

**Factors that influence parents to disclose or
not to disclose HIV status to their children
who are living with HIV/AIDS in the
greater Harare area in Zimbabwe**

by
Edmore Munongo

*Assignment presented in partial fulfilment of the requirements for
the degree Master of Philosophy (HIV/AIDS Management) at the
University of Stellenbosch*



Supervisor: Prof. Johan CD Augustyn
Faculty of Economic and Management Sciences
Africa Centre for HIV/AIDS Management.

March 2012

Declaration

By submitting this thesis/dissertation electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the sole author thereof (save to the extent explicitly otherwise stated), that reproduction and publication thereof by Stellenbosch University will not infringe any third party rights and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

March 2012

Copyright © 2012 Stellenbosch University

All rights reserved

ACRONYMS

AIDS: Acquired immune deficiency syndrome

PMTCT: Prevention of mother to child transmission of HIV

MNCH: Maternal, neonatal and child health

DHS: Demographic health survey

MOHCW: Ministry of health and child welfare

AIDS & TB unit: Department of AIDS and Tuberculosis care

OI/ART: Opportunistic infection/antiretroviral therapy

UNAIDS: The Joint United Nations Programme on HIV/AIDS

ABSTRACT

This study seeks to find factors that influence parents to disclose or withhold HIV status to the children who are living with HIV/AIDS. The observation from practice in the HIV clinics is that some children go to the age of up to 16 years without knowing their status. This is despite the fact that some of them will be taking medication which they are not told what it is for. Different parents give different explanations and most will always say they will disclose to their children when they feel that they are ready... Some cultural and religious beliefs can also influence the parents not to disclose the HIV status to the children. This is because the discussion will lead to a talk about the issues of sex and sexuality which in most African cultures is considered as taboo. The issues of stigma will always haunt the parents who are living with HIV and AIDS. This ranges from the need to avoid discrimination towards themselves and the infected children to the feeling of guilty for having transmitted the disease to the children. The parents feel that the children may not be able to handle the disease and end up disclosing to their peers and be discriminated and others feel that the children may end up feeling like they are lesser human beings. The fear of blame by the child is a strong contributor. Different parental backgrounds may result in different disclosure patterns.

It is however strongly believed that the disclosure of the status to the child improves the adherence to medication. A child who fully understands why he or she is taking the medication is better motivated to take the medication than a child who is taking the medication because 'it is the right thing to do'.

To get an insight into this problem, four sites that are offering HIV treatment to children were randomly selected in Harare. . A cross sectional analytical study was conducted .The target was to do interviews with parents whose children are between the ages of 6 and 16 who will be randomly sampled. One doctor, 2 nurses and 1 primary care counselors who are working in HIV/AIDS clinics for children were also interviewed to get their opinions. These were conveniently sampled. Most parents and health workers claimed that there is a high level of disclosure. However where there is no disclosure the issue of stigmatization and feeling of guilty resulting in self-blame for transmitting the HIV to the child seems like plays a very important role. Some parents also find it difficult to discuss issues of sexuality with their children due to certain cultural back grounds. Most parents will use excuses like the fact that the children are not

yet ready. Some parents also fear that the children are not in position to handle the privacy that goes with the illness and may end up disclosing the illness to the communities in the schools where they go and to the other children that they play with. Some fear that their children will be discriminated and also fear that the children will blame them. More women were prepared to disclose than man.

OPSOMMING

Die doel van hierdie studie was om die faktore te bepaal wat ouers verhoud om hulle MIV/Vigs-status met hulle kinders te deel. Dit is 'n groot probleem indien kinders onbewus is dat hulle ouers MIV-positief is en kan tot verskillende onaanvaarbare gedragspatrone aanleiding gee.

Bogenoemde gee ook aanleiding daartoe dat sommige kinders selfs teen die ouderdom van 16 jaar steeds nie weet dat hulle ouers MIV-positief is nie, hoofsaaklik as gevolg van die feit dat hulle ouers nie hulle status met die kinders gedeel het nie.

Ten einde 'n beter insig in hierdie probleem te kry, is vier areas in Harare vir die studie geïdentifiseer. Onderhoude is met beide kinders en ouers gevoer. Die ouderdom van die kinders was tussen ses en 16 jaar en deelnemers aan hierdie studie is ewekansig geselekteer. Onderhoude is ook gevoer met 'n mediese dokter en verpleegster wat met die kinders werk.

Alhoewel dit gelyk het dat sommige ouers wel hulle MIV-status met hulle kinders gedeel het, is daar nog steeds 'n groot groep wat dit nie doen nie. Een van die grootste redes waarom ouers nie hulle MIV-status aan die kinders bekendmaak nie is die vrees vir stigmatisering van die kinders.

Voorstelle ter verbetering van hierdie situasie word in die studie gedoen. Indien hierdie probleem nie pro-aktief aangespreek word nie sal dit voortgaan om die effektiewe bekamping van die pandemie te vertraag.

ACKNOWLEDGEMENTS

For making this process a walk in the park, I salute the following:

- i. Prof Johan Augustyn (my study leader)
- ii. Dr Prosper Chonzi, the Director of health services Harare city council

TABLE OF CONTENTS

CHAPTER 1: INTRODUCTION	1
1.1. Research question:.....	2
1.2 Research problem.....	3
1.3 Significance of the study:	3
1.4 Aim:	3
1.4.1 Objectives	4
1.5. Method of the study.....	4
1.6. Structure of the study.....	5
CHAPTER 2 : CRITICAL LITERATURE REVIEW	6
2.1 Introduction	6
2.2 Impact of culture and stigma.....	7
2.3 Fear and religious influence.....	11
CHAPTER 3. RESEARCH DESIGN AND METHOD:.....	13
3.1 Introduction	13
3.2 Aim.....	13
3.3 Methodology and design.....	13
3.3.1. Data collection.....	14
3.5. Ethical considerations.....	17
3.8. Data collection cleaning and analysis.....	17
CHAPTER 4. RESULTS AND DISCUSSION	18

4.1 Introduction	18
4.3. Discussion.....	22
4.4. Characteristics of the children whose parents were interviewed.....	23
4.5 Discussion.....	24
4.6 Disclosure status versus parents' treatment status.....	25
4.7. Discussion.....	25
4.8. Reasons for not disclosing.....	26
4.9. Health workers perceptions	27
CHAPTER 5. CONCLUSIONS AND RECOMMENDATIONS	28
5.1 Conclusions	28
5.2 Recommendations.....	29
5.3 Limitations of Research	29
5.4 Areas for further research.....	29
REFERENCES	30
ADDENDA	33

LIST OF FIGURES

Figure 4.1	Distribution of parents by sex.....	20
Figure 4.2	Distribution of parents by permanent residents.....	21
Figure 4.3	Distribution of parents by marital status	22
Figure 4.4	Distribution of disclosure status and marital status	24
Figure 4.5	Disclosure status and parents treatment status.....	25
Figure 4.6.	Reasons for disclosure.....	26

LIST OF TABLES

Table 4.1 Distribution of parents by age, sex and permanent residence.....	19
Table 4.2 Distribution of children by age and treatment status	23

Chapter 1. Introduction

With an adult HIV prevalence of 13.7% in 2009, Zimbabwe (population 12million), is one of the countries most affected by the HIV and AIDS epidemic. It has however, made significant progress in the epidemic response as adult HIV prevalence decreased from 24.6% in 2003 and the prevalence among pregnant women declined from 25.8% in 2002 to 16.1% in 2009. An estimated 1.1 million individuals were living with HIV in Zimbabwe in 2011. Of these, 47,494 were pregnant women and 120,000 were children under the age of 15. About 15,000 children were newly infected with HIV in 2009 mainly through vertical transmission. (DHS report 2009/10)

The city of Harare in which the study was conducted has a population of about 3 million with 46 health facilities of which 32 are offering PMTCT and HIV treatment for both adults and children. Despite all this impressive progress, a significant number of children continue to be born with HIV. At the end of 2010 about 350 000 children were on antiretroviral therapy representing about 30% of the children in need (MOHCW AIDS &TB Annual report 2010). This reflects the magnitude of the problem in the country. However with all these figures showing an improvement in the care of the children, the psychosocial support of the children living with HIV still remains a challenge. Parents still remain reluctant to tell their children their status. This has impacted negatively on the care of the infected children especially those growing into adolescence. They are expected to adhere to their treatment without knowing what it is for. This expected blind compliance has posed a challenge to the health delivery system.

At the global level the problem is not much different, the exact number of children between 6 and 16 years old living with HIV/AIDS in the world is not known. This according to Magda is because HIV is not a notifiable disease (Magda C, 2005). Southern Africa being home to two thirds of world infections and being a poor region where the maternal to child prevention activities and adolescence sex education is lagging behind, children most likely are carrying the biggest burden of HIV. The biggest challenge in dealing with these children has been the issue of disclosure. Disclosure is classified into partial and complete disclosure, where partial disclosure is when the child is told about the immunity and disease symptoms and the importance of taking medication to improve the immunity (Chazal E 2005). According to the same author complete

disclosure is when the disease is named and the child is told about the modes of transmission and issues of sexuality together with the myths and misconceptions about HIV/AIDS are discussed. For the purpose of this study, disclosure is only going to refer to complete disclosure as defined above. From its inceptions, HIV has always been stigmatized and those affected have always been associated with poor morale standards and values especially in African communities where morality is valued so dearly. Parents find it difficult to talk to children about issues that involve sexuality (Huberman B, 2002). The same author stresses that parents who open up to their children about sexuality and diseases associated with sex tend to help their children grow into more responsible adults. She talks about the research that was done in 2001, about the rights and responsibility of the children and parents in their relationship as far as information is concerned.

In the environment in which this study was done, some disturbing events have been observed. There are children who are HIV positive who grow into adolescence without knowing their status. Most of them get worried as they start learning about sex education and HIV/AIDS at school or watch television programs which start enlightening them to the issues of sexuality and HIV/AIDS. They start wondering why they are always sick or why they are not growing as fast as the other children of their age. Some who will be on medication wonder why they are always taking drugs. However most parents always claim that they will disclose the HIV status of the child when they feel that the time is right. Different parents tend to have different reasons. Blame, stigma and fear all seem to be part of the bigger picture. Some children have been driven into depression and their social interaction and intellectual performance have been affected.

One wonders whether better counseling of the parents and making them understand the importance of this disclosure to the children will make them more prepared when they start understanding about the disease and matters of sexuality. It is against this background that the study was to establish the most important factors that affect the parents' decision either to withhold the information to the infected children or disclose to them. It was also important to find out if parents in certain circumstances find it easy or difficult to disclose and to find out if the gender of the parent affects the decision to disclose or not.

1.1. Research question:

What are the most important factors that influence parents to disclose or not to disclose HIV status to their children who are living with HIV/AIDS in the Greater Harare area in Zimbabwe?

1.2 Research problem

The parents of the children living with HIV/AIDS are going through difficulties of their seropositivity and the anguish of seeing their child or children suffer (Chazal E 2005). This on its own is traumatic enough. The feeling of blame and the fear of death makes the situation worse. They may think that the child/children will blame them for giving him/her the disease and get worried about the welfare of the child/children after their death. The issues of stigma also become important to the parent who will not be sure if the child/children will be able to handle the disease and not disclose to everyone at school and in the community. The parents also fear that the child/children may be discriminated by other children. However with the child not knowing the status especially if taking the antiretroviral medication, there may be a problem with adherence. This is because the child will not know why he/she is taking the medication. We do not know exactly which factors are most important in determining the disclosure of HIV status to children living with HIV/AIDS in Greater Harare. Though from previous studies some reasons have been established, we do not know which ones are the most important in our setting and we hope that after this study we will be able to have a good idea and improve on counseling and disclosure and hence management of infected children.

1.3 Significance of the study:

Observations have been that those children to whom disclosure has been made tend to adhere better to medication and accept the disease. Disclosure will make the children more psychologically prepared and prepare them to make appropriate sexual decisions when they become sexually active. The biggest beneficiaries of this study will be the children living with HIV/AIDS. However the benefit that the caregivers and the health workers will derive can never be over emphasized. Counseling will be improved and hence acceptance and adherence will improve.

1.4 Aim of study

The aim of the study was to establish the reasons why parents find it difficult to disclose HIV status to their children living with HIV in order to recommend ways and appropriate timing of disclosure by parents of children infected with HIV.

1.4.1 Objectives

The main objectives of the study are the following:

- To identify existing knowledge about the reasons why parents don't disclose HIV status to children living with HIV/AIDS.
- To establish parents opinions on disclosure of HIV status to children.
- To compare the reasons given by the parents for not disclosing to what is available in the current literature.
- To provide guidelines for counseling of parents to improve disclosure and advice on the appropriate timing of disclosure to children.

1.5. Method of the study

After observing the problems of disclosure of the HIV status to children, an intensive literature review of the topic was done which showed the studies done by other researchers both in Zimbabwe and outside Zimbabwe. Harare was identified as a high volume city for HIV infection and there is prevalence of HIV amongst the children. It was decided to find out the reason for lack of disclosure of the HIV status not only from the parents but also to get the experiences and opinions of the health workers.

Four clinics, Edith Operman clinic, Kuwadzana clinic, Glenview clinic and Rutsanana clinic randomly were selected from the large polyclinics within the city of Harare which offer HIV drugs to children. They were sampled according to the volumes of the patients as given by the city health department. The high volume sites were then randomly selected. An interview schedule was designed which was used to get responses from the caregivers and the healthy workers. Visits were made to the chosen clinics on the days that the children were coming for review. The parents were randomly selected using their booking numbers and called aside and interviewed privately in the absents of the children since some of the children did not know their status and it was also believed that this would give the parents an opportunity to express themselves properly without fear of affecting the child emotionally.

Health workers who included the nurses, doctors and primary care counselors were also interviewed to get their opinion. This was meant to get an insight into the experiences and opinions of the professionals who deal with the parents and the children.

1.6. Structure of the study.

The study will be presented as follows; in chapter 1 an introduction of the study, which introduces the research topic and the research problem and justifies the reasons for doing the study, will be given. It also gives a snapshot of the method that was used in the study and how the data was collected.

The second chapter (Chapter 2) gives a critical literature review. This gives information about what is currently known about the topic and also looks into the findings of the similar studies which have been done before.

In chapter 3 details of the methodology that was used in carrying out the study from its implementation to how the results were analyzed will be described.

Chapter 4 gives the results of the study and the implications of the findings are also discussed. This is done in relation to how it agrees or differs with the current knowledge and the findings of the previous studies done.

The last chapter (Chapter 5) will give a conclusion of the findings and some recommendations to the health delivery system on how to deal with the problem of disclosure as a way of providing psychosocial support to both the infected children and their caregivers. It also briefly gives the challenges and limitations of the study and recommendations for future studies.

Chapter 2. Critical literature review

2.1 Introduction

Telling children about their HIV status has been a dilemma especially for their parents. This is due to the fact that in most cases the children are asymptomatic. Studies from the United States in 1999 showed that between 25% and 90% of HIV infected school going children have not been told about their infection (www.wakeuppane.org/site). The reasons range from family structure, cognitive and emotional development of the child and availability of medical and psychosocial services. According to the studies done mainly in the United States and in Brazil and to some extent in India, it was observed that the cultural, economic and religious influences play a role in the disclosure patterns to children (www.wakeuppane.org/site).

According to the Fayorsey and Colton the decision to make a disclosure is based on the maturity of the child and how the child will understand the disease and be able to deal with the stigma. In the training that they held in Tygerberg in South Africa by Fayorsey and Colton they divided the children into three groups according to age. The preschool children are those below the age of 6 years and they encouraged that full disclosure be deferred. The next age group was the early school age which is 6- 10 years. This age group they encourage partial disclosure where the issues of sickness are discussed and there is encouragement of articulation of feelings. The third group is the 11-15 age group where the basic information about HIV should be given, in this case there is discussion about transmission, types, effects, and prevention and the care giver must always be involved where disclosure is being done by the health worker. (Fayorsey and Colton, 2008)

The human rights watch give 5 reasons why they believe that the children must know their status. They are the following:

- 1) Children who know their status are able to participate more actively in the treatment, and are more likely to adhere to ART, according to the World Health Organization. Health workers and caregivers told Human Rights Watch that some children who do not know why they are taking so many medications every day refuse to take ART, particularly as they grow into adolescence (www.hrw.org).

- 2) Sexually active children, most often older adolescents, who know their HIV status can choose to use protection during sex and other risky activities. When sexually active people who do not know about their status are at risk of spreading HIV.
- 3) Children who are told about their status learn that it is acceptable to talk about HIV, which helps address the stigma surrounding the disease. By not telling a child that they are HIV-positive means that the stigma of the illness gets transmitted to the next generation, and often this result in children feeling ashamed and isolated.
- 4) Children who are told about their status in a supportive way tend to be more self-confident than those who have not been told, according to the American Academy of Pediatrics(www.wakeuppane.org). The Academy has also stressed that a "conspiracy of silence" may isolate children from potential sources of support and undermines trust between adults and children. Health workers in Kenya have found that disclosure before adolescence is preferable, as adolescents often react badly to disclosure (www.hrw.org).
- 5) Children have the right to health information under the Convention on the Rights of the Child. If children are not told their status but are mature enough to understand and appreciate it, their right to health and information may have been violated (www.hrw.org).

2.2 Impact of culture and stigma

A culture is a system of shared beliefs, values practices, language, norms, rituals and material things that group members use to understand their world (Christensen Johnson and Turner, 2011). The behavior and attitude of the different members in a group is strongly influenced by their culture. Its impact on the way people perceive certain diseases cannot be over emphasized.

In a study done in South Africa by Notshe, though she was looking mainly at the issues of the sick parents' disclosure of their own HIV status to their children, there is striking similarities to concepts which are in the scope of this study. The cultural influence was also noted to play a very important role. However Notshe also observed that unemployment affects disclosure patterns by parents to the children living with HIV/AIDS. This same author also notes that some parents give excuses that the children are too young to understand and will be upset and are not

able to cope with the information (Notshe 2007). According to this study done by Notshe, the issue of stigma plays a very important role. She defines stigma as internal and external in which internal stigma is the personal feeling of guilt and shame and external stigma is what the patient experiences from the people around them. This agrees with the study done in Zimbabwe by Mucheto et al which confirms that most rural Zimbabwean women don't want to disclose their HIV status or the status of their children for fear of stigma which may result in divorce (Mucheto et al, 2009). This according to these authors stems from the African belief that anything sexual is blamed on the woman and it is considered taboo or disrespectful for the man to be blamed. These authors also point out that an HIV positive test is associated with promiscuity, many sexual partners and infidelity; this according to the African culture and way of life will be totally unacceptable.

According to the Zimbabwe Ministry of health guidelines on counseling, stigma is the negative and unpleasant actions taken against individuals because they are HIV positive (Zimbabwe Nat Guidelines on counseling, 2007). These same guidelines point out that the positive HIV status of the child also serves as a mirror or proxy to the parents' status and results in the family being discriminated. Some parents think that the children will not be able to handle the information and may end up disclosing to their peers and their teachers who will then start discriminating against them. This was also observed by Prestone –Whyte who observed that stigma is one of the most important aspects in the decision by the parents to disclose or not to disclose the HIV status of their children (Prestone-Whyte 2003).

In a study by Mashiri and Mawomo(2002) in which the disease was put in the context of the African language, the terms and names used to refer to the HIV/ADS make it difficult for most parents to disclose the status to the children (Mashiri , Mawomo, 2002). Terms like 'shuramatongo' in Shona implies that the disease is a one way ticket to death and this makes the parents find it difficult to tell the children about their status. Nosthe also notes that the lack of support services plays a very important role in the disclosure patterns on HIV status. This means that the counseling services if available will prepare the parents and the affected children for the information as it comes.

The study by Mucheto and others which also agrees with the ICAP collaborative PMTCT pediatric HIV strategy also points to the cultural belief that talking about sex in the African

setting if unacceptable and taboo. It goes without saying that if a parent talks to the child about HIV, eventually issues of sexuality will have to be discussed.

In other studies done in Brazil, it showed that few caregivers are willing to tell the children younger than 5 years about their infection with HIV/AIDS (www.wakeuppane.org). The same document mentions that the American Academy of Pediatrics encourages disclosure to all school going children. However the Academy does not explain the exact age of disclosure, circumstances for telling and the potential impact of the disclosure.

In another research by Magda (2002) again the issues of feeling guilty and fear of stigmatization were observed as the main reasons why parents do not disclose (Magda C, 2002). In this research the author observed that if there are support systems in the school and the parents are assured that there is confidentiality even in schools in case the children tell their teachers and peers then they will improve on the disclosure. The same author also noted that the relationship between the parent and the infected child and the relationship that the infected child has with the other siblings play a role in disclosure. It looks like the feeling is also that the parent will be in fear of guilty that the child will question to say why me and not the other siblings. When the parents are being counseled, one of the questions that they are asked is if they are ready to disclose to their children and if they are not ready to give their reasons. The study which was done by Hejoaka in Burkina Faso also confirmed the same fear that the parents have about the children not able to keep secrets and resulting in stigmatization (Hejoaka, 2007). However according to this study the author observed that the children know a lot about HIV/AIDS and suspect that the parents are hiding something from them. He also points out that another indicator may be preferential treatment of the infected child hence suspicion that something is wrong.

Roffman looks at several challenges of parenting itself as a major player in the disclosure problems (Roffman, 2002). He describes the art of parenting as one that needs multi-skills and if one puts this in the perspective of HIV and AIDS one realizes that it becomes an even bigger challenge. However he stresses that the earlier one takes their responsibilities the better it becomes to deal with the challenges. If one leaves the problem for the last minute, it becomes even more difficult.

Several studies though stating the advantages of disclosure advocate the need to consider each child individually and as such a definite age and circumstances for disclosure are not prescribed (www.wakeuppune.org).

A study done in Brazil has shown that there is an age related response by the children (www.wakeuppune.org). This study showed that below six years the child accepts taking medication and they don't ask many questions. However if they do ask questions most parents answer in an authoritarian way like saying everyone takes medication or take because you have to take it. At times they are vague like saying 'so that you feel better'. But the biggest danger of such responses is that the child stops asking questions and becomes reluctant to take the medication. This study observed that at the age between seven and nine the child starts to have a negative attitude about being sick, HIV and AIDS. They also start interacting with other children where often inaccurate and unreliable information is shared. This leads to more confusion. Preadolescence faces the same problems but they become more complex as they grasp the issues of the stigma associated with HIV in their communities. Finally the adolescent has the feeling of invincibility though the issue of confusion is still important there is the risk of engaging in risk sexual behavior if disclosure and proper counseling are not done. This study concludes that disclosure is not a good idea in perinatally acquired HIV and the child must be informed as he/she gets sicker.

Analysis of all the studies done by developmental authors though giving an indication that every child must be treated individually gives a general feeling that the reasons for not disclosing mainly range around the fear of the impact of disclosure on the child's psychological and emotional health. It's seen as it reduces child's will to live and often leads to depression in the child (Columbia University, 1999).

The other reason observed by most studies is fear of inadvertent disclosure to others by children; this is because the child cannot keep secrets. The other reason also observed and quoted by the Columbia University is that other parents feel that they withhold the information to protect their children from social rejection and stigma. This view is also supported by Masindi in his study (Masindi, 2003). However the issues of feeling of guilty about having transmitted the virus to

the child look very vital. This is associated with sexual taboos that exist in the different communities.

However several studies agree that increased knowledge about the disease helps the child to adjust within the family setting and to the issues of the illness itself. The child also adjusts within society and can cope with its views of the illness and the taboos of sexuality and sexual behavior. Most importantly the child adjusts to treatment adherence and doctor visits. The child's self-esteem is also boosted. There is also reduced chance of risky behavior like sex without a condom, multiple sexual partners and intravenous drug use. Disclosure also builds stronger family ties to tackle more problems in the future. The existing literatures based on studies which have been done in different settings give different views. The purpose of this study is to get the commonest views in the setting of Harare in Zimbabwe which hopefully will reflect the general outlook in the Zimbabwean situation and assist in the management of the infected children.

2.3 Fear and religious influence

Notshe states that the fear which the parents have plays a role in the disclosure patterns of HIV status. She notes that the parents withhold information in order to keep their relationship with the children as good as is possible. Supposedly this emanates from the feeling of guilt that the parents have because they think that the child will blame them for passing on the virus to him/her. This is also augmented by ignorance, reluctance, culture and lack of information (Notshe 2007). The ICAP collaborative and pediatric strategy in its training document also points out that the issue of guilty plays a part in disclosure and goes on to claim that some parents feel that the children need to be protected from the 'bad news' (Fayorsey and Colton, 2008).

Another dimension about disclosure patterns was given by Khathidi. This author talks about disclosure issues from a religious perspective. He mentions that because some people think that the HIV is a God given punishment for bad behavior like fornication, adultery and sex outside marriages, there is this aura of shame and fear to talk about it (Khathid, 2003). This also according to the same author is seen in the fact that the parents find it difficult to discuss issues of sexuality with their children. Talking about sex in the home and in the church is considered taboo. According to this author this affects the parents because once they talk about HIV to their children they cannot avoid talking about issues of sexuality and sex. He makes reference to the

way sex is portrayed in the bible, for example that human kind only knew about sex through the snake, which is an evil animal associated with bad things including witchcraft in the African culture when it told Eve and as a result of this information and the acts that followed God punished the human race with death.

Chapter 3. Research design and analysis

3.1 Introduction

A cross sectional study of the parents coming to the opportunistic infection and antiretroviral clinic (OI/ART) was done. The study was a mixed type with both quantitative with a qualitative component. According to Christensen, Johnson and Turner (2011) a mixed research method is a research approach where both a quantitative and a qualitative data or techniques are combined in a single study or in a set of closely related studies. This method is according to the above authors still a new method of study. It can be done with both quantitative and qualitative taking equal importance or with one taking dominance over the other. In this study the qualitative was the dominant method.

3.2 Aim of study

The aim of the study was to establish the reasons why parents find it difficult to disclose the HIV status to their children. It is believed that if the parents disclose the status to the children the outcomes are going to be improved. This will come as a result of the improved adherence to treatment since the child will understand why it is important to take the medication. This will also have long term effects since the children will be prepared to practice safer sex when they grow up. The child's self-confidence is also going to be maintained by knowing that this is a disease that does not bring shame to him/her.

3.3 Methodology and design

The study was a cross sectional study done at 4 health sites, Edith Operman clinic, Kuwadzana clinic, Glenview clinic and Rutsanana clinic in Harare. The sample size was about 15 parents of children living with HIV who perinatally acquired the disease. Four health workers were also interviewed to get their opinion on the matter. These were 1 doctor, 2 nurses and 1 primary care counselor.

The mixed method was used. This is a method which was predominantly qualitative with little quantitative aspects. According to Christensen et al, mixed methods are research methods where both qualitative and quantitative approaches are used in a single research. (Christensen, Johnson, Turner, 2011). According to these authors, like any method they also have advantages and disadvantages. In this research the two methods were used in the same time order which

according to Christensen, Johnson and Turner means that they were done concurrently. The qualitative method was more dominant over the quantitative method. This means that in the paradigm emphasis the quantitative method was given dominant status (Christensen, Johnson, Turner, 2011).

The sampling method that was used was the random sampling of the parents using the numbers in the booking register. The exclusion criterion was all those caregivers who are not real parents. This is because the perceived reasons found in the literature review like stigma will not particularly affect them if they are not the real parents of the children. The clinics that were used in the research were randomly sampled. This was done so that they can be representative of the entire population and the results could be generalized. A small sample used in a study may not be representative of the whole population but the chances of making it representative are increased by randomly sampling the participants (Christensen, Johnson and Turner, 2011).

3.3.1. Data collection:

Four clinics, Edith Operman clinic, Kuwadzana clinic, Glenview clinic and Rutsanana clinic were randomly selected from the high volumes clinics in Harare which are initiating and following up HIV/AIDS infected children for treatment. From the clinics there was random sampling of the participants. The health worker participants at the clinic were selected by convenient sampling. The adults bringing the children had to be real parents. The children who were on treatment also needed to be in the age group between 6 and sixteen. The parents were informed about the study and given an option to participate or to refuse. It was emphasized to them that their refusal to participate in the study would not affect the care that their children would get and that they had the right to pull out of the study at any point of the interview. Interviews were conducted with the parents who visited the HIV/AIDS clinics and agreed to participate in the study and signed the consent form which was in both English and Shona (appendix 1). According to Burns & Grove (2001), as quoted in a research by Katsande (Katsande, 2009) interviews involve verbal communication between the researcher and the subject during which information is provided. The questions for the interview were designed by the researcher to focus on the topic and the researcher exercised control over the content of the interview. An interview guide was developed (see appendix 2 and 3) by the researcher and used to elicit information from the interviewees.

Each interview took the time that was necessary to get the information, but on average most of the interviews lasted around 25-30 minutes with the researcher guiding the discussion but at the same time trying to maintain a good communication rapport with the interviewee. The interviews were conducted in both English and Shona. Due care was taken in dealing with the sensitive issues and the emotions of the interviewee were taken into consideration especially considering that this is a sensitive topic and the subject was bound to feel uncomfortable with some questions. An effort was made to try and exclude the bias of the researcher.

The interview was chosen for this particular research because interviews are a form of self-report, and the researcher assumes that the information provided by the representative is first hand and accurate.(Katsande ,2009) The interview questions were not seen by the interviewee before the interview to allow for instinctive and honest answers.

The researcher acknowledges that interviews have some limitations which include the fact that, compared to other qualitative methods, the respondent is more removed from his or her context and may feel threatened, resulting in a bias of data collected (Katsande,2009). In this type of research given that the patients feel vulnerable and think that certain attitudes and answers may result in them not getting the best services makes this limitation a bigger disadvantage.

The target was to interview 15 parents with closed- ended questions based on previous literature and a few open-ended questions for them to give their own opinions about disclosure to their children. The target group was parents with children who have perinatally acquired HIV coming to HIV/AIDS clinic in Harare whose children are between the ages of 6 and 16 because this is the age that most studies feel that disclosure must be done. One doctor who provides care, 2 nurses and 1 primary care counselors are also interviewed to get their opinions. The health workers were conveniently sampled depending on availability on duty. Convenient sampling according to Christensen, Johnson and Turner (2011) is a sampling method where the researcher uses the people who are available, volunteers or are easily recruited for inclusion into the sample. In this case the health workers who were on duty at the time of the study were asked if they were willing to participate and recruited into the study.

The given reasons were compared with the existing literature.

3.4 Study outcomes.

The main objectives of the study and the core outcomes are listed below:

Objectives	Core study outcomes
To establish parents opinions on disclosure of HIV status to children.	<ul style="list-style-type: none"> • Number of parents who feel that they don't want to disclose the status to their children. • Reason for the parents for not disclosing the HIV status to their children. • relationship between demographic characteristics and disclosure
To compare the reasons given by the parents for not disclosing to what is available in the current literature.	<ul style="list-style-type: none"> • Number of parents who use religion as a reason not to disclose • Number of parents using culture as a reason not to disclose • Number of parents using stigma and discrimination as the reason for not disclosing
To provide guidelines for counseling of parents to improve disclosure and advice on the appropriate timing of disclosure to children.	<ul style="list-style-type: none"> • Relationship between the number of counseling sessions and disclosure • Relationship between the counseling cadres and disclosure
To identify existing knowledge about the reasons why parents don't disclose HIV status to children living with HIV/AIDS	<ul style="list-style-type: none"> • Number of parents who have reasons for not disclosing • Number of parents who feel that disclosure has a positive effect on the child

	<ul style="list-style-type: none"> • Reasons of non-disclosure as seen by the health workers
--	---

3.5. Ethical considerations:

HIV/AIDS is a very sensitive medical issue and patients feel that researchers and health workers take advantage of them to fulfill their personal agendas. Especially in the African context where there is a general belief that people are used as guinea pigs in research due to poverty.

In this study the following were observed:

Confidentiality: There was confidentiality of information and no names were used in the study.

Respect: the researcher respects the rights of the subjects to give the information that they are comfortable with and the right to withdraw from the study at any point in time.

Informed consent (Addendum A): Informed consent was observed as defined by Shasha as the right of the participants to know the purpose of the study and make them accept participation willingly. (Shasha, 2005).

The laws on research: the laws of the country and the regulations of the university about research were observed and followed in that ethical approval with the Stellenbosch University human research and ethics board was obtained and the approval by the Zimbabwe medical research council was also obtained (addendum E). Authority to conduct the study in the city clinics was obtained from the Harare city health department which runs the clinics in the study (AddendumD)

There was no deception of participants.

3.8. Data collection cleaning and analysis:

Data was collected by interviewing the parents of HIV perinatally infected children as they were coming to the clinics.

Health workers on duty including doctors, nurses and counselors were also interviewed to give their opinion

Double data entry and rechecking was done. The data was captured and analyzed .Descriptive statistics using frequencies, summary measures of central tendency, and cross tabulations were used to draw summary statistics.

Chapter 4. Results and discussion

4.1 Introduction

The results were analyzed looking at the demographic characteristics of the subjects. This was critically compared to the findings in the critical literature review that .Comparison of the attitudes of the subjects with what other researchers found in previous studies was done.

The results of the survey from both the parents and the health workers seem to partly agree with the available literature. Though the number of the participants was relatively low, the fact that they were randomly selected may imply that the views that were expressed here are a reflection of the situation that is on the ground in the greater Harare and indeed in Zimbabwe. The Table 4.1 below indicates the sex and permanent residence distribution. It shows that most of the subjects interviewed were female and the majority of them resided in the urban areas. Like any typical African setting in the high density suburb, the men go to work and it is the females who bring the children to the clinic. The table shows that only a few men will bring the children to the clinic and usually this happens in situations where they are widowers or divorced.

Table 4.1: Distribution of parents by sex and permanent residents

Age	Sex	Area of permanent residence
22	female	Rural
32	female	urban
47	female	urban
34	female	Urban
42	male	Urban
37	female	Urban
29	female	Urban
38	male	Farm
32	female	Urban
46	male	Urban
28	female	Urban
41	female	Urban
21	male	urban
31	female	urban

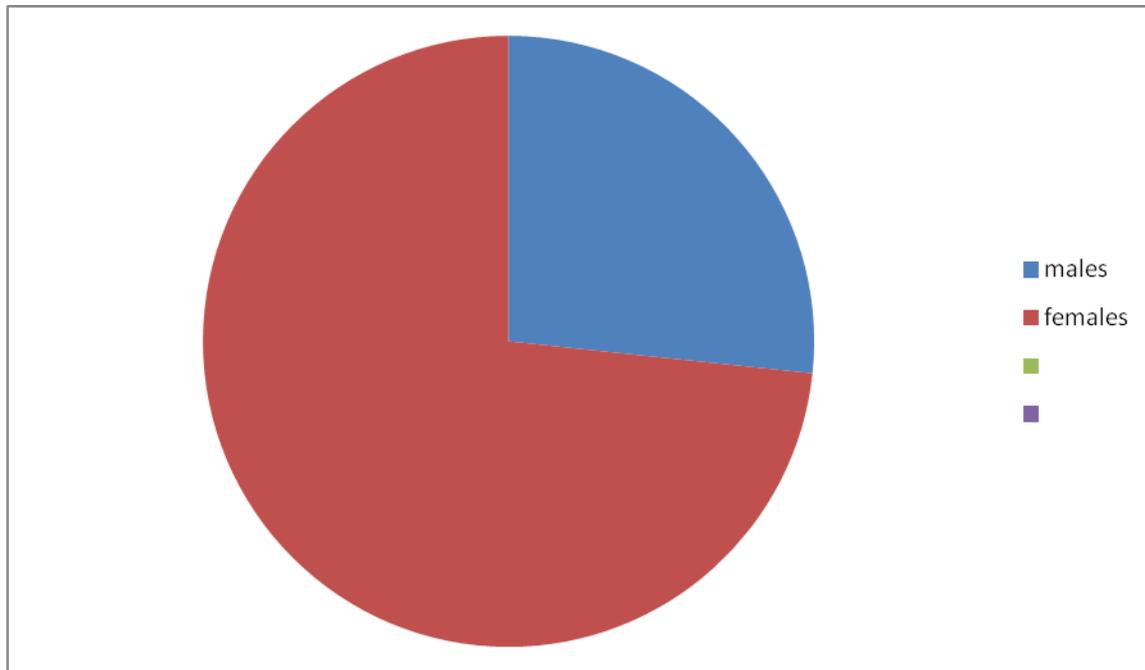


Figure 4.1 Distribution of parents by sex

Figure 4.1 which shows the demographic distribution of the subjects in the form of a pie chart clearly indicates that the majority of the subjects interviewed were females. This again is in agreement with the fact that being an urban setting where men go to work the females are the ones bringing the children to clinics. Their attitudes towards disclosure are most likely reflecting on the family position that they will have taken with their husbands.

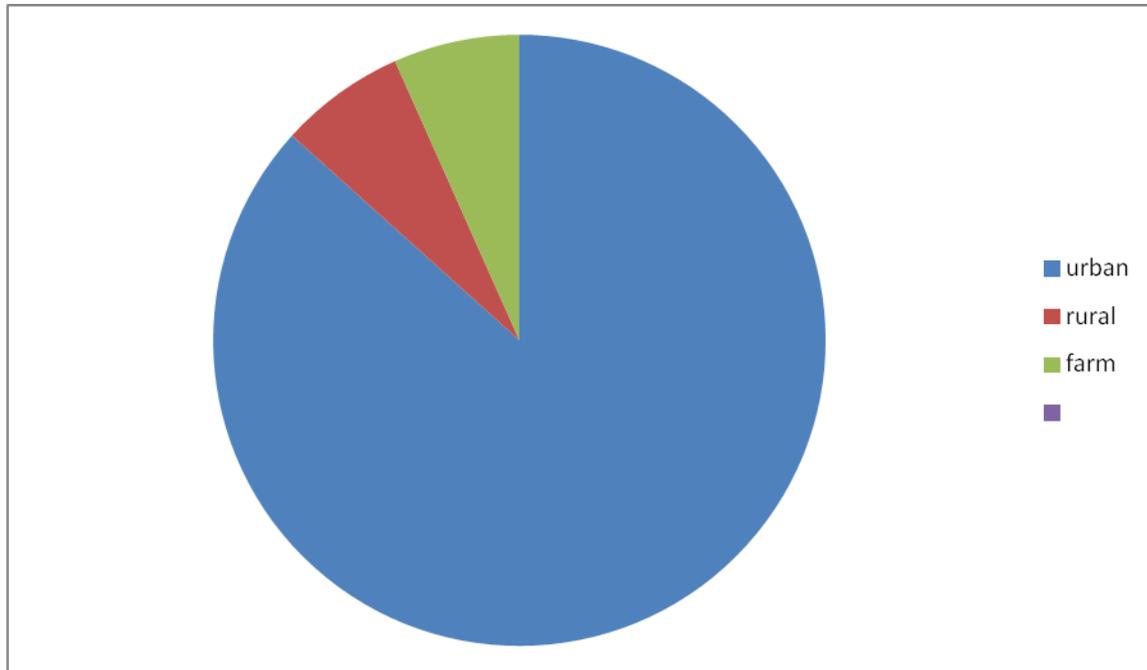


Figure 4.2 Distribution of parents by permanent residence

As shown in Figure 4.2 the majority of the subjects interviewed were urban dwellers. This is because the study was done in an urban setting. There are a few from the rural areas and farms. Since the interview schedule was asking the subjects about their areas of permanent residence the few could be the women who stay in farms and the rural areas and occasionally visiting the husbands in the town. Some may also be from the surrounding farms especially those from Rutsanana clinic which has a catchment area that includes the farms in Beatrice.

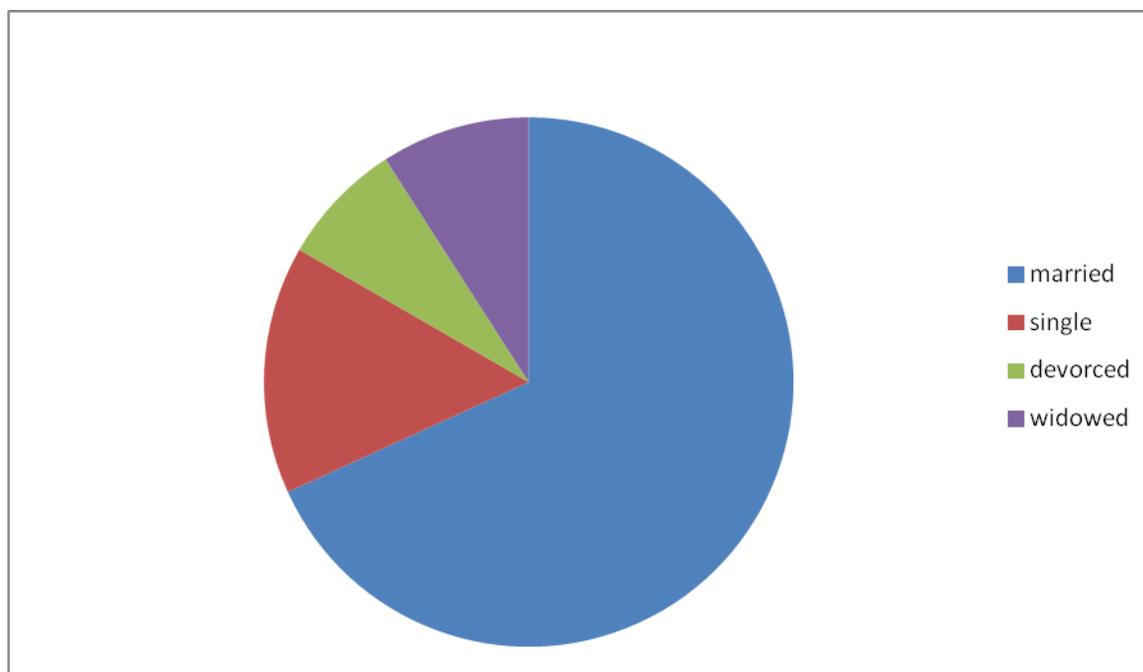


Figure 4.3 Distribution of parents by marital status.

As indicated in Figure 4.3 above most of the subjects were married. Given that Figure 4.1 indicated that the majority were females and Figure 4.2 showed that the majority were from urban areas, this may mean that they were wives of the men who go to work as the wives come to the clinic with the children. The high prevalence of married women may also be an indication that the support structures are there since most of the children are in families where both parents are available. This may be the reason why most of the interviewees had disclosed the HIV status to the children.

4.3. Discussion

This study was done in an urban setting and most of the subjects were urban dwellers. Due to the fact that it was an urban area the majority of the subjects were female. This could be due to the reasons that most of the men were at work. In most of the cases when men came with the children, it was either because they were widowed or they had divorced. The average age of the parents was 34.2, the median was 32 and the mode was 32. These statistics show that the parents who were interviewed were relatively young with an average of 34.2. This agrees with the previous studies that indicated that women are more likely to disclose the status to the children

and those in stable marital relationships were also likely to disclose due to the good support systems in the family.

4.4. Characteristics of the children whose parents were interviewed.

Characteristics of the children whose parents were interviewed are given in the Table below:

Table 4.2 Distribution of children by age and treatment status

Age of child	Number of years on treatment
8	5
13	4
6	6
11	6
16	7
7	2
13	5
7	3
9	4
15	8
11	3
10	4
9	3
11	3
6	3

Table 4.2 shows the distribution of the children by age and the number of years that they have been on antiretroviral treatment. The average age of the children was 10.1 years and the ranged from 6 to 16 years. The number of years on which they were on antiretroviral treatment ranged from 2 to 8 years with an average of 4.4 years. The majority of the parents had disclosed the HIV status to their children. Given the reasons that are in the literature where the issue of the children's age was considered crucial and the fact that most of the parents who had not disclosed were claiming that the children will be too young to understand, the fact that the average age was

above 10 may be the reason why most parents had disclosed. Those who had not disclosed had children who were relatively young and below the average age of ten.

Figure 4.4 below shows the distribution of the disclosure status according to the marital status. It shows that majority of the married women had disclosed the status to the children. This agrees with the previous studies. It also shows that all the single parents had not disclosed the HIV status to the children. This may be due to the lack of social support mechanisms within the single parent family system. Those divorced have a higher chance of disclosure than the single. As shown in the Figure 4.4 below, all the divorced parents had disclosed the HIV status to the children. This can be because it's easy for them to overcome the fear of blame by blaming the divorced partner. They can be using it as a way of turning the child against the other parent. Most of the widowed parents had also disclosed the HIV status to the children.

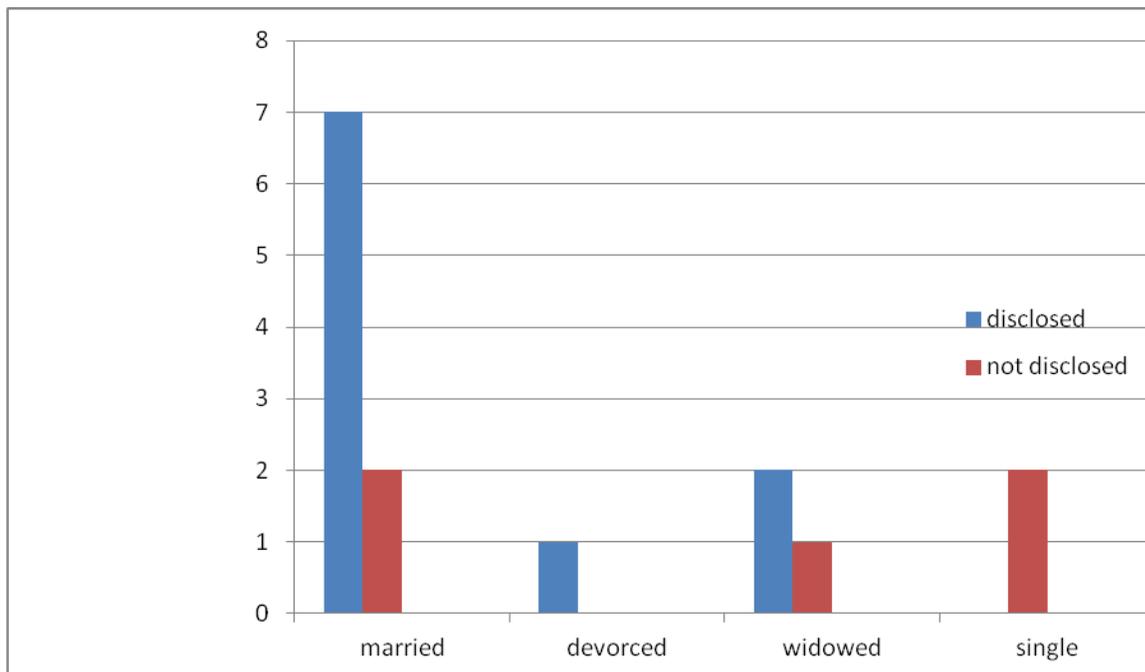


Figure 4.4 Disclosure status and marital status

4.5 Discussion

According to previous studies by Notche (Notshe 2007) and others, it was observed that presents of support structures in the family and community increased the rate of disclosure. This seems to be reflected in this study where those who had family support structures were likely to disclose. The majority of the parents interviewed had disclosed the HIV status to the children. This is

because the majority of the parents were married and the average age of the children was above ten years which even those who had not disclosed used as the age at which they were comfortable to start disclosing to the children. Single parents looked like they were the least in disclosing. This could be due to poor family support structures.

4.6 Disclosure status versus parents’ treatment status

Figure 4.5 below show the relationship between the disclosure status and the parents’ treatment status

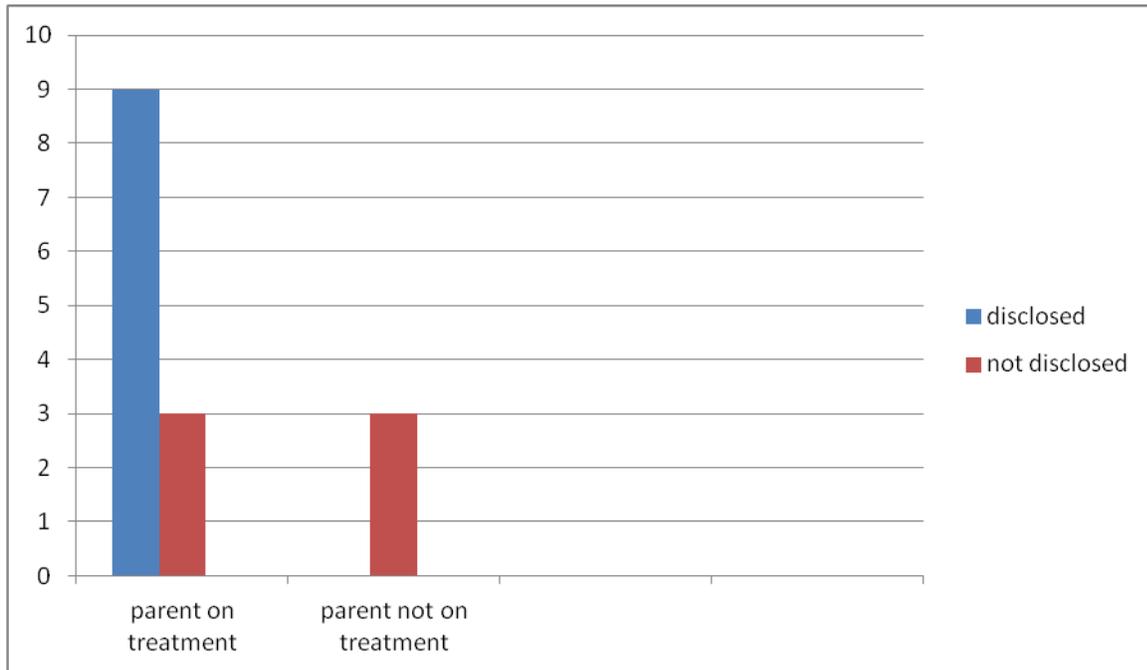


Figure 4.5 Disclosure status and parent treatment status

4.7. Discussion

According to Figure 4.5 the parents who were on treatment looked like were more likely to disclose the HIV status to the children than those who were not. This could be due to the fact that those on treatment will have accepted their status and undergo more regular counseling since they are more in touch with the health workers for their own health. Those parents who were not yet on treatment were less likely to disclose probably due to the fact that they could still be in denial and have a lot of stigma and fear

4.8. Reasons for not disclosing

The Figure 4.6 below shows the reasons for disclosure as given by the parents.

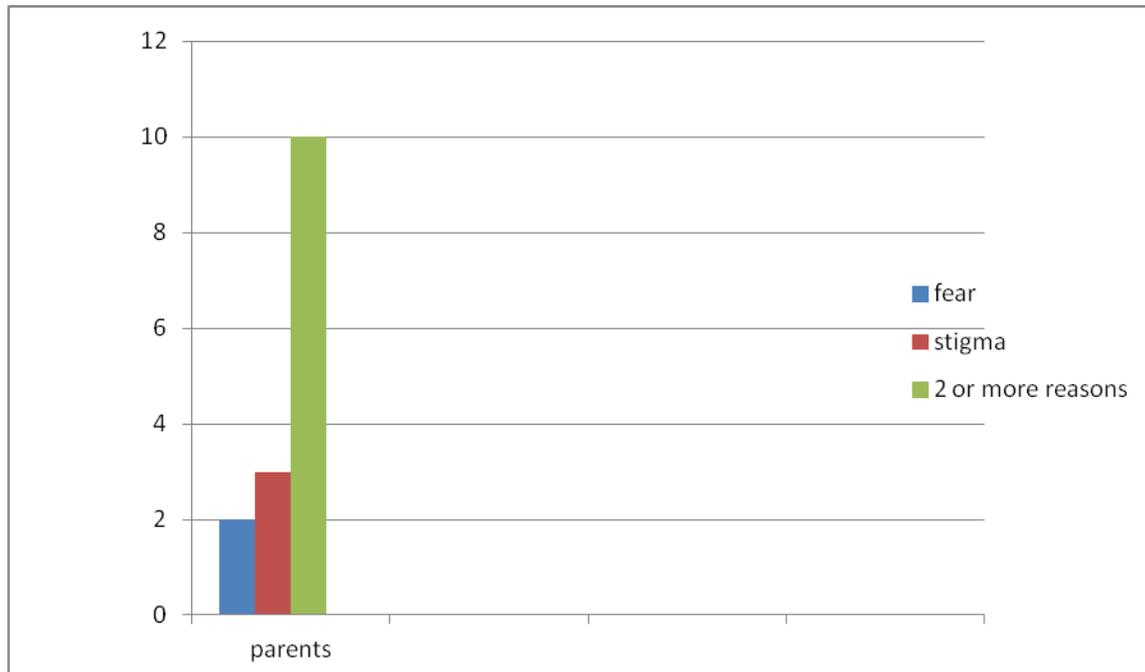


Figure 4.6 Reasons for not disclosing

According to Figure 4.6 above the majority of the parents cited more than two reasons why it is difficult for the parents to disclose the HIV status to the children. The main reasons given were that most of the parents are afraid of the impact that it will have on the children. The other fear was that the children will not be able to keep the secret of their positivity and will therefore face discrimination from their peers and other people. This totally agrees with the study done by Notshe (Notshe, 2009) and one done by Mashidi (Masindi, 2003). The other fear which also came from most of these parents which agrees with the above authors was that parents fear that the status of the children would serve as a proxy to their status as well. This meant that once the people knew that the child was HIV positive it also meant that the parents were likewise positive.

Other parents felt that the other problem was of stigma. This again agrees with other studies done by other researchers like Notshe and Mashidi who also noted that the issue of stigma is a very important factor in the disclosure patterns of the parents to their children. However almost all the parents agreed that the children benefitted from knowing their HIV status. Most agreed with the previous researchers and health workers that the child who knows their status is more likely to

adhere to treatment than the one who does not. However the issue of self-esteem that was mentioned by the American pediatric association never came from the parents.

As opposed to the view by Khalidi, the issue of religion as a major reason for non-disclosure did not feature. Of all the parents who were interviewed none thought that religion plays a part in the disclosure patterns.

4.9. Health workers perceptions

Four health workers were also interviewed for their opinions. These included 1 doctor, 2 nurses and 1 counselor. These were professionals whose experience in dealing with HIV positive parents and children ranged from 4 to 12 years. All these health workers were of the opinion that now that there is treatment and hope for the HIV infected the rate of disclosure is high and most of the parents are disclosing. The health workers noted that there is a higher level of disclosure especially in those children who are symptomatic and sick. The health workers also noted that the female parents disclose more than male parents. However they noted that the males only bring the children if they are divorced or widowed. They claim that most of the parents want to disclose to the children who are more than 6 years.

The health workers noted that where the parents refuse to disclose the problems are mainly due to stigma and fear. They don't agree that there is lack of knowledge since continuous counseling is done and all the information is given. The health workers did not feel that the number of counseling sessions really matter in the parents who feel that they do not want to disclose HIV status to their children. This is because they felt that the parents who do not want to disclose still insisted despite the information being given.

The health workers also agree with the view of the parents that the children who know their status are more likely to adhere to their medication. They also feel that the children who know their status benefit from joining the support groups with other infected children in which they are given life skills and they live a positive and more confident life.

Chapter 5. Conclusions and recommendations

5.1 Conclusions

From this study it can be concluded that the issue of disclosure is no longer a big problem in greater Harare. The majority of the parents understand that there is a big benefit that the children derive from knowing their status. However the reality of other circumstances that force the parents to withhold the information can never be under estimated. As is in the literature there is evidence that the issues of fear and stigma are very crucial in the issues of disclosure. The parents look like they consider the status of the children as the mirror to their own status, so as long as they are not sure of the ability of the child to keep the secret they feel uncomfortable. This is however a reflection of a bigger picture of stigma. If the parents can shed off the stigma and be able to treat the issues of HIV like any other disease then disclosure will be easier. In the same vain there is also need to take cognizance of the fears that the parents have. There are some people who still look at HIV as a stigma attracting condition. This stems from beliefs that the mode of transmission is through engaging in multiple sexual escapades. To this end the need for people to protect their status gets justified. Other people can go as far as discriminating against the children or adults who are positive and as a result the justification that people protect their status.

The other fear that the parents expressed which was also echoed by the health workers is the fear of blame. The parents will feel that if they tell their children then the children will start asking so many questions and even blame them for giving them the disease. This is what is described in the Zimbabwe Ministry of health counseling hand book and by Notshe as internal stigma (MOHCW HIV care and treatment, 2006). This is the type stigma where the person who is affected feels ashamed of a disease condition as opposed to the other type of stigma which is the discriminatory attitude shown by other people who are not infected.

This study showed that the parents who have a good social support network in marriages are more likely to disclose the status to the children.

The issues of culture and religion don't seem to play a very important part in the decision to disclose the HIV status to the children.

It is however clear in this study that most parents accept that there is a benefit in disclosing the HIV status to the children early so that they accept their condition. This will boost their confidence to exist as normal human beings and to grow up as normal children. This however does not make it easy for most of the parents who will need to deal with their own emotional trauma together with the emotional trauma that their child experiences.

5.2 Recommendations

After the views of the parents and the health workers, it is recommended that the issues of stigma and discrimination be addresses seriously. This includes also educating those people who are not infected that they should treat those people who are infected as equal human beings. This will make it easy for the infected people to come out and to easily disclose to their children and other people.

5.3 Limitations of Research

The main limitation was that this was a relatively small study with a small number of subjects interviewed that it might not necessarily reflect the general perception of the parents and health workers in Harare. There is also a possibility of bias based on the fact that most parents may not want the researcher to know that they did not disclose the HIV status to their children. This comes as disadvantages of using interview schedule as a mode of collecting data. There was no way of cross checking with the children if they really know their HIV status and they understand what HIV is and how it is transmitted. The methodology of the study did not provide for the triangulation of the information given by the parent with that given by their particular health worker and the child to get the correct disclosure status.

5.4 Areas for further research

This is a very important topic for the children, health workers and the parents. There is need to conduct similar but bigger researches in which the children are involved. This will allow triangulation of the data that the parents give, with that given by the health worker and the parent on the particular child. Another angle will be to do study through the schools and find out if teachers observe that the children know about their status and can comfortably talk about it to their teachers.

REFERENCES

Burns, N & Grove, S K (2001): *The Practice of Nursing Research: Conduct, Critique and Utilization*. 4th Edition: Philadelphia: WB Saunders

Chazal, E. *Therapeutic education: Recommendations regarding disclosure of HIV status to children under ARV in MSF projects*.2005

Christensen LB, Johnson RB, Turner LA.(2011) *Research Methods, Design, and Analysis*, eleventh edition, Pearson education Inc. 2011.139, 380-381

Columbia University, Mailman school of public health: *Pediatric disclosure: Talking to children about HIV*.1999

Demographic Health Survey (DHS) report (2005/2006)

Fayorsey R, Colton T: *HIV disclosure throughout the pediatric life stages: Better practices, approaches and tools; ICAP Collaborative PMTCT and pediatric HIV strategic planning workshop in partnership with Trygerberg children's hospital, SA and S2S*

www.advocatesforyouth.org

[April 2005]

Huberman, B. (2002) *Raising sexually healthy youth: Advocates for*

Youth publication: 15 [Online] <http://www.unaids.org> [May 2005]

Khathidi, AG: *Teaching and talking about our sexuality: A means of combating HIV/AIDS*, WCC publications. Geneva, 2003

Magda c (2005) *HIV in schools: Good practice guide to supporting children infected and affected by HIV*. www.ncb.org.uk/dotpdf/.../hivforum_schoolsgpg.pdf

Mashiri, P, Mawomo, K, Jom, and P: *Naming the pandemic: Semantic and ethical foundation of HIV/AIDS in shone language*; University of Zimbabwe, 2002.

Masindi, N. (2003) *Siyamkela Stigma and discrimination. Centre for the Study of AIDS.*
University of Pretoria

Ministry of Health and Child Welfare: *PMTCT and Pediatric HIV Prevention, Treatment and Care National Plan 2006-2010*, December 2006

Ministry of Health and Child Welfare: *Prevention of Mother to Child Transmission of HIV in Zimbabwe. A trainer's Manual for the Integrated Approach to HIV and AIDS Prevention, Care, Treatment and Follow Up for Pregnant Women, their Babies and Families.* Second Edition.
December 2006.

MOHCW: *Strategic Plan for Elimination of New Pediatric HIV infections (2011-2015).*

MOHCW AIDS & TB Unit Annual Report 2010

National HIV estimates 2009

Notshe, MY. *Factors affecting non-disclosure by HIV positive parents to their children; 2007*

Preston-Whyte, E.M. (2003): *Contexts of vulnerability: Sex, secrecy and HIV/AIDS.* African Journal of AIDS Research, 2(2)

Roffman, D. (2002) *Parenting is a five-piece suit.* [Online]

Shasha, N.G. (2006) *Teachers' experiences of aggression in selected secondary schools in the rural Eastern Cape.* The Nelson Mandela Metropolitan University

Tendayi Juliet Katsande: *The impact of HIV/AIDS on primary school teachers: an investigation into HIV/AIDS linked support systems and resource material that promote positive attitudes,* 2009

UNAIDS HIV Estimates 2009

UNAIDS HIV Estimates 2009

www.hrw.org : *Why governments should support disclosure.*

www.wakeuppane.org/site : *Disclosure of HIV status to children and adolescents: when and How?*

ADDENDA

Addendum A

CONSENT TO PARTICIPATE IN RESEARCH

Study on factors that influence parents to disclose or not to disclose HIV status to children living with HIV/AIDS.

You are asked to participate in a research study conducted by Dr Edmore Munongo, a student from the Africa Centre for HIV and AIDS at the Stellenbosch University. The results of this study will anonymously be processed into the study report.

1. PURPOSE OF THE STUDY

The purpose of the study is to evaluate the attitudes of parents and some health workers about disclosure of HIV to children.

PROCEDURES

If you volunteer to participate in this study, we would ask you to do one of the following activities:

Interview

A short Interview with the researcher will be conducted with you will be conducted where a few questions will be asked about what you think about disclosure of HIV to children and why you think so. This will take approximately one hour of your time at a time this has been identified as convenient. An interview will also be contacted with the health workers to get their opinion.

2. POTENTIAL RISKS AND DISCOMFORTS

Information required by the interviewer will require prior knowledge about children living with HIV that's why there has been a deliberate choice of parents who have children who are infected or exposed. For the parents who will show discomfort, counseling will be provided by the health workers and the researcher who is adequately trained to do so.

3. POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY

It is envisioned that the research can assist the counselors to improve on counseling skills and assist parents whose children are infected or exposed in the best possible way.

PAYMENT FOR PARTICIPATION

There will be no payment for participation. This is a voluntary exercise that is contingent on your participation.

4. CONFIDENTIALITY

Confidentiality will be maintained at all times. As no personal details will be collected from the participants, there is no direct threat to the participants.

The information might also be inspected by the University of Stellenbosch, Human Research Ethics Committee. The records will only be utilized by them in carrying out their obligations relating to this study.

5. PARTICIPATION AND WITHDRAWAL

You can choose whether to participate in this study. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so.

6. IDENTIFICATION OF INVESTIGATORS

If you have any questions or concerns about the research, please feel free to contact

Dr Edmore Munongo at Work Telephone: 04-302144 (day), Cell: 0778285338, email: edimunongo@yahoo.com or Prof Augustyn (study leader) E-mail: jcda@sun.ac.za

Tel: +2783 626 3081

7. RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research subject, contact Dr Chonzi, Director of Health Services. Harare city council on 774141/43.

SIGNATURE OF RESEARCH SUBJECT

The information above was described to me.....by Dr Edmore Munongo in English and Shona. I am in command of this language..... and where necessary it was satisfactorily explained to me.

I.....was given the opportunity to ask questions and these questions were answered to my satisfaction. I am aware that the results of the study will anonymously be processed into a study report and that at any stage I can withdraw my consent and participation in the study.

I hereby consent voluntarily to participate in this study. I have been given a copy of this form.

Name of Subject/Participant

Name of Legal Representative (if applicable)

Signature of Subject/Participant or Legal Representative

Date

SIGNATURE OF INVESTIGATOR

I declare that I explained the information given in this document to _____ [name of the subject/participant] and/or [his/her] representative _____ [name of the representative]. [He/she] was encouraged and given ample time to ask me any questions. This

conversation was conducted in /*English/*Shona] and [no translator was used/this conversation was translated into _____ by _____].

Signature of Investigator

Addendum B

Interview schedule for health workers

1. Name of facility?

2. What work do you do?

Doctor nurse counselor

3. How long have you worked with parents and children living with HIV?

4. Do most of your patients disclose HIV status to their children?

5. If not what are the commonest reasons for not disclosing?

6. Do you think children benefit from knowing their status?

Addendum C

Interview schedule

1. Age

<24 24-34 35 -45 >45

2. Sex male/female

3. Where do you stay?

Rural farm urban

4. Are you married?

Yes/no

5. Are you taking ARVs?

6. Does the child know her/his HIV status? Yes/no

7. How old is your child who is HIV positive?

8. If 6 is NO when do you indent to tell the child?

9. For how long has the child been taking ARVs?

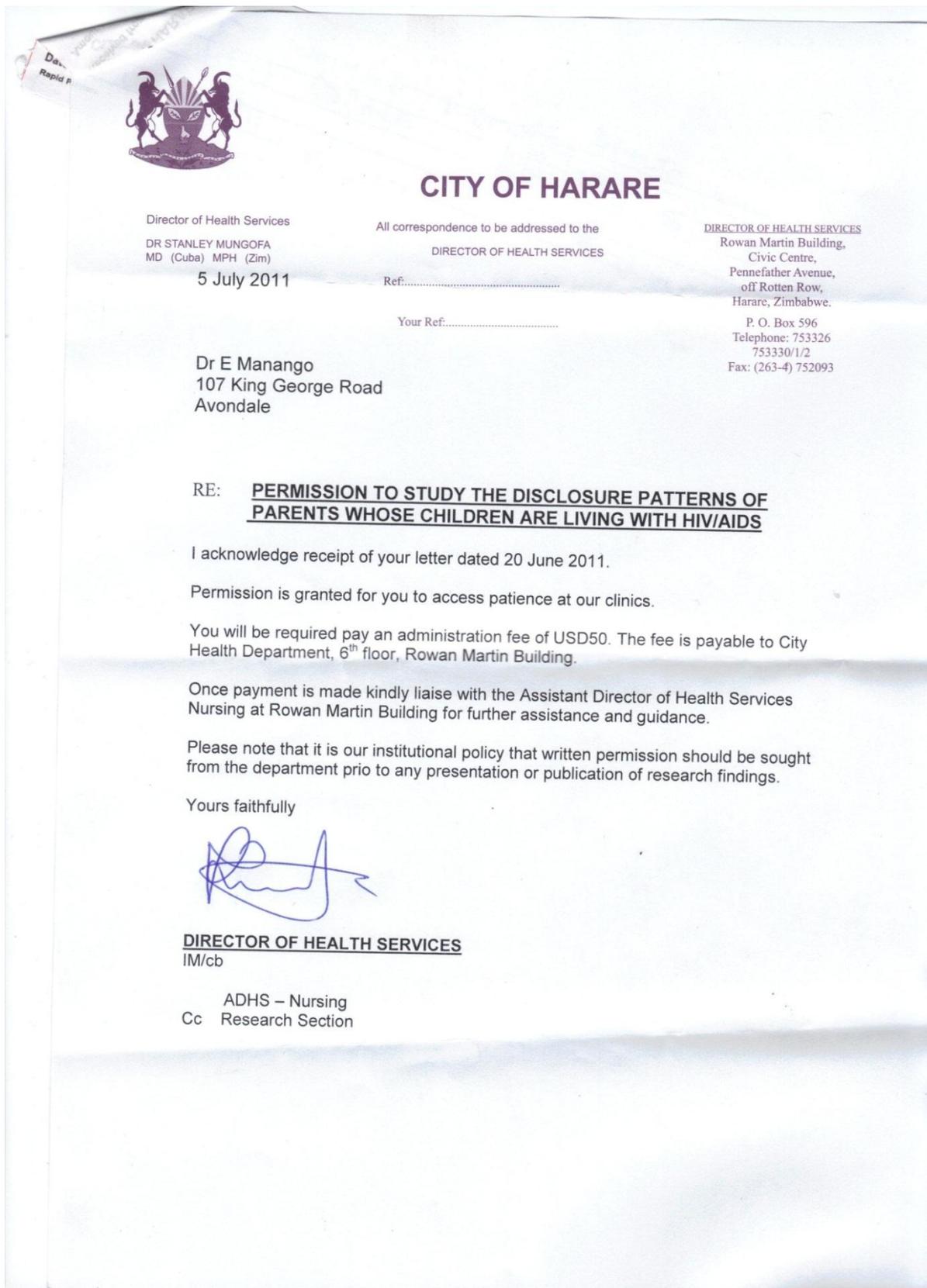
10. Why do you think it's not easy for many parents to tell their children their HIV status?

11. Do you think HIV positive children benefit from knowing their HIV status?

12. What other medication is the child taking?

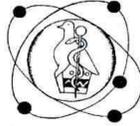
13. How many counseling sessions did you have?

Addendum D



Addendum E

Telephone: 791792/791193
 Telefax: (263) - 4 - 790715
 E-mail: mrcz@mrczimshared.co.zw
 Website: <http://www.mrcz.org.zw>



Medical Research Council of Zimbabwe
Josiah Tongogara / Mazoe Street
P. O. Box CY 573
Causeway
Harare

MRCZ APPROVAL LETTER

Ref: MRCZ/B/291

4 January, 2012

Dr. Edmore Munongo
 107 King George Road
 Avondale
 Harare
Zimbabwe

RE: FACTORS THAT INFLUENCE PARENTS TO DISCLOSE OR NOT TO DISCLOSE HIV STATUS TO THEIR CHILDREN WHO ARE LIVING WITH HIV/AIDS IN GREATER HARARE AREA OF ZIMBABWE

Thank you for the above titled proposal that you submitted to the Medical Research Council of Zimbabwe (MRCZ) for review. Please be advised that the Medical Research Council of Zimbabwe has **reviewed** and **approved** your application to conduct the above titled study. This is based on the following documents that were submitted to the MRCZ for review:

- a) Study proposal.
- b) English and Shona Consent Forms

- **APPROVAL NUMBER** : MRCZ/B/291
- **APPROVAL DATE** : 4 January, 2012
- **EXPIRATION DATE** : 3 January, 2013
- **TYPE OF MEETING** : EXPEDITED REVIEW

This number should be used on all correspondence, consent forms and documents as appropriate.

After this date, this project may only continue upon renewal. For purposes of renewal, a progress report on a standard form obtainable from the MRCZ Offices should be submitted one month before the expiration date for continuing review.

- **SERIOUS ADVERSE EVENT REPORTING:** All serious problems having to do with subject safety must be reported to the Institutional Ethical Review Committee (IERC) as well as the MRCZ within 3 working days using standard forms obtainable from the MRCZ Offices.
- **MODIFICATIONS:** Prior MRCZ and IERC approval using standard forms obtainable from the MRCZ Offices is required before implementing any changes in the Protocol (including changes in the consent documents).
- **TERMINATION OF STUDY:** On termination of a study, a report has to be submitted to the MRCZ using standard forms obtainable from the MRCZ Offices.
- **QUESTIONS:** Please contact the MRCZ on Telephone No. (04) 791792, 791193 or by e-mail on mrcz@mrczimshared.co.zw.
- **Other**
- Please be reminded to send in copies of your research results for our records as well as for Health Research Database.
- You're also encouraged to submit electronic copies of your publications in peer-reviewed journals that may emanate from this study.

Yours Faithfully

**MRCZ SECRETARIAT
 FOR CHAIRPERSON
 MEDICAL RESEARCH COUNCIL OF ZIMBABWE**



PROMOTING THE ETHICAL CONDUCT OF HEALTH RESEARCH
 Registered with the USA Office for Human Research Protections (OHRP) as an International IRB (Number IRB00002409 IORG0001913)