know the best time to disclose to their children.
- While current knowledge is insufficient for determining whether the choice and time of HIV status disclosure to children should be based on age groups or developmental milestones, increased attention to training in counselling and development of simplified tools for developmental assessments by primary health workers is necessary.
CHAPTER ONE - BACKGROUND

1.0 Introduction

The former Secretary-General of the United Nations, Kofi Annan, once said, “The global Acquired Immunodeficiency Syndrome (AIDS) epidemic is one of the greatest challenges facing our generation. AIDS is a new type of global emergency – an unprecedented threat to human development requiring sustained action and commitment over the long term” (BIPAI 2006: iii). AIDS has also been described as a long-term issue that requires a response that is grounded in evidence and human rights (UNAIDS 2008).

An estimated 33 million people are living with Human Immunodeficiency Virus (HIV) worldwide. 2.7 million were newly infected in 2007 and 2 million died of AIDS in the same year. There are about 7,500 new infections each day. About 3 million people are receiving anti-retroviral drugs in low- and middle-income countries. AIDS continues to be the leading cause of death in Africa, which is home to 67% of people living with HIV/AIDS (UNAIDS 2008). Zambia is among the seven countries most affected by HIV/AIDS in the world, with prevalence currently at 14% in adults (ZDHS 2007).

HIV/AIDS was first described in children in 1983. Since then, the epidemiology of paediatric AIDS has evolved significantly (Oleske 1983:2345-2349). In 2007, it was estimated that worldwide, 2.1 million children under 15 years old were living with HIV and 290,000 children died of AIDS. 420,000 children were newly-infected with HIV. Worldwide, over 15 million children under 18 years of age have lost one or both parents to AIDS (UNAIDS 2007).

Zambia has carried out a study on the drivers of the epidemic and held national Think Tank meetings. Key drivers identified include multiple and concurrent
sexual partners, low male circumcision, low rates of condom use, untreated sexually-transmitted infections (STIs), denial, stigma and discrimination; socio-cultural practices and traditions; gender and sexual violence; high alcohol and drug abuse; low risk perception; high population mobility; and poverty. 71% of new infections (21%) are in those who say they have only one sexual partner so behaviour change for risk reduction is needed also in this area. (HIV Southern Africa).

Regarding prevalence of HIV in children, a study done in a peri-urban area of Lusaka found the distribution of HIV in the paediatric age group in the community was 5.5 percent, with higher prevalence rate in infants (Muyanga 1994, unpublished), while a study done by UTH Virology lab in Lusaka in 1995 showed that the prevalence of HIV in children aged 1-4 years was 4.1 percent. In the age group of less than one year, prevalence was 18-22 percent (Viral infections in Zambia 1995:45-46). In January 2007, the spokesperson of the Ministry of Health in Zambia was quoted as saying there are about 40,000 children born with HIV per year in Zambia and there are only 5000 children on anti-retroviral treatment (IRIN 2007:1).

1.1 Statement of the Problem

Disclosing the diagnosis of HIV or AIDS to a child is controversial and emotionally-charged issue among health workers, parents and caregivers of these children. HIV/AIDS is a potentially life-threatening, highly-stigmatised and transmissible illness. Worldwide, one of the most controversial topics of discussion among families of children who are infected with HIV/AIDS is whether or not to tell the child about the child’s own diagnosis and if they do, whether or not to allow the child to tell others (Sherman et al., 2000:238-247, Armstead et al, 2001:11-20). In certain treatment centres in the United States of America, for
example, some parents were known to ask healthcare providers and caregivers not to mention the words HIV and AIDS around their school age children.

Currently, many children with HIV and AIDS are surviving to adolescence and young adulthood as anti-retroviral drugs become more widely available worldwide. A corresponding shift in the conception of from a terminal disease to one that is chronic, underscores an important research agenda for the identification of specific psychosocial variables that may influence the long-term survival of these children.

Noting that HIV/AIDS is a chronic illness and its treatment is life long, young persons infected with the illness need to know their status and details about their treatment. Without knowing this, problems of adherence to treatment come in, which may predispose these children to problems such as development of drug resistance or treatment failure. In addition, for as long as these children or adolescents don’t know what they are suffering from, there’s the danger of them transmitting the infection to others through, for instance, unprotected sex or sharing of needles for those who are involved in injection drug use. There is also the problem of negative psychological effects which may arise if the child finds out about their status in an unsupportive way. Children may also miss out on the all important social support if they are continually kept in the dark about their illness. In the light of the above-mentioned developments, parents and guardians have an insurmountable task to disclose the children and adolescent’s HIV status to them.

Studies relying on caregiver report, done between 1995 and 2004 in various parts of the world, found great variations in rates of HIV status disclosure to children infected with the disease, ranging from 10% in some areas to 75% in others. (Wiener 2007:8). In Zambia disclosure to children is said to be low due to cultural factors, stigma and service-related factors (IRIN 2007:1). The problem with this publication is that it did not mention the actual rates in Zambia the process of disclosure to children in Zambia.
Factors Affecting Parental Disclosure of HIV status to infected children/adolescents

There are a number of factors that affect parental disclosure of HIV status to HIV-infected children. Some of these are stigma and parental perceptions, e.g. anticipation of negative psychological consequences on the child, secrecy regarding the illness and issues that may be related to it like mode of parental infection, parents still in denial of their own or the child’s illness. On the positive side, some parents hope for improved treatment adherence following disclosure. Inadequate professional counselling on how to go about the disclosure process, cultural factors and socio-demographic factors like the age of the child and parental educational level are some of the other factors affecting the process. As for available interventions to deal with the problem, decades into the HIV/AIDS pandemic, disclosure of perinatal HIV infection is often delayed until older childhood and beyond and few empirically based interventions or guidelines are available for assisting parents and providers to make decisions about disclosure (Wiener 2007:2).

1.2 Justification and Benefits of the Study

This study is justified for the following reasons:

The first one is related to building reference literature for Zambia in the domain of disclosure. The process of disclosure of HIV status to children who are HIV-infected in Zambia is still a grossly under-studied field and as a result, there is a wide gap in ascertaining factors that affect parents in deciding to disclose HIV status to children and adolescents that are HIV positive, as currently, no studies regarding the subject have been done in Zambia. A wide search for the information requested in relation to this only yielded two publications. Unfortunately, they did not address the process of disclosure per se but focused on other aspects. The first was an article which stated the following: ‘In Zambia
disclosure to children is said to be low due to cultural factors, stigma and service-related factors’ (IRIN 2007:1). The problem with this indication is that it did not mention the actual rates of disclosure of HIV status nor the process of disclosure of HIV status to HIV-positive children in Zambia.

The second study was entitled ‘Mental Health and Disclosure of HIV status in Zambian adolescents with HIV Infection: Implications for peer-support programs’ (Menon et al, 2007). This study found that rates of disclosure were low, out mentioning actual figures. It also alluded to the fact that disclosure of HIV status to children still remained a controversial issue, with stigma and concern for psychological reactions being among the major barriers. It did not, however, go into the actual process of disclosure. Even a study am couples done by Rutenberg in Zambia and Kenya only mentioned the rates and not the process of disclosure (Rutenberg 2003). Some studies showing disclosure among adults, therefore, are quoted below just to give a rough idea of the process:

The results of a study in Southwest Ethiopia ( Kassaye 2005:126-131) showed disclosure among women to be 69%. In a second study in the same area, targeting both men and women, the vast majority (94.5%) disclosed their result to at least one person and 90.8% disclosed to their current main partner. However, 14.2% of disclosure was delayed and 20.6% did not know their partner’s HIV status. Among those who did not disclose, 54% stated their reason as fear of negative reaction from their partner. Among those disclosures however, only 5% reported any negative reaction from the partner. Most reported that their partners reacted supportively to disclosure of HIV status.

It is envisaged that from this research, we shall be able to yield valuable information to translate into local, district and national plans and strategies for effective counselling of parents, guardians and HIV-infected children before, during and after the disclosure process.

The second justification for this study is associated with the methodology and the research outputs. The research methodology that was used should add
intellectual knowledge to the research fraternity and arly to those who may wish to conduct a similar or a much wider nomothet study.
CHAPTER TWO - LITERATURE REVIEW

2.0 Introduction

In general, deciding whether or not to disclose one’s status to another person is an important decision. The way each person experiences and copes with this illness is reflected in this choice (Levy et al., 1999:1). Disclosure of one’s HIV status may be done at different levels. For instance, one may disclose to sexual partners, friends, family, siblings, children or employers. In this study, our specific interest lies in the disclosure of HIV status to a child or adolescent who is infected with the disease, and who may or may not be on anti-retroviral drugs.

Theories on HIV status disclosure show that while disclosure is generally viewed as being healthy and beneficial, too much disclosure can have significant costs to relationships and be detrimental to one’s social acceptance. In particular, disclosure of distressing information can elicit harsh or negative judgements from others, resulting in a loss of social support and more negative feelings toward the person disclosing. (Comer et al., 2000:449-464).

2.1 Rates of Disclosure of HIV Status to Children Worldwide

Information on rates of disclosure of HIV status to infected children is varies worldwide. A synthesis of research findings on this subject by Wiener et al., in 2007 found that Funck-Bretano (1995:109-139) and colleagues were among the first to describe the various patterns of disclosure. Among 35 Parisian families, the authors found that non-disclosure (23%) and deception (20%) were common, particularly in young children, with complete nondisclosure coinciding with secrecy about the illness or a caregiver’s denial of the child’s illness. Partial disclosure was the most common (40% of the cases), and was often viewed by
some caregivers as a step towards full disclosure. Partial disclosure often occurred in conjunction with illness deception. Deception often entailed caregivers, frequently out of concern for the child’s psychological well-being, telling their children only about a co-morbid condition (e.g. asthma, cancer), and attributing all medical needs (e.g., appointments, medication) to that less-stigmatized condition. These authors also reported that only 17% of their sample had been made fully aware of their HIV illness. Since then, other studies have focused on the prevalence of full HIV disclosure for school age children, adolescents and young adults and have produced inconsistent findings. For instance, studies relying on caregiver report, done between 1995 and 2004 in various parts of the world, have found that 10% to 75% of HIV+ children in the samples have been told about their HIV status. This is a wide range of results from which no meaningful average could be extrapolated (Wiener 2007:8).

In 1999, the American Academy of Paediatrics published guidelines stating that all adolescents should know their HIV status and that disclosure should be considered for school-age children. (A statement of re-affirmation of this policy statement was published on September 1, 2005). At the time the policy was formulated, data from several centres within the United States indicated that between 25% and 90% of school age children with HIV infection and AIDS had not been told of their infection (AAP 1999:2).

2.3 Rates of HIV Status Disclosure to HIV-Infected Children in Zambia

No studies could be found indicating the rates, patterns or process of disclosure of HIV status to children infected with the disease in Zambia. For the sake of argument, a limited study regarding partner disclosure of HIV status among women attending Prevention of Mother-to-Child Transmission of HIV (PMTCT) programmes at three selected sites in Kenya and Zambia, is quoted here. Disclosure rates among these women ranged from 58% in Karatina, Kenya, to 72% in Lusaka, Zambia (Rutenberg 2003). These figures, however, may not be
expected to give the true reflection of disclosure rates among HIV-positive women because they included disclosure among both HIV-positive and HIV-negative women. It is therefore expected that actual disclosure rates among HIV-positive women in these areas would be lower than these results showed. Basing on this figure as a baseline for comparison, it would expected that disclosure rate of status to children, which is generally much lower than partner disclosure rate, would be about 30% in Lusaka.

2.4 Types of Disclosure

There are three types of disclosure, full, partial and non-disclosure. Research has often viewed disclosure as a single, binary event. Over time, it has increasingly been viewed as a process of moving from non-disclosure to full disclosure. While full disclosure may transpire in a single encounter, most commonly it is an on-going process in which pieces of information are discussed over time or at different developmental stages as clinicians and parents see fit. It may be seen as an ongoing process as the child develops cognitive, psychological, and spiritual awareness about the meaning of illness and death (Wiener 2007:7). Several investigators have demonstrated that diagnostic disclosure to children is most successful when accurately mapped to their cognitive and emotional development (Bibace 1980:912-917).

Young children, as young as three, have some concept of death, although they often believe that the dead individual will come back life. (Wiener 2007:4). As they age, they begin to understand the permanency and of death. Partial disclosure is often seen as appropriate when children are younger and the specific name of the illness may not hold meaning for or be as important in helping them cope with fear about their symptoms and medications. Cognitive and developmental limitations of children as well as children’s capacity for magical thinking also play a role in a child’s processing of the diagnosis. It may require multiple sessions and time for the child to fully understand the name of
their disease, its health consequences, and their medical needs. In cancer practice in the 1970s, understanding these facts led to the evolution of practice from one of secrecy to one that advocated presenting accurate information to a child in developmentally meaningful terms. The same thing is being applied in the area of HIV/AIDS with the passage of time (Wiener 2007:4).

All in all, it may be said that 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 (Slavin 1982:179-183, Wiener 1994:485-492). This may be said to be true for HIV/AIDS as well. Adolescents, on the other hand, need to be informed about their illness to assist in their own care and to reduce the risk of transmitting the infection to others through unprotected sex or behaviours associated with illicit drug use (AAP 1999:3).

Finally, disclosure should not only take into account the child’s age, maturity, and the complexity of family dynamics, but the clinical context as well (Grubman 1995:657-663, Lipson 1993:6-12). In critically ill children or adolescents, issues of dying rather than disclosure may be more appropriate to address. On the other hand, in children or adolescents who are clinically stable, disclosure of illness status may be considered.

2.5 Factors Affecting Parental Disclosure of HIV Status to HIV Positive Children and Adolescents

Parents may or may not disclose the HIV status of an infection to that child or adolescent depending on a number of factors. Perceived benefits or risks of disclosure, adequacy of social support and parental illness status are among several factors that will be discussed below:
2.5.1 Perceived Benefits of Disclosure

Attitude towards infection transmission

There are also certain parents and guardians who feel it is important for the child to know their diagnosis because they may otherwise get involved in sexual activities without protection, thereby endangering themselves and others. (Waugh 2003: 169-176, Blasini et al., 2004: 181-189).

Anticipation of improved treatment adherence and improved healthcare in general.

Finally certain people may disclose to a child or adolescent in the hope that it may lead to improved health care or even motivate their child to improve adherence to anti-retroviral treatment and all other supporting treatments. (Waugh 2003: 169-176, Blasini et al., 2004: 181-189).

2.5.2 Perceived Risks of Disclosure

Risk of Negative Emotional and Psychological effects on the child who is perceived to be too young to know

Some of the reasons given by parents for not disclosing are concerns about the impact that disclosure may have on the child’s emotional status because the child is thought not to be old enough or mature enough to understand or cope with the diagnosis, (Waugh 2003:169-176). Among the most strongly endorsed reasons for non-disclosure are the thinking that a child deserves to have as carefree a childhood as possible and the desire that the child should not be hurt by the reactions of others (Ostrom et al., 2006). Parents who have older children have been demonstrated to find disclosing much easier than those with much younger children (Mellins et al., 2002:101-114).
Some parents may also worry about the burden imposed on the child who is expected to keep a seemingly shameful family secret. It potentially would make the child feel like an outcast in society or it may lose the child's self-esteem (Moneyham et al., 1996:209-221, Murphy et al., 2002:191-202). Certain studies have shown that some parents do not wish to disclose HIV status to an infected child or adolescent because they feel the child may lose the will to live once they learn and understand the diagnosis (AAP 1999:2). Lastly, certain parents feel a sense of guilt about having transmitted the illness to the child and fear there may be an angry reaction from the child against the parent once they know how they acquired the infection (Wiener 2007: 4).

Stigma

Disclosure of distressing information can elicit harsh or negative judgements from others, resulting in a loss of social support and more negative feelings toward the disclosee (Comer et al 2000:449-464). In particular, the stigma that is associated with HIV/AIDS makes people very cautious about disclosing their status to others. (BIPAI 2000:6, Bairan et al., 2006:242-250, Ostrom et al., 2006). This is because initially, society started by stigmatising HIV/AIDS as this deadly or incurable pandemic and equated it to a death sentence (IRIN 2007). It is therefore greatly feared that once the child knows the diagnosis and happens to share it with others, there may be ostracism, negative reactions from family, friends and school or lack of community support (Wiener 2007:4, Waugh 2003:1), resulting in the long run, in damaging consequences for both the child and the entire family (Lester 2002:309-317). Consequently, parents may be very reluctant to disclose the HIV status to the child and opt to remain silent.

Loss of secrecy regarding the illness and related matters

Families may also be concerned about the difficulty they have keeping a ‘secret’ and limiting disclosure to selected persons.
Fear of inadvertent disclosure of parental status by the child is also a concern especially of biological parents of infected children. They feel that once a child’s status is known, people will automatically conclude that the parent or parents are HIV positive as well (Moneyham et al., 1996:209-221, Murphy et al., 2002:191-202). Furthermore, disclosing of a child’s HIV status often leads to disclosure of other family secrets, including paternity, and parental history of sexual behaviour and substance abuse (Wiener 2007:8). This may not be very acceptable to the parents or families involved and so may lead them to prefer to keep the child in the dark about his or her diagnosis.

2.5.3 Risk of Non-disclosure

Studies in other parts of the world have demonstrated that some mothers believe that it is better for the children to hear about their status from the mothers themselves rather than somebody else and so they will ahead and disclose to the child before the child hears it from elsewhere (Schrimshaw, 2002:19-43). Children may inadvertently learn of the nature of their illness in a manner that is not supportive and at times if they find out their infection status from someone other than a parent they may feel unable to confide in their parent or feel a need to conceal that they are aware of their diagnosis (AAP Policy 1999:2).

2.5.4 Other Related Factors Affecting Disclosure

Parent/guardian with HIV negative status

It has been found that guardians or caregivers who are HIV-negative usually disclose a child’s status early (Mellins CA et al., 2003:407-416).
Denial of parental or child’s HIV positive status

Some parents may not disclose the health status to their child because they may still be having difficulty coping with their own illness. Denial is common, and parents may not be able to deal with their own infection with HIV or that of a family member (AAP, 1999:2). A parent in denial about their own illness or even the child’s illness may find it very hard to carry the extra burden of disclosure to the child and possible consequences that may have.

Quality of counselling received in preparation for the HIV status disclosure

Parents and guardians of HIV-infected children as well as the children themselves, need counselling in order to prepare them for the process of HIV status disclosure. This is necessary to prepare them psychologically for the possible consequences of disclosure. However, the quality of counselling received may not always be adequate to prepare these clients. In Zambia, for instance, the Ministry of Health encourages that as much as possible families involve health workers when working towards disclosure of HIV status to children or adolescents living with HIV. It is however acknowledged by the ministry that this is a challenge in the sense that there are very few specialised paediatric counsellors in the country at the moment (IRIN, 2007:1).

Attitude towards continued secrecy and perception of a child’s right to know their status

Some caregivers have cited getting tired of keeping the secret as their reason for disclosing to the child, while others just feel that the child has a right to know their diagnosis and health status and so have gone ahead to disclose (Waugh 2003; Blasini et al., 2004).
Cultural Factors

In certain settings, cultural factors may affect a parent or guardian’s ability to disclose a child’s HIV status to that child. For instance, a cultural anthropologist and consultant in the Zambian Ministry of Health was quoted as having said most Zambian families failed to disclose the status to HIV-infected children because of cultural norms that encouraged elders to sieve information passed to children. She went on to say that while colleagues in Western countries promoted a culture of open communication about many issues, Zambians tended to be more cautious, especially when they felt the information could break the child emotionally (IRIN, 2007).

Residence

Studies which compared urban and rural areas found that people living in urban areas were also more likely to disclose than those in rural areas. (Lester et al., 2002:309-317).

2.6 Research Questions

1. What is the disclosure rate of HIV status to HIV Posit Children at Kalingalinga Health Centre?
2. What factors affect parental disclosure of HIV status HIV-infected children and adolescents?

2.7 The Hypothesis

In this study, we are hypothesising that:

1. There is an association between parental disclosure of HIV status and particular risks.
2. There is an association between parental disclosure of HIV status and particular benefits.

2.8 General Objective

To determine the rate and factors affecting parental disclosure of HIV status to HIV-infected children and adolescents at Kalingalinga Health Center, Lusaka.

2.8.1 Specific Objectives

1. To determine the rate and patterns of disclosure of HIV status to HIV-infected children and adolescents at Kalingalinga Health Centre.
2. To establish the extent to which socio-demographic characteristics affect disclosure of status to children.
3. To determine the extent to which parental perceptions regarding risks and benefits affect disclosure of HIV status to children and adolescents.
4. To determine the extent to which quality of counselling affects parental disclosure of HIV status to HIV-infected children and adolescents.
CHAPTER THREE - METHODOLOGY AND RESEARCH DESIGN

3.0 Research Design

An exploratory cross-sectional study design was chosen for this study. The justification for such a design was premised on the fact that the researcher had identified gaps in patterns of disclosure and the factors that determine the types of disclosure. Ideally, when a researcher has questions about events or experiences for which little is known, an exploratory is appropriate to generate foundational knowledge (Denzin and Lincoln, 1994; Baltes et al., 1998, Creswell, 2005). It should be noted that the researcher found it difficult to define what was relevant in advance. A cross sectional study was the most appropriate in this study because for such a basic research, results ought to be obtained with minimum time and cost (Baltes et al.1998; Creswell, 2005).

3.1 Description of the Study Site

Kalingalinga Health Centre is located on the eastern side of the Mass media complex in Lusaka. It is along Alick Nkhata Road near Total Filling Station. The clinic’s nearest referral hospital is the University teaching Hospital. The clinic was opened in 1980. The catchment area of the clinic includes Kalingalinga Compound, Helen Kaunda, Sunningdale, UNZA (main Campus), Olympia, Old Airport, Longacres and Kalundu Residential areas.

The current catchment population of the clinic stands at 55, 687. This catchment population is a mixture of all three basic socio-economic status. These are low, medium and high. This is indicated by the areas which make up or form the catchment area. Those in the high socio-economic bracket are drawn from areas such as Longacres, Kalundu, and parts of Rhodespark, Kabulonga, UNZA Main Campus, Old Airport, Sunningdale parts of
Olympia Park. The major sources of income for people in this bracket are business and formal employment, with people holding senior positions in big companies. It follows that their per capita income is relatively high. Those in the medium socioeconomic brackets come mainly from Helen Kaunda and parts of Kalingalinga Compound itself. These are mainly civil servants, with medium per capita income.

Kalingalinga Compound itself accounts for those clients attending this health centre who fall into the low socio-economic status. Most people in this bracket are unemployed, not in formal employment, or are doing simple businesses which are not very gainful, to say the least, and most of this population are semi-literate.

The health centre has got an in-patient admission facility with thirty (30) beds for general cases and twelve (12) for maternity cases. In addition it has an out patient facility dealing with all general medical cases for both adults and children. It also has a mother and child (MCH) department, where child health and family planning activities are carried out, to name but a few. Kalingalinga Health Centre also has an anti-retroviral treatment (ART) Clinic which takes care of HIV and/or AIDS patients. It caters for both adults and children. Interestingly the Centre for Infectious Diseases Research in Zambia (CIDRZ) Laboratory, which carries out all the investigations related directly to ART treatment for all the government clinics under Lusaka strict Health Management Team, is located at this clinic.

3.2 Study Population

This study targeted parents and guardians of HIV-positive children who were scheduled to attend the anti-retroviral clinic for HIV and AIDS patients at Kalingalinga Health Centre.
Inclusion Criteria

- Parent or guardian (blood relative) of an HIV-positive child aged between 3 to 18 years of age.
- Respondent needed to be clinically stable.

3.3 Sampling

Two types of sampling methods were used and these are simple random sampling for quantitative data and purposive sampling for qualitative data. Each will be described below:

Simple Random sampling

A sampling frame (the clinic register of children enrolled at Kalingalinga Health Center anti-retroviral clinic) of 390 positive children was used to enlist 195 children. Random numbers generated from computer and tagged to each child were used to enlist children. To determine the ideal sample size Yamane formula was used:

\[ n = \frac{N}{1 + N(e)^2} \]

Where: \( n \) is the desired sample size

- \( N \) is the known population size (390) and
- \( e \) is the precision set at .05

Purposive Sampling

Maximum variation purposive sampling was used to select parents who were interviewed to obtain qualitative data. To determine which parents were to be
interviewed, the researcher picked parents who fell into extreme and central categories when the three types of disclosure, full, partial and none disclosure, were analysed from the preliminary explorative quantitative analysis. From this preliminary criterion, a sample of parents that represented a wide range of experiences related to the key demographic features were then selected. The goal of maximum variation sampling was to try to represent a wide range of experiences related to what the researcher intend to study. An interview guide (see Appendix II) was used for this purpose.

3.5 Data Collection

The methodical approach guiding the collection of data in this study was the hypothetical deductive approach and phenomenology. The hypothetical deductive approach required the research to identify a theoretical model to provide concepts and hypotheses to be tested. For this activity, the health belief model was used to derive conceptions of benefits and risks which appear in the two main hypotheses. Concerning phenomenology, an overview of the lived experience of parenting was explicated, part of which was their experience with disclosure of the diagnosis to their children and the quality of counselling that they experienced. Following ethical approval by the Biomedical Research Committee at the University of Zambia, the research was then done.

3.6 Ethical Matters

Since this study involved human participants, it was paramount to obtain consent from the participants.

Informed Consent
Consent to participate in this study was guaranteed as a right so that the person involved should have legal capacity to give consent and exercise free power of choice, without the intervention of any element of force, fraud, deceit, duress, over-reaching, or other ulterior form of constraint or coercion. To do so, all participants were availed sufficient knowledge and comprehens of the elements of the subject matter involved as to enable them to make an understood and enlightened decision. This latter element required that before acceptance of an affirmative decision by the participants, it was made known to them the nature, duration, and purpose of the research; the method and means by which it was to be conducted and all possible inconveniences. Participants were informed of their rights to withdraw from the study at any time without any sanctions.

Risks

The researcher did not anticipate any risks or harm to the participants because this was not an intervention study. However, the researcher endeavoured to minimise any immediate and subsequent potential discom on the participants as a result of participating in this research by applying the dictates of patient confidentiality as well as providing professional counselling services for any clients who would need these. Respondents were informed of what was to be done and how they would be involved in the study. The respondents were asked to answer a survey questionnaire.

The respondents were informed that their names would not be on any paper and the questionnaire would be destroyed after six months following the analysis. They were assured that by participating in the st possible risks were not there at all. However, if they felt some discomfort or in case they were anxious about some questions or spending some time wit the researcher and felt the need to decline to take part or stop everything, they would have to do so
voluntarily. This was because the decision to be part of the study was entirely up to them. Whatever they decided would not be held against them.

Confidentiality

Respondents were informed that participation in this study guaranteed confidentiality. None of the information was going to be held against the respondent by name. All information provided by the participants was to be considered confidential and grouped with responses from other participants and was be stored only for six months under lock and key only accessible to the researcher. Research data was going to be destroyed at the end of the study. This guaranteed the participants that no other person would have information related to them.

Reimbursement:

Participants were paid K25, 000 as a consideration of transport money spent to and from home (bus fare) as well as time spent being interviewed.

Rights and complaints:

If the respondents or health authorities had any concerns about the study, they were advised to contact the Chairperson, University of Zambia Biomedical Sciences Research Ethics Committee, PO BOX 50110, Lusaka, Zambia.

E-mail: unzarec@zamtel.zm

Fax +260-1-250753

Tel. 10 256067

Questionnaire Administration
A structured pre-tested questionnaire was used to obtain data from eligible respondents attending the ART clinic for review or refill of medication. Prior to completion of the questionnaire, respondents were given an introductory letter introducing the researcher and explaining the purpose of the study. A consent form was then given to those parents/guardians wishing to participate in the study. Once this had been signed, the researcher went ahead to administer the questionnaire. All this was done in a private room.

In depth Interviews

From the preliminary explorative quantitative data analysis, using maximum variation sampling, a sample of parents/guardians who fell into extreme and central categories when all three types of disclosure full, partial and none were analysed, were purposively selected for in-depth interviews. The selected respondents were then interviewed using an in-depth interview guide under strict confidentiality. Interviews were audio taped and most of the respondents except five were willing. The tapes were transcribed, and content analyzed, informed by a modified grounded theoretical approach (Strauss and Corbin, 1990).

3.6 Data Analysis

Qualitative data Analysis

Initial analyses were conducted during the period in which the interviews were being held. In order to answer the research questions, from the verbatim written transcripts the researcher with the help of two trained research assistants, searched for the presence of words or concepts or emerging themes, phrases, characters, or sentences as outlined by Berelson, (1952:74). These words, emerging themes, phrases, characters or sentences were taken as the units of analysis or meaning units. The meaning units were the elements that
were used in coding data. Together with the researcher, the team assessed similarities and differences between participants, examining categories that emerged, ranges of variation within categories, and variables that may be involved. A coding manual was developed, and areas of agreement were examined until consensus was reached. It is from this process that coding of themes; headers and sub headers was created. ‘Codes are tools to think with’ and ‘heuristic devices’ (themes) to organise the data. These codes and sub-codes were then used in analysis of all of the interviews. A code can be assigned to, for example, discrete objects, events and other phenomena, and should be understood in relation to the context. Using NVIVO software, nodes were created to link up all meaning units. This linking continued by induction and deduction along the nodal trees and by doing this, it was easy to show any phenomena of interest. From this process, it was possible to uncover the invariant features of phenomena in order to provide a description of them by looking for common themes as well as individual variations (Boyatzis (1998:4-6; Gillham, 2000:71).

Quantitative data Analysis

Data entry and analysis was done in SPSS version 17. Chi square tests were performed to test the association between variables. We report data in figures and tables and all tests are set at significance level $p = 0.05$ and any result with $p$ value $= 0.05$ or less was considered significant.
CHAPTER FOUR - RESEARCH FINDINGS

4.0 Introduction

For ease of presentation of the findings, the study is described using the themes in the research questions and objectives to help the reader follow the development of the research. Between 12th July, 2010 and 31st August 2010, a total of 195 survey questionnaires were administered and 27 in-depth interviews were conducted. This study integrated qualitative and quantitative data, looking at them in combination to get a deeper insight into the problem under study and possibly inspire a deeper and more rewarding analysis.

4.1 Demographic Characteristics

All participants were youthful black Zambians aged 17 to 66 of mean age 36.92 ± SD 9.8 (mean + standard deviation) and predominantly women took care of a child who was female and HIV positive. A greater majority of the residents were literate and either had secondary education or college and university education. Majority of the respondents were married and were residing in Kalingalinga though a few were residing in the neighbouring suburbs like Mutendere and Kabulonga. Nearly all the respondents were Christians with the majority being Protestants. A very negligible number of them did not believe in God or were Muslims. Information about these key demographic characteristics is summarised in (Table 4.1).
<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent’s sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>47</td>
<td>24.1%</td>
</tr>
<tr>
<td>Female</td>
<td>148</td>
<td>75.9%</td>
</tr>
<tr>
<td>Total</td>
<td>195</td>
<td>100%</td>
</tr>
<tr>
<td>Child’s sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>90</td>
<td>46.2%</td>
</tr>
<tr>
<td>Female</td>
<td>105</td>
<td>53.8%</td>
</tr>
<tr>
<td>Total</td>
<td>195</td>
<td>100%</td>
</tr>
<tr>
<td>Residence</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kalingalinga</td>
<td>114</td>
<td>51.4%</td>
</tr>
<tr>
<td>Mtendere</td>
<td>87</td>
<td>45%</td>
</tr>
<tr>
<td>Helen Kaunda</td>
<td>4</td>
<td>2.1%</td>
</tr>
<tr>
<td>Kabulonga</td>
<td>3</td>
<td>1.5%</td>
</tr>
<tr>
<td>Longacres</td>
<td>1</td>
<td>0.5%</td>
</tr>
<tr>
<td>Total</td>
<td>195</td>
<td>100%</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>115</td>
<td>59.0%</td>
</tr>
<tr>
<td>Widowed</td>
<td>35</td>
<td>18.5%</td>
</tr>
<tr>
<td>Single</td>
<td>29</td>
<td>14.9%</td>
</tr>
<tr>
<td>Status</td>
<td>Count</td>
<td>Percentage</td>
</tr>
<tr>
<td>--------------</td>
<td>-------</td>
<td>------------</td>
</tr>
<tr>
<td>Divorced</td>
<td>13</td>
<td>6.7%</td>
</tr>
<tr>
<td>Separated</td>
<td>3</td>
<td>2%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>195</td>
<td>100%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Education</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>4</td>
<td>2.1%</td>
</tr>
<tr>
<td>Primary school</td>
<td>62</td>
<td>29.7%</td>
</tr>
<tr>
<td>Secondary school</td>
<td>101</td>
<td>48.2%</td>
</tr>
<tr>
<td>College</td>
<td>22</td>
<td>11%</td>
</tr>
<tr>
<td>University</td>
<td>6</td>
<td>3.1%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>195</td>
<td>100%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Religion</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Protestant</td>
<td>131</td>
<td>67.2%</td>
</tr>
<tr>
<td>Catholic</td>
<td>40</td>
<td>20.5%</td>
</tr>
<tr>
<td>Jehovah’s Witness</td>
<td>17</td>
<td>9.2%</td>
</tr>
<tr>
<td>Muslim</td>
<td>4</td>
<td>2.1%</td>
</tr>
<tr>
<td>Non-religious</td>
<td>3</td>
<td>1.0%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>195</td>
<td>100%</td>
</tr>
</tbody>
</table>

### 4.2 Disclosure Rate and Pattern of Disclosure

More of the biological parents took their own child to receive drugs or review than any one else. The probability of having a female child who was positive was 0.61.
Table 4.2.1 Disclosure by Type of Relationship with child

<table>
<thead>
<tr>
<th>Relationship With Child</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Son</td>
<td>56</td>
<td>28.7</td>
</tr>
<tr>
<td>Daughter</td>
<td>63</td>
<td>32.3</td>
</tr>
<tr>
<td>Nephew</td>
<td>22</td>
<td>11.3</td>
</tr>
<tr>
<td>Niece</td>
<td>28</td>
<td>14.4</td>
</tr>
<tr>
<td>Grandson</td>
<td>4</td>
<td>2.1</td>
</tr>
<tr>
<td>Grand daughter</td>
<td>10</td>
<td>5.1</td>
</tr>
<tr>
<td>Sister</td>
<td>10</td>
<td>5.1</td>
</tr>
<tr>
<td>Cousin</td>
<td>2</td>
<td>1.0</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>195</strong></td>
<td><strong>100.0</strong></td>
</tr>
</tbody>
</table>

Disclosure of the child’s HIV status, in terms of the child having been told his or her status fully or partially, was very low n= 63 (32.3%). Among these 63 parents or guardians who opted to disclose some information regarding the child’s status, among them n= 32 (51%) opted for full disclosure whereas n= 31 (49%) opted for partial disclosure (Table 4.2.2). This brought the percentage of parents or guardians that had done full disclosure of HIV status to their child/adolescent among the total study population to only 16%. One hundred and thirty two (67.7%) of the parents or guardians expressed no need to give a child any information about their HIV status (No disclosure). See Figure 4.2.
In addition, it was noted that 77% of the parents or guardians of children in the age ranges 6 to 10 and over 10 years thought a child older than 5 years should be told something about his/her status either in full or in part. The proportions opting for full disclosure of the child’s HIV status were also higher in the same age groups. Age was statistically significant for those less than five years children (p = 0.000).

<table>
<thead>
<tr>
<th>If Yes, What was the age of the child when he/she was told he/she is HIV-positive</th>
<th>I disclosed in full</th>
<th>I disclosed only in part</th>
<th>I have not disclosed at all</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 5 years</td>
<td>6</td>
<td>8</td>
<td>130</td>
<td>144</td>
</tr>
<tr>
<td>6 to 10 years</td>
<td>15</td>
<td>15</td>
<td>2</td>
<td>32</td>
</tr>
<tr>
<td>Over 10 years</td>
<td>12</td>
<td>7</td>
<td>0</td>
<td>19</td>
</tr>
<tr>
<td>Total</td>
<td>32</td>
<td>31</td>
<td>132</td>
<td>195</td>
</tr>
</tbody>
</table>

**Chi-Square Tests**

<table>
<thead>
<tr>
<th></th>
<th>Value</th>
<th>df</th>
<th>Asymp. Sig. (2-sided)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pearson Chi-Square</td>
<td>131.724</td>
<td>4</td>
<td>.000</td>
</tr>
<tr>
<td>Likelihood Ratio</td>
<td>140.034</td>
<td>4</td>
<td>.000</td>
</tr>
<tr>
<td>Linear-by-Linear Association</td>
<td>107.355</td>
<td>1</td>
<td>.000</td>
</tr>
<tr>
<td>N of Valid Cases</td>
<td>195</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Although the choices for the type of disclosure among parents or guardians were not comparable for children of the same age and opposite gender, there were significantly more female than male parents or guardians opting for only partial instead of full disclosure. The proportions for full disclosure were not high among parents who had biological children but this did not reach the significance level (p = 0.489).
Table 4.2.3 Child Knowledge of HIV Status and Relationship

<table>
<thead>
<tr>
<th>What is the relationship between you and the child/adolescent?</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Son</td>
<td>Daugh</td>
</tr>
<tr>
<td>------</td>
<td>-------</td>
</tr>
<tr>
<td>Child knowing of HIV-positive</td>
<td>56</td>
</tr>
<tr>
<td>Yes</td>
<td>16</td>
</tr>
<tr>
<td>No</td>
<td>40</td>
</tr>
</tbody>
</table>

Chi-Square Tests

<table>
<thead>
<tr>
<th></th>
<th>Value</th>
<th>df</th>
<th>Asymp. Sig. (2-sided)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pearson Chi-Square</td>
<td>6.443</td>
<td>7</td>
<td>.489</td>
</tr>
<tr>
<td>Likelihood Ratio</td>
<td>7.446</td>
<td>7</td>
<td>.384</td>
</tr>
<tr>
<td>N of Valid Cases</td>
<td>195</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The level of education had no clear association with parent’s desire to disclose the child’s status (p = 0.544).

Table 4.2.5 Child Knowledge of HIV Status and Parent’s Level of Education

<table>
<thead>
<tr>
<th>Classification of level of education</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>Primary</td>
</tr>
<tr>
<td>------</td>
<td>---------</td>
</tr>
<tr>
<td>Does this child know that he/she is HIV-positive?</td>
<td>63</td>
</tr>
<tr>
<td>Yes</td>
<td>1</td>
</tr>
<tr>
<td>No</td>
<td>3</td>
</tr>
<tr>
<td>Total</td>
<td>4</td>
</tr>
</tbody>
</table>

Chi-Square Tests

<table>
<thead>
<tr>
<th></th>
<th>Value</th>
<th>df</th>
<th>Asymp. Sig. (2-sided)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pearson Chi-Square</td>
<td>2.139</td>
<td>3</td>
<td>.544</td>
</tr>
<tr>
<td>Likelihood Ratio</td>
<td>2.089</td>
<td>3</td>
<td>.554</td>
</tr>
<tr>
<td>N of Valid Cases</td>
<td>195</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
For all education categories, a significantly higher proportion of parents or guardians who either had college or university education than secondary or primary and no education opted for full disclosure of the child’s HIV status. However, when level of education was associated with type of disclosure, higher educated community members had higher proportions for full disclosure but this did not reach the significance level and was not consistent among parents or guardians.

The preferred minimum age for both partial disclosure was 6 and for full disclosure it was 6 years as well. A guideline summarizes the information above (Fig. 4.2.2).
4.3 Quality of Counselling and Parental Disclosure

In this study, a slight majority of the respondents n= 116 (59%) were counselled as compared to n= 79 (48.5%) who were not. Perhaps these were guardians who took over the care of the child long after the parent or guardian had a counselling experience (Figure 4.3.1).

Figure 4.3.1 Guardians and Parents who were counselled

Different categories of staff conducted counselling. However, the majority of the parents/guardians were counselled by community counsellors n= 72 (36.9%). Other staff like nurses, clinical officers and doctors conducted only 19.5% of the
counselling sessions (Figure 4.3.2). The more the amount of clinical work done on one hand and the fewer the number of staff in a specific category, on the other hand, seemed to be a factor limiting nurses, clinical officers and doctors to be engaged in counselling.

Figure 4.3.2 Types of Counselling Staff

The quality of counselling was rated as excellent by n= 58 (29.7%), good by n= 51 (26.2%) and fair by n= 3 (1.5%) and n= 83 (42.6%) gave no response (Figure 4.3.3).

Figure 4.3.3 Quality of Counselling
When the parents or guardians were prodded about the quality of counselling, it was not expected that there would be n = 83 (42.6%) parents or guardians giving no response. As for those who did, n = 112 (57.4%) said the quality of counselling was excellent, good or fair (Table 4.3.1). Although there were parents or guardians who did not give an opinion on the quality of counselling, partly because they had not actually been counselled, there were significantly more parents or guardians who were satisfied with quality of counselling than those who were not and ended up either fully disclosing or partially disclosing the HIV status of the child (p = 0.000) (table 4.3.1).

<table>
<thead>
<tr>
<th>How do you rate the quality of counselling</th>
<th>How much did you disclose to the child?</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>I disclosed in full</td>
<td>I disclosed only in part</td>
</tr>
<tr>
<td>excellent</td>
<td>20</td>
<td>10</td>
</tr>
<tr>
<td>good</td>
<td>6</td>
<td>15</td>
</tr>
<tr>
<td>fair</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>no response</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>Total</td>
<td>33</td>
<td>30</td>
</tr>
</tbody>
</table>

**Chi-Square Tests**

<table>
<thead>
<tr>
<th></th>
<th>Value</th>
<th>df</th>
<th>Asymp. Sig. (2-sided)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pearson Chi-Square</td>
<td>39.138</td>
<td>6</td>
<td>.000</td>
</tr>
<tr>
<td>Likelihood Ratio</td>
<td>38.689</td>
<td>6</td>
<td>.000</td>
</tr>
<tr>
<td>N of Valid Cases</td>
<td>195</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

It appears that counselling was well arranged and done as seen from the availability of a private room where counsellors talked to the clients and the fact that counsellors were polite and patient during the discussion (Table 4.3.2).
Table 4.3.2 Counselling Factors

<table>
<thead>
<tr>
<th></th>
<th>Response Type</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Was there a private room where the counsellor talked to you?</td>
<td>107</td>
<td>5</td>
</tr>
<tr>
<td>Was the counsellor polite and patient with you during the discussion?</td>
<td>110</td>
<td>2</td>
</tr>
</tbody>
</table>

4.4 Factors Affecting Parental Disclosure (Hypotheses)

In this section, we condense all factors that could be associated with HIV status disclosure. The socio-demographic Characteristics and Disclosure of HIV status have been discussed already under patterns of disclosure in section 4.2. The listed factors for refusal to disclose or willingness to disclose the child’s status are grouped under perceived risks and perceived benefits. Noting that the specific variables under each core hypothesis are quite many and including contingency tables would make the section lengthy, only summaries and decisions of tested hypotheses appear. All contingency tables appear as appendices.

4.4.1 Disclosure and Perceived Benefits

Four hypotheses under perceived benefits were tested (table 4.4.1.2). The listed reasons for parental willingness to disclose the child HIV status express significant hopes for possible positive impacts on the child as follows, (a) the child would know the truth (b) the parent may gain the child’s trust and (c) the
family would work out steps to prevent the child infecting others if he/she knew that he or she was infected and (d) improving the way the child takes medicines. However improving the way the child takes medicines and preventing infecting others were not significant benefits for revealing the child’s status.

Table 4.4.1.1 Perceived Benefits of Status Disclosure

<table>
<thead>
<tr>
<th>Variable</th>
<th>Significant level</th>
<th>Result</th>
</tr>
</thead>
<tbody>
<tr>
<td>child should know the truth</td>
<td>$\chi^2 = 25.259; p = 0.000$</td>
<td>Significant to reject null hypothesis</td>
</tr>
<tr>
<td>To prevent the child hearing of the illness from someone else and lose trust in me</td>
<td>$\chi^2 = 30.797; p = 0.000$</td>
<td>Significant to reject null hypothesis</td>
</tr>
<tr>
<td>Disclosure seen as a way of improving the way he/she takes his/her medicines for HIV.</td>
<td>$\chi^2 = 6.125; p = 0.130$</td>
<td>Not significant to reject null hypothesis</td>
</tr>
<tr>
<td>Disclosure seen as way to prevent infecting others</td>
<td>$\chi^2 = 7.688; p = 0.060$</td>
<td>Significant to reject null hypothesis</td>
</tr>
</tbody>
</table>

4.4.2 Disclosure and perceived risks

Four hypotheses under perceived risks were tested (table 4.4.1.2). The listed reasons for parental unwillingness to disclose the child’s HIV status express significant concerns for possible negative impacts on the child (a) The child may react like being angry with the parent or guardian for infecting him/her, (b) the child may die too soon on account of knowing his or her status, (c) the child may experience stigma like feeling ashamed, or experiencing rejection or isolation by the community, and (d) denial of information to the child to maintain the secrecy of HIV infection. However, denial of information to the
child to maintain the secrecy of HIV infection was not a significant risk of refusal to reveal to the child his or her HIV status.

<table>
<thead>
<tr>
<th>Table 4.4.1.2 Perceived Risks of Status Disclosure</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Variable</strong></td>
</tr>
<tr>
<td>The child may react like being angry with parent for infecting him/her</td>
</tr>
<tr>
<td>The child may die on account of knowing the truth</td>
</tr>
<tr>
<td>The child may feel ashamed of himself or herself</td>
</tr>
<tr>
<td>The child may be rejected or isolated by the community</td>
</tr>
<tr>
<td>The child may reveal the secret of the infection to other people</td>
</tr>
</tbody>
</table>

When parents or guardians were followed up to elaborate their experiences with regards to disclosure, it was interesting to note that most of them had specific criteria for deciding to disclose the child’s HIV status. Concerning refusal to disclose, fears about the consequences and how disclosure of the child/adolescent’s HIV infection would affect their child was an important consideration for many. There were benefits of disclosure that were highlighted like to ease the taking of drugs and preparing children to take care of themselves and to be mindful of others. The descriptions below speak for themselves.
Risks of Disclosure

Telling a child that he is ‘positive’, it is a bad thing. You just kill the child there and then. Yeah it’s talked about in the counselling circles citing the advantages but for me, no it is bad.

[Father to boy 9]

Normally I don’t really say anything like that to a child. He will discover on his own and when asked, I will be in position to tell him. I fear that he will be speaking about this to every Jim and Jack.

[Mother to a boy 7]

You see my child does not ask me why she has to come to the clinic very often. I personally believe that I’m in danger of being blamed by my relatives. They say he is too young to know and besides there is this family identity we have to protect.

[Mother to a boy 6]

Interpretation of Findings

From the comments of parents and guardians indicated above, the perceived risks of disclosure border around secrecy, fear of stigmatisation and fear that the child may lose the will to live.

Benefits of Disclosure

In the past, it seemed difficult to tell a child you are positive. Now after counselling, it seems like a foregone conclusion. I do not have any fears. I speak to her and tell her about the illness.

[Grand mother to a boy 11]

Interpretation of Findings

The comment of this grandmother indicates that one of the perceived benefits of disclosure is the ability to speak to the child freely about the illness and this would help in seeking medical help and compliance to treatment.
Criteria for disclosure

Most parents or guardians had specific criteria for deciding to disclose or not the child’s status. These criteria were generally based on one of three factors: the age of the child, fear of being blamed and level of development of a child. Some examples are outlined below:

  Ability to handle the matter

  Five parents and guardians said,

  ‘Told him because he is a bit old to handle it.

  ‘My child handled it well when I told her. I gave her my position too’

  ‘I told her now you are old you must know. Your mother and my sister died of this illness. You have it and I’ve to take care of you. You must know how to handle it and yourself.

  ‘I knew I had to tell my grand daughter’. What will I do when she asks me and particularly some else tells her?

  ‘I’ve decided to tell my son because me and him live together and I don’t want to keep it from him’.

Emotional disclosure

Though some parents were able to disclose to their child, the process of disclosure seemed to be a difficult one. Many participants based their decision to disclose their child’s HIV infection on the basis of trust that the child may not reveal to outsiders and that it would not harm the child. Some women described a more intuitive basis on which they made disclosure decisions. The following were emotive examples of the disclosure experiences:

  ‘I had to think about what to say and how to say it’.

  ‘I choose her birthday because I had to buy her the most cherished present.'
‘I prayed and prayed about it. I meditated on it’

‘I just felt that it was the right time to discuss the matter with him. It was taking a toll on me. I had kept it for a long time. I had to tell him. It was like having a gun to my head’.

‘Yes, it is relatively easy deciding to tell your child. It is just how to tell them that is hard. ‘My stress level was so bad that I had to tell my mother to do it, but it was one-and-a-half to two years later that I told my son...’.
CHAPTER FIVE - DISCUSSION AND CONCLUSIONS

5.0 Introduction

This chapter discusses the findings and presents conclusions of the study. The findings are initially discussed thematically using concepts drawn from the objectives and the hypotheses. This is done in order for the researcher to give an interpretation of the findings later on. It’s a discussion of the corroborate facts as compared to existing literature. In this way, the study grants convergent validation to the data that has been generated. A conclusion follows the discussion and the strengths and significance of this research are presented thereafter. This chapter winds up on the limitations of the study since these play an important role in making suggestions for future research and coming up with recommendations.

5.1 What this Study Has Found

With regard to objective number one (To determine the and patterns of disclosure of HIV status to HIV-infected children and adolescents at Kalingalinga Health Centre), the study found that HIV status disclosure by the parent or guardian was very low and stood at a total of 32.3% for partial and full disclosure combined, and only 16% for full disclosure.

The pattern of disclosure was such that among those 63 respondents that carried out some extent of disclosure, n = 32 (51%) opted for full disclosure whereas n = 31 (49%) opted for partial disclosure. The opting for full disclosure of the child’s HIV status were higher the age groups of children 6 to 10 and over 10 years (that is when the child was older than five years) and age was statistically significant for those less than five years children (p = 0.000).
Concerning objective two (To establish the extent to which socio-demographic characteristics affect disclosure of status to children) we found that there were significantly more female than male parents or guardians opting for only partial instead of full disclosure. The proportions for full disclosure were not high among parents who had biological children but this did not reach the significance level (p = 0.489). Neither did the level of education have any clear association with parent's desire to disclose the child status (p = 0.544). For all education categories, a significantly higher proportion of parents or guardians who either had college or university education rather than secondary, primary or no education at all, opted for full disclosure of the child’s HIV status. However, when level of education was associated with type of disclosure, higher educated community members had higher proportions for full disclosure but this did not reach the significance level and was not consistent among parents or guardians. The preferred minimum age for partial disclosure was 6 and for full disclosure it was also 6 years.

When the two main hypotheses were tested to determine the extent to which parental perceptions of the benefits and risks of HIV status disclosure affect disclosure of HIV status to children and adolescents the following were observed:

1. With regard to main hypothesis \( H_01 \), “There is no association between disclosing HIV status to a child/adolescent and particular risks” the listed reasons for parental willingness to disclose the child’s HIV status expressed significant concerns for possible negative impacts on the child if the child knew the truth, like (a) the child was going to react like being angry with the parent or guardian for infecting him/her, (b) the parent or guardian perceived that the child could die too soon on account of
knowing his or her status, (c) the child experienced stigma like feeling ashamed, rejection or isolation by the community or the child may react on account of being rejected or isolated by the community. However, denial of information to the child to maintain the secrecy of HIV infection was not a significant risk factor in refusal to reveal to the child his or her status.

2. With regard to main hypothesis H02, “There is no association between disclosing HIV status to a child/adolescent and particular benefits,” The listed reasons for parental willingness to disclose the child’s HIV status express significant hopes for possible positive impact on the child as follows, (a) the child would know the truth (b) the parent may gain the child’s trust and (c) the family would work out steps to prevent the child infecting others if he/she knew that he or she was infected and (d) improving the way the child takes medicines. However improving the way the child takes medicines and preventing infecting others were not significant benefits for revealing the child’s status.

Referring to objective four (To determine the extent to which quality of counselling received in preparation for the process of disclosure affects parental disclosure of HIV status to HIV-infected children and adolescents), though much of the counselling was done by community counsellors, the quality of counselling was rated between excellent n= 58 (29.7%) to good by n= 51 (26.2%). When the parents or guardians were prodded about the quality of counselling, n= 83 (42.6%) parents or guardians gave no response. Although there were parents or guardians who did not give an opinion on the quality of counselling, there were significantly more parents or guardians who were satisfied with quality of counselling than not and either ended up fully disclosing or partially disclosing the HIV status of the child (p = 0.000). It
appears that counselling was well arranged and done as seen from the availability of a private room where counsellors talked to the clients and the fact that counsellors were polite and patient during the discussion.

5.3 Discussion

The current study represents the first of its kind in Zambia to explore factors affecting parental disclosure of HIV status to HIV-positive children and not how decisions concerning disclosure are made. Many parents or guardians' descriptions of their decision to disclose or not to reflected weighing benefits and costs of disclosure similar to that described in theories of reasoned actions (Fishbein and Middlestadt, 1994) and the Health Belief Model (Strecher and Rosenstock, 1997) as well as ways to apply criteria regarding the appropriateness or not of disclosure. However, many of the parents or guardians who declined to disclose the HIV status of their children discussed making decisions based on their emotional and intuitive processes as their sole criteria for disclosure. This more clearly reflected their personal appraisal of the negative consequences associated with disclosure than reasoned actions. These parents or guardians were less likely to tell children of their HIV infection as compared to parents or guardians providing other categories of responses like partial or full disclosure.

Past research done in other parts of the world, like the current one, supports the fact that parents or guardians’ concerns about risks like stigma and rejection related to disclosing the child’s HIV sero-status are not unwarranted (Defeu et al., 1994; Zierler et al., 2000). While these cited studies document parents or guardian’s concerns about negative responses such as rejection and abandonment primarily within the context of parents or guardian’s relationships, parents or guardian may also fear similar negative consequences associated with disclosure to children or adolescents.
The small group of parents or guardians that found it comfortable disclosing fully the HIV status to their children or adolescents had markedly different appraisals of the consequences associated with disclosure as compared to parents or guardian who had hesitation at first or disclosed in part. These parents or guardians seemed unafraid of potential negative consequences of disclosing their child’s HIV sero-positive status and a number of the parents or guardian actively worked to increase awareness of HIV in their children. This belief in the benefits of openness and/or confrontation of HIV-related stigma may have served as a resource for these parents or guardian, reducing the fear of disclosure (Lazarus and Folkman, 1984). Parents or guardian described as ‘full’ disclosers were much more likely to tell ‘all’ across categories, although significantly higher levels of disclosure were only found for bosses, and close and casual friends. Perhaps bosses and friends are more on the periphery of one’s social network—this is where full disclosure would make the most differences. Because these parents or guardian seem unafraid of being ‘out’ about their HIV infection, they may be the persons in the community whom people ‘know’ has the disease. Further studies need to look at the long-term impact that these parents or guardian may make on the attitudes of community members and other persons with HIV infection. However, these parents or guardian may, also, be the group most likely to suffer stigma and/or discrimination because of their disclosure.

Conversely, as has been documented elsewhere (Levy et al. 1999), another small group of parents or guardian had not disclosed to their children. This group of parents or guardian had appraised the disclosure process to be too difficult or risky to undertake and engaged in avoidant behaviours to hide their illness. Clinically, avoidant behaviour is associated with a host of negative outcomes including depression and anxiety (Folkman et al. 1993).

This study has shown that disclosing a diagnosis of HIV to a child or adolescent is one of the most important yet most difficult issues facing some
guardians or parents today. Though research on parental disclosure to a child is rarer, the difficulties or risks as well as the benefits of disclosure in other types of relationships seem to be the same as shown in previous studies involving HIV positive parents or spouses (Murphy et al. 2003; Nelms, 2005; Sandelowski et al., 2004; Sheckter, 2002). In one classical phenomenological research by Nelms (2005) regarding mothering issues experienced by HIV-infected parents or guardians with children showed that a diagnosis of HIV presented a number of disclosure burdens to these parents or guardian. Like this study, one of the burdens described by the parents or guardian was the struggle of whether or not to disclose the diagnosis to their children. Of the 16 women interviewed in Nelms’s study, 11 had purposefully not revealed their HIV status to their children. Although some said they wanted to tell their children or thought they should tell, they said they were afraid of the children’s reactions and did not know how to disclose. The women reported that the main reasons for not disclosing the diagnosis to their children were the desire for their children to have a happy childhood and the stigma associated with HIV (Nelms, 2005).

Unlike this study, previous studies conducted on the subject indicate that HIV status disclosure is not a random event. A study by Lee and others (2002) on parents or guardians’ disclosure patterns to their children showed that mothers disclosed more often to their daughters than their sons. The study further established that disclosure was significantly more common among parents or guardians with poor health and stressful life events than those without stressful events. This is one aspect the current study did not examine. In addition, this research and just like previous research have shown that the child’s age is an important predictor of whether or not the child would be told about his or her infection. Brady et al., (1996); Wiener et al. (1996) and Rotheram-Borus et al. (1997).
The findings in this study have public health implications. The low disclosure rates are suggestive of higher perception of risks than benefits in the study population. Although there may be other explanations, it could be argued that provision of better counselling services is one way of countering risks given that the study was conducted in a healthcare delivery setting. The pervasive HIV-related risks of disclosure that exist within the community could be attributed to labelling. A child’s HIV status disclosure rate of 16% was significantly low in comparison with some classical studies though not involving children. A South African study by Lurie and others (2003) involving 168 HIV infected male miners and their female partners scored 43% of status disclosure. In one study by Fako (2006), more than 60% of the participants thought that something should be communicated to the children in a hypothetical situation and 60–89% expressed the desire to have such issues discussed with their own children in cases where they were found to be infected with HIV. These percentages were higher than anticipated given the common assumption that there is so much stigma and risks around HIV in rural communities (Fako, 2006).

It was not surprising to observe that the younger the child was the more unlikely the parent or guardian would be to disclose the child’s HIV status. ‘Non-disclosure’ was preferred for children of less than 6 years old, ‘partial disclosure’ for children from age 6 to 10 years, ‘partial followed by full disclosure’ for children from 7 years old or so and ‘full disclosure’ for children above 10 years. It was also not surprising to note that a similar pattern was noticed when comparing higher educated participants to lower educated ones. This could possibly be explained differentially on account of increased attention given to HIV in general education and communication provided to these groups. This differs from the guidelines for children with terminally ill parents or guardians affected by HIV/AIDS reported by ANECCA (2004), where partial disclosure is possible for children older than 3 years and full
disclosure for children older than 8 years. This difference highlights the need for further research sensitive to local, cultural constraints and beliefs.

The perceived emotional maturity and intellectual capacity of children should be considered because they are important factors in determining the most suitable time and type of HIV disclosure.

Limitations

There is no research that is not impregnated with limitations. This study had several limitations based on the research design that should be kept in mind when interpreting the results.

First, the study focused only on HIV positive children who were receiving medical care. The reference population did not include parents of HIV-positive children who were not receiving medical care for HIV. Moreover, most of the people we studied had been receiving care for at least 4 years. Because many individuals do not seek treatment until they begin having symptoms, this study represents those whose HIV disease is more advanced or had Low CD4 counts, on average, than would be found in the population of all diagnosed HIV positive persons. Patterns of disclosure may well differ between people with early-stage HIV illness who have not yet sought care and the people represented in our study.

Second, the HIV-infected parents or guardians who participated in this study were limited to one area of the city and country, this limits generalisation. However, the findings have some considerable credit because the experiences of our respondents were confirmed by the body of disclosure literature. In addition, the strength of this study is its focus on parents or
guardians who are in direct care of ailing children, a particularly important
group for health educators to address.

Third, while the results of the survey report that there is definitely a need and
desire for parental open communication about HIV and its consequences in
the family vis a vis risks and benefits, the actual disclosure practices of the
parents cannot be deduced from these findings because was no
opportunity for the researcher to witness any disclosure.

Strengths

Despite these limitations this study has notable strengths. Random sampling,
allows the results to influence and direct future research and help us
question common assumptions in the field such as, inter alia, less educated
people not wanting to disclose HIV status to children, adults not perceiving a
need to talk about HIV to children, Western counselling models being
applicable and acceptable for Zambian African families, and current
counselling training models paying sufficient attention to variant African
family structures.

5.4 Conclusions

Because of the complexity and the on-going nature of HIV-infected parents
or guardian’s struggle with disclosure issues, counselling support from health
educators is critical to help parents or guardians realistically appraise their
concerns related to disclosure so that they can access needed support and
services. Even though a majority of the parents or guardians described the
importance of disclosing in order to maximize life and health care options of
their children, many parents or guardians require continued support to
successfully assess the potential consequences of disclosure and cope with
the stress of the disclosure process. The fact that the rate of disclosure was very low in this study shows that parents or guardians may have a critical need for health education counselling in order to develop a plan for disclosing to their children and coping with reactions of people with negative attitudes about individuals with HIV infection.

Following on from Lazarus and Folkman’s theory of stress and coping, the theory suggests that a better understanding of HIV-infected parents or guardian’s cognitive appraisals of HIV stigma, and the potential reactions family, friends, sexual partners and health care providers, is a key to maximizing positive health outcomes and access to needed services (Lazarus and Folkman, 1984) like counselling. Health professionals working with parents of HIV-infected children need to be aware of the wide range of decision-making criteria that parents use to decide how to disclose to a variety of people and routinely assess concerns about the disclosure processes. Health educators may be in a unique situation to intervene to assist parents, especially those with children or at risk of having children, in understanding the importance of disclosure in making long-term plans for their children. By being aware of and sensitive to conceptual linkages proposed by stress theory, educators can more effectively counsel parents or guardians in the benefits of disclosure as well as assist parents or guardians develop plans for disclosing. Additionally, the health educator who understands cognitive processes is better prepared to respond effectively to a range of parents or guardian’s decisions in order to provide appropriate counselling to reduce unsafe and unhealthy behaviour.

5.5 Recommendations
Following the completion of this survey, the author recommends the following:

- There is need for mandatory counselling of parents or guardians of HIV-infected children and adolescents and for
provision of on-going help and support with the difficult and distressing task of disclosing the diagnosis to their children.

- Parental and child factors both need to be considered regarding disclosure of HIV status to children and adolescents.

- There is need to offer continued education, support, and encouragement from HIV-care staff because this could benefit parents or guardians and children in the disclosure process.

- Parents or guardians of HIV-infected children need to be empowered to believe they have the best knowledge of themselves and their family and will know the best time to disclose to their children.

- While current knowledge is insufficient in determining whether the choice and time of HIV disclosure to children should be based on age groups or developmental milestones, increased attention to training in paediatric counselling, and development of simplified tools for developmental assessments by primary health care workers is necessary.
3. REFERENCES


APPENDICES
Appendix I Questionnaire
Health facility interview schedule for parents and guardians 2009

Questionnaire Number

Identification of Respondent

<table>
<thead>
<tr>
<th>Name of facility</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Age of Parent/guardian state age at last Birthday in years</td>
<td></td>
</tr>
<tr>
<td>2. Sex</td>
<td></td>
</tr>
<tr>
<td>a. Male</td>
<td></td>
</tr>
<tr>
<td>b. Female</td>
<td></td>
</tr>
<tr>
<td>3. Residence</td>
<td></td>
</tr>
<tr>
<td>a. Kalingalinga</td>
<td></td>
</tr>
<tr>
<td>b. Mtendere</td>
<td></td>
</tr>
<tr>
<td>c. Helen Kaunda</td>
<td></td>
</tr>
<tr>
<td>d. Sunningdale</td>
<td></td>
</tr>
<tr>
<td>e. Olympia</td>
<td></td>
</tr>
<tr>
<td>f. Old Airport</td>
<td></td>
</tr>
<tr>
<td>g. Long acres</td>
<td></td>
</tr>
<tr>
<td>h. Kalundu</td>
<td></td>
</tr>
<tr>
<td>i. Kabulonga</td>
<td></td>
</tr>
<tr>
<td>j. Other</td>
<td></td>
</tr>
</tbody>
</table>

Identification of Interviewer

Interviewer’s name............................................................... .................

Date of Interviews

<table>
<thead>
<tr>
<th>Date</th>
<th>Month</th>
<th>Year</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**Section A: Demographic characteristics**

4. Marital status?
   a. Single ( )
   b. Married ( )
   c. Divorced ( )
   d. Widowed ( )
   e. Separated ( )

5. Where do you live?..............................

6. How far have you gone in school?
   a. Never been to school ( )
   b. Primary ( )
   c. Secondary ( )
   d. College ( )
   e. University ( )

7. What is your religious faith
   a. Catholic ( )
   b. Protestant ( )
   c. Jehovah’s witness ( )
   d. Muslim ( )
   e. Hindu ( )
   f. Non-religious ( )
   g. Other ------------------------ ( )

8. What is the age of the child you bring to the clinic? (state age at last birthday in years)..............................

9. What is the sex of your child
   a. Male ( )
   b. Female ( )

10. What is the relationship between you and the child/adolescent? He/She is my


## Section B: Child’s Knowledge of HIV status

11. Does this child know that he/she is HIV-positive?
   - a. Yes ( )
   - b. No ( )
   - c. I don’t know ( )

12. **If yes**, Who told the child that he/she is HIV-positive
   - a. Myself ( )
   - b. The counsellor at the clinic ( )
   - c. Myself together with the counsellor ( )
   - d. The counsellor alone ( )
   - e. Someone else ( )
   - f. I don’t know ( )

13. **If Yes**, What was the age of the child when he/she was told he/she is HIV-positive (State the age in years)..............................................................

14. **If no**, What does the child know about his/her illness?
   - a) He/she knows only about other illnesses, e.g malaria, cough. ( )
   - b) I have not told the child about any illness ( )
   - c) I don’t know ( )
### Section C - Psychosocial, cultural and Service-related factors

**1) Psychosocial and cultural factors**

(For each option tick only one answer)

#### a. Age of the child

15. How did you feel about disclosing to the child considering the age?  
   
   | a. Felt that the child was not old enough to know | ( ) |
   | b. Felt that child was old enough to know | ( ) |

#### b. Psychological effects

16. Were you afraid of getting an angry reaction from the child if he knew?  
   
   | a. was not afraid the child would be angry if he/she knew | ( ) |
   | b. was afraid the child would be angry if he/she knew | ( ) |

17. Were you afraid the child would start thinking they would die soon?  
   
   | a. not afraid they would think they would die soon. |
   | b. Was afraid child would think they would die soon. |

18. Were you afraid the child would start feeling ashamed of themselves?  
   
   | a. not afraid the child would be ashamed of himself |
   | b. Was afraid the child would be ashamed of himself |

#### c. Stigma

19. Were you afraid the child would be rejected by the community?  
   
   | a. Not afraid the child would be rejected by the community |
   | b. Afraid child would be rejected by the community |

20. Were you afraid the child would be isolated by the community?  
   
   | a. Not afraid the child would be isolated by the community |
   | b. Afraid child would be isolated by the community |
### d. secrecy

21. Were you afraid the child may reveal the secret to other people?  
   a. Not afraid the child would reveal the secret to other people  
   b. Afraid the child would reveal the secret to other people  

22. Did you want the child to know the truth about the illness?  
   a. Wanted the child to know the truth  
   b. Did not want the child to know the truth  

23. How did you feel about keeping the secret?  
   a. Found it easy to keep the secret  
   b. Got tired of keeping the secret  

24. Were you afraid the child would hear of the illness from someone else and lose trust in you?  
   a. Was afraid the child would hear of the illness from someone else.  
   b. Was not afraid the child would hear of the illness from someone else.  

### e. clinical perceptions

25. Did you think telling the child would help to improve the way he/she takes his/her medicines for HIV.?  
   a. Thought telling the child would help to improve the way he/she takes the medicines  
   b. Did not think telling the child would improve the way he/she takes the medicines  

### f. infection prevention concerns

26. Did you think the child would infect others if he/she did not know about his/her HIV status?  

II) Availability and Quality of Counselling

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
<th>27. Have you ever been talked to by a clinic counsellor to prepare you for the process of telling the child that he/she is HIV-positive?</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Thinks the child would infect others if he did not know</td>
<td>( )</td>
<td></td>
</tr>
<tr>
<td>b. Doesn't think the child would infect others if he/she did not know</td>
<td>( )</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
<th>28. How do you rate the quality of counselling</th>
</tr>
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<tbody>
<tr>
<td>a. Yes</td>
<td>( )</td>
<td></td>
</tr>
<tr>
<td>b. No</td>
<td>( )</td>
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<tr>
<th>Question</th>
<th>Options</th>
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<tbody>
<tr>
<td>28. How do you rate the quality of counselling</td>
<td>a) Excellent</td>
<td>( )</td>
</tr>
<tr>
<td></td>
<td>b) Good</td>
<td>( )</td>
</tr>
<tr>
<td></td>
<td>c) Fair</td>
<td>( )</td>
</tr>
<tr>
<td></td>
<td>d) Poor</td>
<td>( )</td>
</tr>
<tr>
<td></td>
<td>e) Very poor</td>
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<tr>
<th>Question</th>
<th>Options</th>
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<tbody>
<tr>
<td>29. Who counselled you?</td>
<td>a) Doctor</td>
<td>( )</td>
</tr>
<tr>
<td></td>
<td>b) Clinical officer</td>
<td>( )</td>
</tr>
<tr>
<td></td>
<td>c) Nurse</td>
<td>( )</td>
</tr>
<tr>
<td></td>
<td>d) Community counsellor</td>
<td>( )</td>
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<tr>
<th>Question</th>
<th>Options</th>
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<tbody>
<tr>
<td>30. Did the counselling you received from this person help you to tell the child that he/she is HIV-positive?</td>
<td>a) Yes</td>
<td>( )</td>
</tr>
<tr>
<td></td>
<td>b) No</td>
<td>( )</td>
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</tbody>
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<tr>
<th>Question</th>
<th>Options</th>
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<tbody>
<tr>
<td>31. Was there a private room where the counsellor talked to you?</td>
<td>a) Yes</td>
<td>( )</td>
</tr>
<tr>
<td></td>
<td>b) No</td>
<td>( )</td>
</tr>
</tbody>
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<tr>
<th>Question</th>
<th>Options</th>
<th></th>
</tr>
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<tbody>
<tr>
<td>32. Was the counsellor polite and patient with you during the discussion?</td>
<td>a) Yes</td>
<td>( )</td>
</tr>
<tr>
<td></td>
<td>b) No</td>
<td>( )</td>
</tr>
</tbody>
</table>

THANK YOU FOR YOUR PARTICIPATION!
Appendix II In-depth Interview Guide With the Parents

Theme I: Feelings
How do you feel about the child you bring here/brought here?
Probe for fears, successes, perceived benefits and risks of disclosing the child’s status.

Theme II: Type of relationship
What’s the relationship between you and the child/adolescent?
Probe for actual relationship, e.g. son, niece, cousin, and for degree of intimacy.

Theme III: Type of Disclosure
Is the child aware about his/her health status/ Does the child know that he has HIV/AIDS?
Probe:
   a) If yes, how did the child become aware?
   b) If no, what does the child know about his/her illness?
   c) Do you intend to tell the child about his illness sometime?

Probe for types of disclosure, timing or intended timing of disclosure and content of the disclosure information.

Theme IV: Motive for Explaining or not
If the child is not aware of his status, do you intend to tell him/her?
Probe:
   a) Why will you or won’t you tell the child/adolescent?

Probe for perceived benefits and risks to self and child
Probe for cultural beliefs regarding disclosure of HIV status to the child.
Theme V: Process of Disclosure

If you intend to disclose the child’s status to him/her, how will you go about it?

Or

If you have disclosed the child’s status to him/her, how did you go about it?

Probe for

a) methods of disclosure and need of helpers, e.g. counsellor at clinic.

b) Quality of Counselling, e.g. was there privacy, who counselled, satisfaction with the counselling, skill of the counsellor, etc. Reasons for particular response.
Appendix III Permission to Under Take the Study

The District Medical officer,
Lusaka District Health Management Team,
P.O Box 50827,
Lusaka.
Dear Madam,

**RE: PERMISSION TO CONDUCT RESEARCH AT KALINGALINGA CLINIC**

I am a medical officer at Kalingalinga Health Centre pursuing a postgraduate master’s degree program in Public Health The University of Zambia, School of Medicine. I am currently pursuing Part II of the course which involves research.

I am writing to seek permission to conduct my research at the above-named health centre. The title of the research is “Factors Affecting Parental Disclosure of HIV status to HIV-positive Children and Adolescents.” Below are some of details about the study:

**SAMPLES:**

1. Parents/guardians that have a child who has tested positive for HIV.

**DATA COLLECTING TOOLS:**

1. Survey questionnaire.
2. In-depth face to face Interviews.

**SAMPLING METHODS**

Simple Random and Purposive Sampling.

**STUDY DURATION:** Six months.
Attached is a summary of the research proposal. I have also applied to the University of Zambia Research Ethics Committee for ethical clearance.

Should there be need for me to do other things, I shall most grateful to oblige. Thanking you in advance for your cooperation.

Yours faithfully,

Dr Sylvia Kansembe.
Appendix IV Respondents' Introductory Letter

Dear Sir/ Madam,

My name is Sylvia Kansenbe. I am student at the University of Zambia doing my masters degree. May I ask for your help concerning the study I am doing for my masters' degree thesis? I am finding out a few important facts about on Factors affecting parental disclosure of HIV status to HIV-positive children and adolescents. I shall explain the project to you in detail should this information contained here be not sufficient.

I have sent this letter to you and a few other people. To make sure that I hear all your points of view, I am eager to get a reply from you. You will find a copy of the consent form that you may sign as acknowledgement for you to participate in the study. This is enclosed herein and if you could be kind enough, please read them both. I am optimistic that you will be of great help to this cause.

I do hope that you will agree to assist me in this study and spare some time later at your convenience for a discussion concerning my study.

I will not interfere in the clinical examination at all. What you will share with me will be highly appreciated. I present herewith, a copy of the consent form for you to sign, should you be willing to help me in this I should be most grateful for your help.

Yours sincerely

Sylvia Kansenbe
Appendix V Respondent's Information Sheet

The request:

Dear sir/madam,

You have been asked by Sylvia Kansembe to take part in the project. She will explain to you in detail about the project. You should feel free to ask her questions pertaining to the project. If you have additional questions later, Sylvia Kansembe, the person who is responsible for the project, will come here to discuss them with you.

Description of the project:

You have been asked to take part in the project that is dealing with Factors Affecting Parental Disclosure of HIV status to HIV-positive Children and Adolescents.

What will be done?

If you decide to take part in the project, you will be involved in an interview and answering a questionnaire. The questionnaire will take ten to fifteen minutes to answer. The interview will last between twenty to sixty minutes and the interview may be recorded if you are willing. Your name will not be on the tape if you agree to have the interview recorded and after the interview is typed, the tape will be destroyed.

Risks:

The possible risks in the project are not there at all. You may, however, feel some discomfort with some questions, which is usual, incase you are anxious. If that will be the case, and if you feel the need to stop the interview, you shall do so voluntarily because the decision to be part of the study is entirely up to you and you may terminate at any time. Whatever you decide will not be held against you. You understand that Sylvia Kansembe, the person who is responsible for the project, is not a member of any health regulatory board and that your participation will not have any impact on your job or on any other matter.

Benefits:

There are no guaranteed direct benefits to you immediately on account of this research. However the findings of the research will go a long
way in improving the management of children with HIV/AIDS, and will also help health workers provide professionally sound in dealing with parents of these children when they are contemplating disclosing the HIV status to these children.

**Confidentiality:**

Your participation in the project is confidential to the extent permitted by law. None of the information will identify you by name. All information provided by you will be confidential. No information that will be traceable to you will be on the transcript. This guarantees you that no other person will have information related to you.

**Reimbursement:**

You will be paid K25,000 as transport money to and fro home (bus fare) and reimbursement for your time. If you are in anyway psychologically affected or depressed by the questions you will receive professional counselling provided in the research study. The costs of such counselling will be paid for by the researcher. Further information about this, you may contact the Research Biomedical Ethics Committee of the University of Zambia, School of Medicine, P.O BOX 50110, Ridgeway campus, Lusaka.

**Decision to quit:**

The decision whether to take part or not to is entirely up to you. You do not have to be in the study. If you decide to take part in the study, you can quit any time. Whatever you decide is okay for you. You shall tell Sylvia Kansembe the person who is responsible for the project that you are quitting or you cannot go further in the interview. You are free to refuse to take part or withdraw at anytime without affecting or jeopardizing your future medical care.

**Rights and complaints:**

If you have concerns about the project; you may contact the Chairperson Biomedical Research Ethics Committee at the University Of Zambia, School of Medicine PO BOX 50110 Lusaka.

E-mail: unzarec@zamtel.zm, Fax +260-1-250753, Tel. 01 256067
Questions

Mr/Mrs/Miss........................................................., the research assistant, has discussed this information with you and offered to answer your questions. If you have any further questions, you can contact him/her on 0966 240880 or Sylvia Kansembe the Principal researcher of the study, on 0966 459544.
Appendix VI Respondent’s Consent Form

Respondent’s ID number

I have read the consent information form and understand what is stated. Any questions I have about the research have been answered. By signing the form, I am indicating my willingness to participate in this good cause. The consent form will be kept in the locker in safety and will not be attached to any transcripts or other materials.

..........................................................

Participant’s signature/thumbprint

..........................................................

Witness’ signature/thumbprint

..........................................................

Researcher / Research Assistant’s signature