

**PERCEPTIONS OF NURSES ON DISCLOSURE OF CHILDREN'S
HIV POSITIVE STATUS IN ADDIS ABABA, ETHIOPIA**

by

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SUPERVISOR: PROFESSOR SP HUMAN

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DECLARATION

I declare that **PERCEPTIONS OF NURSES ON DISCLOSURE OF CHILDREN'S HIV POSITIVE STATUS IN ADDIS ABABA, ETHIOPIA** is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references and that this work has not been submitted before for any other degree at any other institution.

.....

Full names

.....

Date

ACKNOWLEDGEMENTS

Above all, I Praise My Lord, who gave me strength and grace to complete this dissertation and reach this milestone in my life.

O Lord God Almighty, who is like you?

You are mighty, O Lord, and your faithfulness surrounds you."

Psalm 89:8

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**PERCEPTIONS OF NURSES ON DISCLOSURE OF CHILDREN'S
HIV POSITIVE STATUS IN ADDIS ABABA, ETHIOPIA**

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ABSTRACT

A quantitative, descriptive, explorative survey was conducted to explore and describe nurses' perceptions of disclosure to children of their HIV positive status in Addis Ababa. 100 nurses working in six conveniently sampled health centres participated by completing a self-administered questionnaire. The findings revealed that the majority of participants were of the opinion that children have the right to know their HIV status, participate in their own treatment, and that disclosure contributes towards improved adherence. Forty-one of the participants said that it is nurses' role to support caregivers in the disclosure process. But 56.3% felt they lacked the training to disclose to children that they are infected with HIV. Accordingly, it is recommended that relevant and applied training is required to equip nurses with the knowledge and skills to disclose to children their status. The importance of nurses' proactive role in disclosure to children of their HIV status needs to be emphasised.

KEY CONCEPTS

Perception; Children living with HIV; Disclosure.

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ACRONYMS AND ABBREVIATIONS COMMONLY USED IN THIS PAPER

AIDS	Acquired Immunodeficiency syndrome
ART	Antiretroviral Therapy
ARV	Antiretroviral
FMOH	Federal Ministry of Health
HIV	Human Immunodeficiency virus
SPSS	Statistical package for Social Sciences
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNISA	University of South Africa

CHAPTER 1

ORIENTATION TO THE STUDY

1.1. INTRODUCTION

This is a descriptive quantitative study aiming at describing nurses' perception towards the disclosure of their HIV positive status to children living with HIV in Addis Ababa, Ethiopia. This study is important because caregivers will need support from nurses to disclose to these children their HIV status in an age-appropriate and developmental way. Ensuring that children living with HIV know their status is important if they are to participate in making decisions on their own treatment and receive adequate support. It is also important for prevention purposes.

1.2. BACKGROUND TO THE STUDY

A global challenge for more than two decades, according to the UNAIDS 2008 *Report on the global AIDS epidemic*, globally an estimated 33 million people are living with HIV, with 67% in Sub-Saharan Africa. Two million people died and 2.7 million were newly infected in 2007, whilst the number of children younger than 15 living with HIV is estimated to be two million, with 90% in Sub-Saharan Africa. 370,000 were estimated to be newly infected in 2007, and the number of children living with HIV has increased from the previous years (UNAIDS 2008:32-33). The total number of deaths of children with AIDS was 270,000 in 2007 (most in sub-Saharan Africa) and has been seen to decrease steadily. This decline is estimated to be due to a decline in new infections and an increase in access to antiretroviral (ARV) therapy (UNAIDS 2008:38).

With an increasing number of children living with HIV reaching adolescence and adulthood, the risk of them becoming sexually active and inadvertently infecting others requires research. The importance of disclosure of their HIV positive status to children was highlighted in 1999 by the American Academy of Pediatrics, in a

paper titled “*Disclosure of illness status to children and Adolescents with HIV infection*”. This stated that it is essential to disclose illness status to children: “taking into consideration their age, psychosocial maturity, the complexity of family dynamics, and the clinical context” (AAP 1999:164). In the early years, the recommendations for disclosure were mainly based on the experiences of cancer patients and did not take into account the different dynamics that come into play with the diagnosis of HIV both at family level and in the larger community.

Though it is difficult to generalize, many caregivers are reluctant for children living with HIV to know their status, arguing that they are too young, may not understand fully what is happening, may encounter emotional disturbances as a result, may blame their parents and ask questions on how they got the disease, and may inadvertently “blurt out the secret”, exposing the family to stigma and discrimination (Kouyoumdjian et al. 2005; Rwemisisi et al. 2008, Waugh et al. 2003). Therefore, questions such as “when to disclose?”, “who should disclose?”, “how and how much to tell?” have been controversial for some time. It has also at times placed caregivers and healthcare providers on opposing ends of a spectrum of disclosure, with the prior arguing for no or minimal disclosure, while the latter stand by the child’s right to know and participate in decision-making about treatment in an age-appropriate manner (Lester et al. 2002; Myer et al. 2006).

Different studies have assessed the relationship between disclosure and health-related quality of life (Butler et al., 2009:935-943), disease progression (Ferris et al., 2007) and adherence (Biadgilign et al. 2008; Giacomet et al. 2003; Mellis et al. 2004; Simoni et al. 2007), all with differing results that leave the child at the centre of debate. Some children may already know the diagnosis but keep it a secret so as to protect their parents, even though they are burdened with the knowledge. Without the necessary support to interpret correctly the knowledge or to manage the situation in an effective way (Instone 2000:241), they may lose trust in both the caregiver and health caregiver and feel lonely. Pfaff (2004:35-36) reported on a case study, *Telling a child he is HIV positive*, about an 8-year old child in South Africa who discovered his diagnosis accidentally during a consultation. The child was very distressed, and started crying and wailing, despite the mother’s reassurance that he did not have HIV, an encounter which left the Medical Officer

“...feeling very disturbed.” The author of this paper has also experienced tension with caregivers who refuse to inform children about their status, even when there are signs that the child may already suspect or be aware of it. The issue of how long the child or adolescent needs to be kept unaware of his own HIV status, and the effect on health and quality of life, has been examined in different studies with at times very controversial results (Ferris et al. 2007; Giacomet et al. 2003; Mellins et al. 2004; Oberdorfer et al. 2006).

The *Guidelines for Paediatric HIV/AIDS Care and treatment in Ethiopia*, issued by the Federal Ministry of Health (FMOH) give broad advice on disclosure of their HIV status to children, describing steps leading to disclosure as involving preparation, education, planning and follow up. After stating that disclosure needs to be made in an age-appropriate manner, examples fall into three age categories. It is suggested that there is no need for specific disclose for age groups 4-6, but that adolescents of 14 and over should definitely know their status. For age group 7-13 the decision seems to be left to the health caregivers, depending on the situation (FMOH 2008:94).

1.3. STATEMENT OF THE PROBLEM

The frequency of disclosure of HIV status to infected children has been found to be low in different countries, but a study in Ethiopia of the rate and factors associated with adherence of paediatric patients to Antiretroviral therapy (ART), estimated as only 21% the number aware of their HIV status (Biadgilign et al. 2008:1). As nurses play an important role in the treatment and follow up of HIV positive children, their perception with regards to the importance of and their role in disclosure of HIV status to children is important in supporting caregivers through the process.

Different studies point out the need for professional support to caregivers with regards to disclosure (Kouyoumdjian et al. 2005:285, Lee et al. 2002:2201, Moodley et al. 2006:201, Myer et al. 2006:293, Oberdorfer et al. 2006:283, the devastating...2006:424). An understanding of nurses' perception to disclosure may

therefore help in preparation of implementation strategies to improve disclosure processes and the quality of life of children living with HIV/AIDS.

1.4. AIM OF THE STUDY

The aim of the study may be broken down into the research purpose and the objectives of the research.

1.4.1. Research purpose

The main purpose of this study is to explore and describe nurses' perception of the disclosure to children of their HIV positive status in different health centres in Addis Ababa.

1.4.2. Research objectives

The objectives of the study are:

- 1) To explore and describe nurses' perceptions about the importance and implications of disclosing to children their HIV status
- 2) To explore and describe the perceptions of nurses about their role in disclosing to children their HIV status

1.5. SIGNIFICANCE OF THE STUDY

Disclosure to children of their HIV positive status is important in helping them to adjust, to participate in decision-making in their treatment option in an age-appropriate manner, and to access and receive appropriate support. It is also important to society at large as an increasing number of children living with HIV are reaching adolescence and adulthood. Children need to know their status by

the time they become sexually active so as to avoid further transmission or even second generation vertical transmission. The recommendations of this study will be significant to the implementation of different strategies aimed at raising the percentage of children living with HIV who know their status, and improving the care and support provided for them in settings similar to the study.

1.6. DEFINITIONS OF KEY CONCEPTS

It is important to clarify key concepts used in this study, in the sense in which they are understood and used in the argument.

Disclosure

Disclosure is the act of disclosing, uncovering or revealing; bringing to light; exposure (*Webster Dictionary*, online). For this study, the term will be considered as the act of disclosing to children their HIV status, and will entail full disclosure with the children knowing not only that they are just sick but also the actual name of the disease.

Child

According to the *Convention for Child Rights*, to which Ethiopia is party, "... a child means every human being below the age of eighteen years unless under the law applicable to the child, majority is attained earlier" (1990:2). According to Article 15 of the *Ethiopian Revised Family Code*, a minor is defined as "... a person of either sex who has attained the full age of eighteen years" (2000:35). For this study, a child is defined as between 10 and 15, in line with HIV/AIDS-related publications (e.g. UNAIDS, AIDS in Ethiopia report), which used 15 years of age as the cut-off point for children. In addition, persons over 15 years can access Voluntary Counselling and Testing, and do not depend on parental consent to find out their HIV status.

Perception

The Oxford Advanced Learner's Dictionary of Current English (2000: 864) defines perception as "the ability to understand the true nature of things; an idea, belief or image that you have as a result of how you see or understand things". The Cambridge Advanced Learner Dictionary (2003) describes it as "a belief or opinion, often held by many people and based on appearances". This study aims to describe and explore the perception of nurses about disclosing to children their HIV status.

Nurse

Collins English Dictionary (1991:1073) defines nurse as "a person, usually a woman, who tends the sick, injured, or infirm". For the purpose of this study, nurse refer to someone trained in one of the government or private owned Schools/Colleges of nursing , offering nursing program in the country, and who is registered in Ethiopia by the health Professional council established in 2002 by the Ministers act Number 72/2002.

Caregiver

The American Heritage Stedman's Medical dictionary (2002) defines a caregiver as " an individual, such as a parent, foster parent, or head of a household, who attends to the needs of a child or dependent adult".

1.7. FOUNDATIONS OF THE STUDY

The assumption of this study is that different perceptions affect the belief, attitude and behaviour of nurses, and it is the combination of all these that will affect the recommendations and support that the nurse will offer the caregivers in disclosing HIV positive status to children. Nurses' perception as to the benefit of disclosure of HIV status to children and their knowledge of the different challenges attached to it will be explored.

1.8. RESEARCH DESIGN

A descriptive, exploratory non-experimental quantitative design was used to address the research problem in this case.

1.9. RESEARCH METHODS

This study employed a quantitative approach, with survey method using a self-administered questionnaire using open and closed end questions.

1.9.1 Study population

The study population consists of all clinical nurses working in the 24 governmental health centres in Addis Ababa, with 1,108 clinical nurses as of 2007/2008 (Health and Health indicators, 2008:23). The number of nurses specifically working in governmental health institutions was 658, which included those working in health centres, hospitals and clinics (Addis Ababa City administration, 2007). The perception of nurses working in health centres was specifically sought as they were involved in ART treatment of children rather than those working in hospitals where physicians take this responsibility.

1.9.2. Sample selection

Convenience sampling was used with nurses being handed self-administered questionnaires to assess their perception of disclosure of their status to children living with HIV. Convenience sampling uses the most conveniently available participants, though it may be problematic in terms of bias and a potential for having a sample that is not representative of the overall population (Polit 2004:292).

Out of the 24 health centres, six were sampled using convenience sampling and all the clinical nurses available in these health centres during the data collection

period were asked by a nurse research assistant if they were willing to participate in the study. The data collection proceeded until a minimum of 100 participants were recruited. In case of insufficient volunteers in the six health centres initially selected, the plan was to include an additional health centre until the predetermined minimum sample was reached but this was not found to be necessary.

1.9.3. Data collection

Data was collected using theoretically based structured questionnaires with both closed and open ended questions. Burns et al. write that a questionnaire is "...a printed self-report form designed to elicit information that can be obtained through written or verbal responses of the subject" (Burns & Groove 1999:272) Pre-testing of the questionnaire was conducted after preparing the questionnaire before conducting the study to ensure that the tool will measure the needed information. Respondents were asked to complete and sign consent forms.

1.9.4. Data Analysis

Quantitative data from the structured questionnaires was analyzed using the Statistical Package for Social Sciences (SPSS), version 17.0.

1.10. DESIGN VALIDITY

In descriptive studies, "the research design must make enough provision for protection against bias and must maximize reliability, with due concern for the economical completion of the research study" (Kothari 2004:37). To minimize bias associated with convenience sampling, a relatively large sample size was used and the structured questionnaire carefully designed and pre-tested to ensure reliability. The researcher ensured that no bias was introduced when the

questionnaire was handed out and the study objective presented. No personal views on the topic were expressed.

1.11. ETHICAL CONSIDERATIONS

Ethical clearance was obtained from the University of South Africa (UNISA), and formal permission for conducting research obtained from Addis Ababa Health Bureau and all the Health Centres involved in the research, following administrative hierarchy. The ethical considerations that were emphasized and addressed were:

- ✚ **Autonomy and respect for the dignity of persons**, which is one of the four widely accepted philosophical principles applied to “...determine whether research is ethical” (Terre Blanche 2006:67). In this regard, voluntary participation was ensured and informed consent secured from all participants. Confidentiality was assured and the participants’ names remain confidential, as promised when they agreed to take part. The questionnaire was coded to ensure confidentiality.
- ✚ **Non-maleficence** was ensured as no participant was harmed during the filling in of questionnaires in any way. Deception was avoided.
- ✚ **Beneficence**: The benefit will be to the health system in general, based on the better understanding of perceptions of the researched, and recommendations made arising from the findings. No payment was extended to participants.

1.12. STRUCTURE OF THE DISSERTATION

The research report is divided into the following chapters:

Chapter 1: Introduction, background information, Orientation of the study.

Chapter 2: Literature review.

Chapter 3: Research design and methodology.

Chapter 4: Analysis, presentation and description of the research findings.

Chapter 5: Conclusions and Recommendations.

1.13. CONCLUSION

Disclosure of HIV positive status to children is an important aspect of paediatric HIV/AIDS treatment and support, and knowing nurses' perception in Addis Ababa in this regard will inform strategic implementations to improve current practice in all areas where the study results can be transferred.

CHAPTER 2

LITERATURE REVIEW

2.1. INTRODUCTION

According to the 2009 UNAIDS report, “the number of people living with HIV worldwide continued to grow in 2008, reaching an estimated 33.4 million [31.1 million–35.8 million]”. In 2008 alone, between 2.4 million and 3.0 million people became infected with the virus, and between 1.7 million and 2.4 million people died of HIV-related causes. (2009:7). Sub-Saharan Africa still carries the greatest burden, with 67% of the people living with HIV/AIDS in this area, 68% of new HIV infections worldwide amongst the adults, and the greatest share (91%) of new infections amongst children occurring in this region (UNAIDS 2009:21).

The number of children below 15 living with HIV is estimated to have increased to 2.1 million in 2008, out of whom between 240 000 and 610 000 were newly infected in 2008 (2009:8). The UNAIDS 2008 report stated that 90% of children’s infections occur through vertical transmission and that the number living with HIV has been steadily increasing. The reason for this is that even though new infections reached their peak around 2000 to 2002, the total number of child deaths due to AIDS is decreasing steadily due to the above and to the availability of ARV treatment (UNAIDS 2008:37-38).

In Ethiopia, the total number of people estimated to be living with HIV in 2007 was between 880,000 and 1,100,000, of whom. 92,000 were children under 14, as opposed to 75,000 in 2001. Free ART was started in Ethiopia in January 2005 and 180,477 have embarked upon treatment in the last four years, which represents an estimated 64% of those needing ART (Seyoum et al. 2009:5). The “AIDS in Ethiopia” sixth report states that “Due to the planned PMTCT program and ART among children, the number of under-five AIDS deaths is expected to decline from 2006 onwards and is projected to be 41% lower in 2010 compared to 2005.” With the number of AIDS deaths decreasing, the number of children living with HIV is likely to increase. As in many countries, with the number of children living with HIV

increasing, such issues as disclosure of HIV status to children are becoming important and need to be addressed as part of their care and support. Disclosure rates of HIV status to HIV positive children are estimated to range from 10% to 75%, according to a review of different studies (Wiener et al. 2007). In a study entitled “*Adherence to highly active antiretroviral therapy and its correlates among HIV infected pediatric patients in Ethiopia*”, disclosure had been made to 68 children out of the 390 participants (21%) (Biadgilign 2008:4).

The literature review was conducted to identify the already existing knowledge base upon which this research will be built. Therefore, disclosure-related processes and the role of healthcare providers and nurses will now be examined.

2.2. HISTORICAL BACKGROUND

After the advent of the HIV epidemics, initially due the short survival time of perinatally infected infants and children, disclosure of their HIV positive status was not given close attention. Later, experience from other chronic illnesses, especially cancer, was considered in stating that disclosure to children is beneficial to their self-esteem and will help them to participate in their own medical treatment. However, the premises of the affirmation did not consider the wide difference between HIV and other illnesses. Wiener et al. (2007) state that:

Applying the evidence-based knowledge being practiced within oncology to pediatric HIV disease is difficult given significant differences in epidemiology, the multigenerational nature of the illness, and the unique social stigma surrounding HIV transmission. (156-157)

A landmark publication in this area was the paper by the American Academy of Pediatrics in 1999, that admitted “studies on the impact of HIV infection/AIDS disclosure to children are limited”, but that it was still important to disclose to children, taking into account “their age, psychosocial maturity, the complexity of family dynamics, and the clinical context” (1999:165).

2.3. BARRIERS TO DISCLOSURE

Identifying the reasons caregivers delay or do not disclose is important for healthcare providers as these issues need to be addressed to support appropriate disclosure. Five of the commonly given reasons for non-disclosure will be discussed here.

2.3.1. Age: “too young?”

One of the reasons parents/caregivers give for non-disclosure is that the child is too young, and from fear that he or she will not be able to understand. A study states concern that parents/caregivers are afraid they will be at “...risk of depriving the child of a happy childhood” (Kmita et al. 2004), and will overburden the child with worries that are beyond its age. In a study in Kenya, 48% of parents/caregivers felt that their child was too young, while the same was true for 28.1% in a study in Thailand (Oberdorfer 2006:285; Wariua et al. 2008). Ostrom et al. (2006) stated that:

The most strongly endorsed reasons for non-disclosure included thinking the child deserves to have as carefree a childhood as possible, not wanting to scare the child, not wanting the child to worry about the mother and not wanting the child to be hurt by the reactions of others (63).

The reason the child is too young is given by caregivers in different studies (Abadia-Barrero et al. 2006:38), and though it is true that children may be too young to understand their disease, this needs to be discussed and validated with caregivers so that age-appropriate disclosure can be conducted, based on the child’s level of illness understanding.

2.3.2. Guilt

Naeem-Sheik et al. state that “One of the major difficulties is that one is dealing with many layers of disclosure: disclosure of HIV status to the child; the

concomitant disclosure of HIV status of the parent/s and other siblings or other family members...” (2005:46). Parents/caregivers may not want to discuss because they do not have enough time to process the diagnosis themselves. They may still be in denial (AAP 1999:164). They may also need to disclose a family secret about how the disease was acquired. Biological parents may be specially challenged if disclosing the child’s status means they automatically disclose their own (Punpanich 2009:52), and so may also feel guilty for having transmitted the HIV virus to the child. This may result in questions from the child that they are not ready to answer. Studies cite cases of fear in parents that the child might ask how they got the disease, be angry at them for giving him HIV and act out these feelings. This could explain why one study find a higher association between disclosing early and not being biological parents (Oberdorfer et al. 2006:286).

2.3.3. Fear of emotional distress

Studies state that one of the barriers to disclosure is the fear of causing children emotional or psychological problems (Waugh 2003:174). Parents fear that the children will experience depression upon hearing their diagnosis and may lose their will to live. 53.4% of caregivers in one study stated that they “...fear that disclosure might have negative psychological consequences to the child” (Oberdorfer et al. 2006:283).

However, beyond the direct effects on children's neuro-cognitive and psychological functioning, HIV infection may disrupt many of the social support systems that children depend on for optimal development (Steele et al. 2007:58).

2.3.4. Stigma

Many studies identify stigma as being one of the main reasons parents delay disclosure. Kouyoumdjian et al. state that “Caregivers identified barriers to disclosure including fear of discrimination, fear of social rejection and isolation, and the fear of being judged as being promiscuous or associated with a disease of

gay people” (2005:286). Caregivers fear that the disclosure to the child will lead to inadvertent disclosure by him or her to others, so that the secret of the family will be known, leading to discrimination against the child and the whole family. Moodley et al., in a study carried out in South Africa, state that 73% of caregivers fear the child will disclose to others, and that this is especially sensitive in large families with both HIV positive and negative members. The study states that “as HIV infection remains highly stigmatized in many communities, disclosure of paediatric HIV infection may also be accompanied by threats to the child’s physical and/or psychological health” (2006: 22).

Though further analysis of the 2005 Ethiopia Demographic and Health Survey to assess “*Changes in HIV-Related Knowledge and Behavior in Ethiopia, 2000-2005*” showed that “...in general, stigma against PLHIV decreased over the past five years” (Suzuki et al. 2008:8), another study shows that stigma is still present in Ethiopia and is amongst the “... four cultural and social structural factors that influenced the family caregivers’ conceptions of care and care giving” (Aga et al. 2009: 247).

In “*HIV/AIDS, Stigma and children: a literature review*”, the author states that “...stigma and discrimination play an important role in determining the process and effects of disclosure” and that “... stigma , discrimination and expected stigma and discrimination play a major role in parental and children’s decision making on, and the impact of, disclosure of HIV-status”. This also implies that children may experience stigma even without it through secondary disclosure (Deacon et al. 2007:28-29).

2.3.5. Lack of knowledge

According to Punpanich (2009:52):

Although many of them realized that the child has to be told, they felt helpless since they did not know how to do this in the least painful way possible. Therefore, they tended to postpone this as long as possible.

Some even hope that the child would be able to find out about their status on their own.

In research on barriers to disclosure: “Caregivers felt that they did not know enough about HIV to be able to explain it or answer questions” (Kouyoumdjian et al. 2005:286). Parents have also been described as anxious because of their “... lack of understanding and preparation for dealing with HIV/AIDS information in a developmentally appropriate way” (Abadia-Barrero et al. 2006:38).

2.4. FACTORS ASSOCIATED WITH DISCLOSURE

Domek (2006) states that disclosing to HIV positive children that they have HIV is one of the major areas that requires attention in era of ART. He states that while this was not important previously, as they were not expected to grow beyond their first years, now

...as children get older and particularly as they reach puberty, knowing why they are unwell and understanding the nature of the virus becomes crucially important. Young adults have to make decisions about romantic relationships, sexual activity, experimentation with drugs and alcohol, and planning for the future. For the adolescent living with HIV, these choices can be made only with an accurate and appropriate understanding of their infection status and the nature of HIV. Social support and open communication are important in making such an understanding possible (Domek 2006:1,367).

2.4.1. Child’s right to know

One of the reasons for disclosure is the child’s right to know the diagnosis. Aiges states that 33% of biological parents in her research stated that concern for the right of the child to know his diagnosis was their main reason for full disclosure (2008:110). In another study in South Africa, this number was even higher, as 98% of caregivers gave this reason for disclosing to the child (Moodley et al.

2006:202). Chinouya (2006) found that “Parents expressed concerns about the language of rights, which they perceived as bestowing ‘too much liberties’ on children”, but despite that “...parents also believed that children, depending on their age, had a right to know that the virus affected them” (Chinouya 2006:7). In another study, disclosure for children under six was found to be mostly influenced by parents’ perception of child needs, including the right to know (Lester et al. 2002:91), but the rights are not limited to knowledge of the disease, but also involve the right to participate in decisions with regards to their treatment (Thorne et al. 2002:396; Waugh et al. 2003:174). One dilemma that will be discussed later in the literature review is when a healthcare provider is faced with the right of the child to know his or her HIV status and the “right” of the parent/caregiver to withhold the information.

2.4.2. Maintaining trust

De Matteo et al. state that in their research “‘Trust’ emerged as the major theme and core value upon which disclosure decisions rest for both parents and children”. Children gave a high rating for the desire to give truthful answers to children’s questions (88%) and to preserve family trust (83%) as reasons for disclosure, while these reasons were rated as 100% in both categories for children younger than 11. The very limited number studies of what constitute important factors related to disclosure from the perspective of children makes this finding interesting, and shows how maintaining trust is important for children (2002:348).

For disclosure to children less than six, one study found that parental factors were more important and parents described themselves as believers of open communication in general. Others said that their experience of betrayal about family secrets in their own childhood led them to be forthcoming in disclosing HIV to children (Lester et al. 2002:90-91). A good example of trust was given by a biological mother who, though talking about disclosure to sibling of affected children, can represent the trust issue: “... I feel that if they’re not told, that when they do find out, there’s going to be some lost trust between the parent and the

child. I think you should be honest with your kids... but you got to tell them on their level” (Nehring et al. 2000:10).

2.4.3. Better participation regarding treatment and adherence

There is a general expectation that after disclosure the child will be able to participate in his or her own care and support. For example, parents of children who refuse to take medicine or go to the clinic may wish to use disclosure as a means of creating better involvement by the child to all treatment, but more specifically for improved adherence to ART. There are also instances when disclosure happens accidentally by parents who come up with the truth in a burst of anger at their child’s unwillingness to take the drugs.

Studies state that disclosure of HIV status has resulted in better adherence (Arun et al. 2006:S85), while Oberdorfer et al., in an abstract presented in 2004 at International AIDS conference, stated that the majority (58%) of children who knew their HIV status adhered well to their HAART regimen. Punpanich stated after a qualitative study that “In addition to the poor palatability of medication and/or high pill load, two major barriers to adherence are children's lack of awareness of his/her HIV status and the monotony of the never-ending treatment process” (Punpanich 2009:53). On the other hand, Williams et al. found that:

Having an adult other than the biological parent as the primary caregiver, using a buddy system to remember to take antiretroviral therapy medications, higher caregiver education level, previous adherence assessments, and taking antipsychotic medications were each associated with improved adherence”.

The study further found that if these factors were controlled, there was no significant association between adherence and disclosure (Williams et al. 2006:e1745).

Despite the general assumption that disclosure improves adherence by creating a better understanding by children of the need to take ART and enhancing trust,

other studies have found that children who knew their status are less adherent or non adherent (Mellins et al. 2004:1035; Giacomet et al. 2003:1398; Biadgilign et al. 2008; Marhefka 2006:429). According to Wiener et al. (2007), the association between failure to adhere and disclosure could be age, as disclosure is likely to occur at adolescence, when adherence usually becomes a problem. However, he cites one study that found worsened adherence after disclosure, even after controlling age. Other possibilities mentioned are negative reactions to disclosure leading to non-adherence and abstaining from taking medication due to fear of one's status being discovered by others. One other possibility is that after disclosure parents assume that children will take full responsibility for their medication, as in one study which found that prematurely releasing responsibility for ART to children results in poor adherence (Martin et al. 2007:61).

The difficulty in comparing these studies with those that claim better adherence with disclosure is due to such factors as different methodologies, sample and age groups. As a significant number of studies with adherence use self report to assess adherence, recall bias can also be a challenge. Many being cross sectional, the question arises as to how it is possible to assess the time factor, and whether non-adherence precedes disclosure or if disclosure has resulted in non-adherence. The following studies seem to support this argument. The first, a qualitative study by Hammami et al. (2004:e593-594) found that disclosure was taken as “...a necessary step to enhance adherence...”, because children could not understand why they needed medicine while they were “healthy”. However, an interesting finding in this study was that adherent caregivers who disclosed to children agreed that children were more adherent, but less adherent caregivers reported that non-adherent children became even more difficult after disclosure. This may require further research on a larger scale, as the sample size consisted only of 11 caregivers, but similar findings were also reported in another study, which found that “Disclosure to the child of his or her HIV status was used as a strategy to promote adherence but seemed to be effective only under certain circumstances as children who were already refusing to take the medication didn't get motivated by the disclosure” (Merzel 2008:977,982).

In conclusion, despite contradictory findings about disclosure and adherence that needs further research, disclosure still needs to be considered as an important strategy to ensure adherence. These different findings indicate that disclosure at all cost is not a “magic bullet” that can “cure” non-adherence, but rather the different circumstances as to who discloses, how and at what age need to be taken into account.

2.4.4. Support

Another factor associated with disclosure of HIV status is that it will enable children access to support. The American Academy of Pediatrics describes non-disclosure as “a conspiracy of silence” that surrounds children and separates them from possible support (1999:165). This was important for Thorne et al. (2002:400), as:

Support groups for young people with HIV can provide an opportunity to talk to infected peers, to obtain answers to questions about HIV and its treatment, and to discuss issues such as disclosure, developing intimate relationships and sexual health matters in a supportive environment.

In another study, “Social support was significantly negatively correlated with problem behaviour” (Battles 2002:161).

The issue of accessing support brings about the question as to whom the child should disclose. This has been described as the greatest fear by parents who delay disclosure so that the child will not tell others. Disclosure with parental requirement that the child keep the secret from everyone may send a mixed message to the child. It may somehow undermine the fact that HIV is nothing to be ashamed of, but on the other hand being told to hide it from everyone is inclined to produce a feeling of shame. In one study, due to social stigma, two children said that “having to keep their HIV status from their friends was a bad part of their lives” (Fielden et al. 2006:1051).

Though children need to disclose to others to gain support, they will need assistance to identify those to whom they should do so (Thorne 2002).

2.4.5. Psychological benefits

In contrast to children having mental or emotional problems as one of the barriers to disclosure mentioned by families, in one study conducted in South Africa, 90% of caregivers described their reason for disclosing as related to their children's mental health (Moodley et al. 2006:202). The AAP (1999:165) acknowledged the limited number of studies that demonstrate the impact of disclosure on children, but quoted preliminary work stating that "children who know their HIV status have higher self-esteem than infected children who are unaware of their status". The statement further describes a benefit to parents in disclosing to their children and thus reducing depression, whereas a lack of communication might deprive the child of a chance to discuss the issues with the parents, exacerbated by parental death.

Later studies conducted in this area confirm the beneficial effect on disclosure for the mental status of children. Mellins et al. (2002:101) found that "... contrary to the beliefs of many caregivers, disclosure did not result in increased mental health problems." Rather, the children who were aware of their status were found to be less depressed. Meanwhile, Bachanas et al. stated that "Children with HIV disease who have not been told their diagnosis and children who endorse more emotion-focused coping strategies tend to exhibit more psychological adjustment problems." (2007:343). In a cross-sectional study of HIV positive adolescents, the authors stated that they did not find negative effects on mental health as a result of disclosure (Menon et al. 2007:349).

Instone (2000) stated that, since disclosure occurred on average four years after diagnosis for those who have been disclosed to , children exhibited "severe emotional distress, disturbed self-image, and social isolation". The author further stated that these feelings, identified through stories and drawings, can remain after disclosure (Instone 2000:235,243). Abadia-Barrero et al. found that "... lack of communication about HIV/AIDS creates a context of confusion and mistrust, is

detrimental to psychosocial development and coping, compromises disease knowledge, and increases vulnerability to risk behaviour” (2006:36).

Of two other studies with different findings, the first, by Lester et al., found higher parent-rated anxiety for children associated with HIV disclosure, but neither anxiety nor depression was found to be statistically significant in the associated child self-report in the study. Hence, one could argue that parents expecting anxiety after disclosure could be biased, but further studies are needed in this area (Lester et al. 2002:314). On the other hand, the second study, into a prospective cohort study of 1,808 children younger than 15, found that in general children with HIV were at higher risk of psychiatric hospitalization than those not infected. Knowledge of HIV status and recent significant life events were the most significant association related to the illness (Gaughan et al. 2004:e5444).

In summary, despite variations in the debate, and contrary to the belief of many caregivers who delay disclosure because of fear that their children will develop emotional problems, the literature in general states the beneficial effect of disclosure for psychosocial adjustment and the detrimental effect of non-disclosure.

2.4.6. Avoidance of accidental disclosure

One factor that emphasizes the importance of disclosing at the appropriate time is the risk of accidental disclosure to the child, which can happen either at home or in clinical settings. There are reports in the literature about parents who are tempted to disclose to their child in anger, for example when the child refuses to take medication. This is a less than ideal situation and can be traumatic for the child who may associate the experience of disclosure with guilty feeling. Another possibility is for children to find out their status inadvertently in clinical settings. The case of an eight year old child finding his diagnosis accidentally in a clinic resulted in the child's screaming and being very disturbed by the news. The problem was compounded by a mother who was not ready and denied to the child that he was HIV positive (Pfaff 2004:35).

Children finding out their diagnosis in less than a “supportive way” may not want to discuss with their parents, especially if they hear their diagnosis from someone else (AAP 1999:165). Mighten conducted a study on how well health professionals maintain confidentiality for children and young people with HIV and their families, and concluded that though confidentiality was adequately maintained in the organization studied, the risk of inappropriate disclosure remains high and requires constant vigilance (2009:14). In a study in Thailand, 3.6 % of the children discovered their HIV status when they accidentally saw their blood result, and 3.6 % when their friends derided them (Oberdorfer et al. 2006:285). The likelihood of children inadvertently learning about their status in a hospital setting is high (AAP 1999). As related by Wiener et al. (2006:108), 45% of children reported not being surprised when disclosed to, with 11% saying their life got better after learning their diagnosis, 49% reporting no change, and 30% feeling their life had changed for the worst.

2.4.7. Quality of life

One study that examined six quality-of-life domains concluded that there was no statistically significant difference between quality of life before and after disclosure, and suggested that disclosure needs to be conducted at an appropriate time (Butler et al. 2009:935). On the other hand, Ferris et al. (2007:1088) conducted a three year retrospective study on a cohort of 325 HIV-infected Romanian children receiving highly active antiretroviral therapy, finding “...significant associations between not knowing the HIV diagnosis and death, and not knowing the HIV diagnosis and disease progression defined as either death or CD4 decline” . The authors state that in the era of highly active antiretroviral therapy, “... knowledge of one’s own HIV infection status is associated with delayed HIV disease progression” (Ferris et al. 2007:1088). This would need further research as it would increase the importance of disclosing their HIV status to children.

2.4.8. Prevention

As children with HIV are living longer due to better care and treatment, more specifically ART, a concern emerging is the fear that they will reach puberty and become sexually active before they are aware of their status. This involves the great risk of transmitting the virus to others and may even result in a “second generation” of children to which the virus is transmitted vertically. Vaz et al. captured the concern of one mother as follows: “According to me, I notice that she has reached the age of puberty, an age at which a girl starts having active sex life with boys” (Biological mother of a 17-year-old girl) (2008:844). Disclosing to children their HIV status and providing them with adequate support may in turn limit the spread of the disease (Naeem-Sheik 2005:46). The importance of disclosure needs also to be looked into from a perspective of public health.

In conclusion, disclosure of their status to children helps to maintain their right to know and participate in their care, maintains their trust in their family, healthcare providers and community, and may improve adherence. It also provides them with access to support. Conversely, non-disclosure seems to have a more profoundly negative effect on children’s emotional and mental status. With public health a key issue, the importance of sexually active children knowing their status and being aware of the risk of accidental discovery, all these factors shows the importance of disclosure as part of HIV/AIDS care and support, that the need for it to be addressed routinely.

2.5. DISCLOSURE PROCESS

As the importance of disclosure to children is established, the next concerns are the appropriate age for disclosure, who should disclose and how.

2.5.1. Appropriate age for disclosure

The American Academy of Pediatrics “...strongly encourages disclosure of HIV infection status to school-age children ... and recommends [that] adolescents

should know their HIV status” (AAP 1999:165). Child age has been significantly associated with disclosure, with older children being more likely to have been disclosed to (Wariua 2008). The age of 10 was considered to be crucial in some studies of the area of disclosure, with Wariua et al. reporting that caregivers felt that children younger than 10 would not be able to understand if disclosed to. The median age of disclosure for those who were aware of their status was 10 years (10-13), but those who had not yet disclosed felt that 12 (10-14) years was the appropriate age to do so (2008). Merzel et al. also stated that 10 years seems to be an “important transition stage for disclosure” (2008:982). In one study conducted in South Africa, caregivers felt that general discussion with children should occur at the age of 11, and HIV-specific disclosure at 12 (Moodley et al. 2006:202). Oberdorfer et al. (2006:286) found that child’s age above 10 years is one of predicting factors for disclosure. But in the same study, caregivers who have not yet disclosed felt that they should disclose when children are older i.e. average year of 13.6 (range 8-20).

A study in India, found that the majority of caregivers stated that the appropriate age for disclose was the mid-teenage years (Arun et al. 2009:805), while another study involving both parents/caregivers and healthcare providers found that “The participants preferred that partial disclosure occurs from the age of 10.8 (± 4.2) years and full disclosure from the age of 14.4 (± 4.5) years, health care workers were significantly more open to full disclosure and disclosure at a younger age ...” (De Baets 2008: 483). Healthcare providers in another study felt that general discussion should take place at six years of age, while more specific discussions involving HIV-specific communications should occur at a median age of 10 (Myers 2006:293). Moodley et al. discussed the finding in their research into the difference between the age at which caregivers would want disclosure to happen and the age when it actually happens. The caregivers would like disclosure to happen at 12 years of age, but it was happening at an average of 8.1 years at the time of the study (2006:202).

Chronological age, however, may not be the only important factor, so it would be difficult to identify the appropriate age for all children. The AAP recommends that not only age but also psychosocial maturity needs to be taken into account

amongst other factors (1999:164). Fifty percent (50%) of health workers and 59.9% of community members in one study considered the "...majority of HIV-infected children to be less emotionally mature than their uninfected counterparts", with 49.5% thinking that "... the majority of HIV-infected children are as intelligent as their uninfected counterparts while 45.7% thought them to be of lower intellectual capacity." The perception of emotional maturity and intellectual capacity of children living with HIV would affect the age of disclosure (De Baets 2008:484).

That some caregivers feel disclosure should occur at 14 and above is of concern, in view of the possibility of sexual debut at younger ages in some settings. The same concern has been expressed in an article in the *Lancet* that discussed the public health risk in Romania, where 20% youth are not disclosed to. In addition to parents' reluctance to inform their children in this specific case, the healthcare workers are restrained by Romanian law, which forbids them from disclosing without parental consent before the children reach 18 years of age (Ionescu 2006:1566).

2.5.2. Who should disclose

In many studies, the majority of respondents identified parents or primary caregivers as the appropriate persons to disclose children's HIV Status to them. In a study in India to determine the perception of caregivers, 42% indicated caregivers as appropriate "... to reveal the infection status" (Arun 2009:805). Moodley et al. state that when assessing the perception of caregivers in South Africa, 83% felt that parent/caregiver should be the one to discuss HIV status with the child, while 16% felt a healthcare provider, i.e. doctor, nurse or counsellor, would be best (2006: 201). In a study in Thailand amongst parents who had not yet disclosed, "57% of caregivers reported they would like to be the one to disclose the HIV/AIDS status to the child, and 43.0% reported that they needed the healthcare provider to help them to tell the child about the status" (Oberdorfer 2006:285). Wariua et al. report that in their study in Kenya, disclosure was carried

out by caregivers in 36% of the cases and by healthcare providers in 36% of cases (2008).

De Baets et al. found in their study in Eastern Zimbabwe that “Up to a third of the participants would prefer to initiate HIV disclosure and discussions about grief with their own children without any assistance.” As to who they would like to help them with the disclosure process, 51.3 to 55.7% would like to involve the healthcare worker, while 42,3 to 52,2 % would like a family member. Interestingly, the family members chosen were a father’s sister (36.7%) or a grandmother (40%), rather than a partner (4.8 to 14.8%). This study brings about the interesting concept that, as in many things, those family dynamics that are different from the Western style need to be considered, as they may hinder the mother from disclosing (2008:479,485). In a study by Myer et al. (2006:294) involving healthcare providers, three quarters recommended that caregivers should disclose to the child.

2.5.3. How to disclose

Disclosure needs to be a process rather than a single event, according to different papers. For Naeem-Sheik et al., it needs to take place over a period of time that takes into account different phases of the child’s life and entails ongoing communication with families. The process may even last several years, “depending on the cognitive development of the child.” The paper emphasizes the importance of “respect [for] family needs, wishes and expectations as well as community norms and pressures.” It also cautions that rushing the process before the family is ready might jeopardize the ongoing care of the child (Naeem-Sheik et al. 2005:47). Domek also advises against disclosure being a single revelation, favouring instead a gradual process that should be culturally sensitive and take into account each individual child’s context (2006:1368). Pfaff suggests considering the broader context, i.e. who else needs to be told in the family, as well as considering such factors as whether the child already suspects, is asking questions, or his/her age (2004:39).

Abadia –Barrero et al. argues against a disclosure model and conclude from ethnographic research that it is better to provide developmentally age-appropriate information about HIV/AIDS matching children's illness experience (2006:36,41).

In summary, disclosure needs to involve planning, discussions with the parents, helping parents deal with any outstanding issues, and preparing them for possible questions (Naeem-Sheik 2005:47; Pfaff 2004:46).

2.6. HEALTHCARE PROVIDERS AND DISCLOSURE

A number of factors are involved in the role of healthcare givers in disclosure to children of their HIV status.

2.6.1. Need of support

In different studies, parents/caregivers state that they need to have support from healthcare providers to disclose to children their HIV positive status. As they feel that they lack the necessary knowledge and skill to tell their child, they require personalized support from healthcare providers (Merzel et al. 2008: 984; Nöstlinger 2006; Oberdorfer 2006:283; Vaz et al. 2008:842). In a study in South Africa, a number of caregivers suggested the involvement of doctors in the disclosure. The 25% who had discussed with a healthcare provider about disclosure were found to be more likely to disclose to the child, while 96% of those who had not discussed disclosure said they would like to do so with a health care provider. This indicates that discussion with a healthcare provider is valued and needs to be given attention as part of the care provided in clinical settings (Moodley 2006:202).

2.6.2. Ethical dilemma

At times, parents and healthcare providers may be at the opposite end of the spectrum, with caregivers being reluctant to disclose and clinicians advocating the

right of the child to know his or her HIV status. This may lead to some tension as clinicians may advocate earlier disclosure than parents. Pfaff argues that:

The issue of whether HIV positive children should be told the truth is discussed in the light of contrasting ethical issues: the autonomy of the mother versus the autonomy of the child; the autonomy of the mother versus the doctor's duty to tell the truth; the beneficence versus the maleficence of knowing the result; and family and cultural issues. (2004:35)

The AAP cautions paediatricians not to grant parental requests to withhold the diagnosis under all situations (1999:165), but one should be cognizant and careful about specific laws that could place the healthcare providers at risk. The example of Romanian law cited above, in which physicians cannot disclose without parental consent until 18 years, and the resultant challenges, have been discussed in the *Lancet* (Ionescu 2006:1566). But in cases where the primary caregivers are not ready there can also be many challenges, which in turn lead to disruption of the care provided to the child.

2. 6.3. Knowledge and Attitude

As claimed by Horwood et al., "Health workers are the key to service provision for HIV-infected mothers and their children, but unless adequately trained, skilled and motivated, they may become a constraint to scaling up of services". HIV care for children depends greatly on their skill and willingness. Lack of adequate knowledge and self-confidence could be a challenge to HIV care, especially since poor attitudes towards people living with HIV can result from lack of knowledge and even experience. This can be improved by AIDS-specific training, which has been shown to develop their attitude, skills and confidence. Special emphasis is given to the fact that very few health workers are trained on how to break "bad news", which it is clear that disclosure can be. Such encounters can result in stress and can be unpleasant. Health workers may even avoid doing so to preserve their own emotional wellbeing (Horwood et al. 2010:314), while the presence of stigmatizing attitudes in health institutions, and the time constraints of

healthcare providers being overburdened, can make the care provided to people/children living with HIV/AIDS less than adequate.

With specific regards to supporting child caregivers with child disclosure, studies mention that health caregivers need to be aware of the range of related concerns, and that HIV/AIDS programmes need to be ready to address these issues (Vaz et al 2008:842; Mialky et al 2001: 575). Nehring et al states that the practical implication of their study is that:

It is important for nurses to realize that parental disclosure of the diagnosis of HIV infection is a long-term, age-appropriate process that will take place over many discussions and time, and should have the support of the interdisciplinary team. Additional psychological support should also be available (2000:5).

However, one can argue that such team involvement is not feasible in many of the primary care settings in developing countries.

Different papers advocate the preparation of guidelines to help caregivers support families in the disclosure process, as healthcare providers may also feel ill-prepared to deal with disclosure issues with parents (Arun et al. 2009; Boon-Yasidhi 2005:S100; Oberdorfer et al. 2006:283). Meanwhile, for Ostrom et al. (2006), “Counselling policy directors confirmed the absence of policy and training guidelines on the subject of parent-child disclosure. Counsellors reported improvising and giving inconsistent advice on this common concern of clients.”

In discussing the effect of a standardized model for disclosure, Blasini et al. suggested the strategies of:

- “1) in-training seminars for health professionals with strategies for developmentally appropriate pediatric disclosure
- 2) parent education and peer support groups for longitudinal assessment and intervention along the phases of disclosure, and

3) longitudinal individual assessment/intervention and teaching-support groups for HIV infected children in order to optimize the effect of early disclosure” .

The reported result after using this model was that most of the families in the study agreed to the disclosure as the process was made easier, and change was noticed in the staff, ranging from fear and resistance to the process to positive acceptance and active participation. Children generally showed good post-disclosure adjustment and received adequate support (Blasini 1998:181). It would seem that the provision of some type of framework could enhance the confidence of healthcare providers, though each individual case will need to be carefully considered.

2.7. CONCLUSION

With the advent of ART, children with HIV are living longer and the issue of disclosure of their status is gaining importance as part of paediatric HIV comprehensive care. The issues associated with disclosure barriers, importance of disclosure, who should disclose, when and how, have been examined. According to the literature review, the support of healthcare providers is crucial for parents or primary caregivers who want to disclose to their HIV positive children their status. But to provide this important support, the knowledge, attitude and beliefs of healthcare providers is important as it will determine the type of care and support provided. The role of health caregivers has been described according to the literature in this chapter, but this research will go on to assess specifically the perception of nurses in Addis Ababa in this regard, to identify areas of intervention for better care of children living with HIV virus.

CHAPTER 3

RESEARCH DESIGN AND METHOD

3.1. INTRODUCTION

The previous chapter discussed the literature review. Chapter Three describes the approach which will be used to explore nurses' perception about the importance and implication of disclosure to children of their HIV positive status, and the nurses' role in the disclosure process.

3.2. RESEARCH OBJECTIVES

The following research objectives will guide this study:

- 1) To explore and describe nurses' perceptions about the importance and implications of disclosing to children their HIV status
- 2) To explore and describe the perceptions of nurses about their role in disclosing to children their HIV status

3.3. DELIMITATION OF STUDY

The study will focus on the perceptions of nurses in relation to disclosure of their HIV positive status only in health centres in Addis Ababa city, Ethiopia.

3.4. RESEARCH DESIGN

The research design has been described as the "blueprint" of the research or as the itinerary before taking a trip to identify the 'best' way to reach a predetermined destination based on the available resources. It is also defined as a "set of guidelines and instructions to be followed in addressing the research problem"

(Kothari 2004:31-32; Mouton 1996:107). One important factor in the design is the degree of control that is needed and which determines the level of details involved in the design phase. According to Mouton (1996:108), “The rationale for a research design is to plan and structure a research project in such a way that the eventual validity of the research findings is maximized through either minimizing or, where possible, eliminating potential error”.

The quest for objective results entails different decisions to be taken in order to identify the best design to address the research problem. According to Creswell, “Informing this decision should be the world view assumptions the researcher brings to the study; procedures of inquiry (called strategies); and specific data collection, analysis and interpretation” (2009:3). The different judgments with regards to these will be discussed below.

3.4.1. Non-experimental quantitative

The philosophical worldview that shaped the approach to this research is mainly post-positivism, which contests the existence of absolute truth and claims that knowledge is hypothetical and shaped by data and evidence. It also states that research is a process of “making claims” that will then be refined or rejected and that “...seeks to develop relevant and true statements, ones that can serve to explain the situation of concern ...” In addition to this, objectivity is described as being fundamental to scientific enquiry, hence the importance of validity and reliability in quantitative research (Creswell 2009:7).

Quantitative studies are structured with most of the decisions being taken at the beginning of the research, as opposed to qualitative studies which are flexible with modification to the research design being undertaken even after the research has started. These initial decisions include the specification of any intervention to be undertaken, methods to be used, timing of data collection, settings, and even the information to be provided to participants. These are predetermined even ... “before a single piece of data is gathered” (Polit 2004:164).

The two main groups in quantitative designs are experimental and non-experimental research. Experimental research especially randomized clinical trial is described as the 'ideal' research mainly because it enables the researcher to ensure control over extraneous variables. However, not all research problems can be addressed through this type of design, as is true for this research which will try to determine nurses' perception about disclosure. Like many other human characteristics, perception is not inherently subject to experimental manipulation, therefore a non-experimental design was deemed appropriate to address the research problem in the current dissertation (Polit 2008:272).

3.4.2. Descriptive

Polit states "the purpose of descriptive studies is to observe, describe and document aspects of a situation as it naturally occurs ..." (2008:274). It provides the opportunity to investigate a phenomenon in a real life situation and not only to obtain an accurate version of characteristics of particular individuals, situations or groups, but also to produce new knowledge about topics or concepts on which limited research was conducted (Burns & Groove 2009:45). This study will describe the perceptions of nurses with regards to disclosure to children in Addis Ababa of their HIV status.

3.4.3. Exploratory

This approach is most often used to investigate a research problem that is relatively new, to learn more about the topic. One of the main purposes of this type of study, according to Babbie, is to gratify the researcher's curiosity and wish for better understanding (2007:88). The issue of disclosure to children of their HIV status, being relatively new, mandates the use of an exploratory research design. This study will explore perceptions of nurses in relation to disclosure to children living with the HIV virus of their status, especially the importance of the issue and the nurses' perception about their role in the process of disclosure.

3.4.4. Survey

Amongst different quantitative strategies, the method used in this research is that of a survey. As quoted in Creswell:

survey research provides a quantitative or numeric description of trends, attitudes, or opinions of a population by studying a sample of that population. It includes cross-sectional and longitudinal studies using questionnaires or structured interviews for data collection, with the intent of generalizing from a sample to a population. (Creswell 2009:12).

Meanwhile, for Polit (2004:234), "A survey is designed to obtain information about the prevalence distribution, and interrelations of variables within populations". Surveys are mostly carried out to describe certain traits or attributes in a population and as such the researcher may be concerned about what the distribution is rather than why it occurred (Babbie 1998:51).

This study is a cross-sectional 'snapshot' of nurses' perception about disclosure to children taken at a specific time.

3.5. RESEARCH METHODOLOGY

The methodology involves population identification and sampling, theoretically-based data collection instruments, pre-testing of the questionnaire, data collection, careful consideration of ethical issues, and reliability and validity. These will be discussed as follows:

3.5.1. Population and sampling

This section will describe the population and sampling method used in this research.

3.5.1.1. Population

Polit defines the term 'population' as the total aggregation of cases in which a researcher is interested (2004:289). As quoted in Mouton, "the 'population' is 'aggregate of all the cases that conform to some designated set of specifications'" (1996:134). In this research, the study population consists of all clinical nurses working in the 24 governmental health centres in Addis Ababa. The number of clinical nurses working in the city as of 2007/2008 was 1108 (Health and Health indicators, 2008:23). The number of nurses specifically working in governmental health institutions was 658, which includes nurses working not only in health centres but also in hospitals and clinics (Addis Ababa City administration, 2007 [online]).

The perception of nurses working in health centres will be specifically sought in this study as they are more likely to be involved in ART treatment of children, rather than those working in hospitals, where physicians will usually take this responsibility.

3.5.1.2. Sampling

It is usually not feasible, and in some cases not necessary, to study all individuals in a population, as in many studies sampling was used to study a smaller portion. Mouton states that "...the aim of research is often to study a representative number of events or people with a view to generalizing the results of the study to a defined population or universe" (1996:133). The most important factor in sampling is ensuring that the sample is representative of the population to which the research findings will later be generalized. Non Probability sampling will be used in this study.

Non probability sampling does not give all elements in the population an equal chance of being selected to be part of the sample. Convenience sampling is one of the methods used in non probability sampling, which although less likely to produce accurate and representative samples, is often used because it is convenient and economic (Polit et al. 2004:292).

The sampling unit was governmental health centres, with a source list containing 24, of which six were sampled using convenience sampling. All the clinical nurses available in these health centres during the data collection period were asked by a nurse research assistant if they were willing to participate in the study.

Another important factor in sampling is the sampling size as “ it is generally true that as the size of the sample increases, it become less likely that we will obtain inaccurate results purely by chance” (Mouton 1996 :139). In this study, the data collection proceeded until a minimum of 100 participants had been recruited. In case of insufficient volunteers in the six health centres initially selected, the plan was to add an additional health centre until the predetermined minimum sample was reached.

3.5.2. Data collection

The collection of data involved a number of procedures, outlined here.

3.5.2.1. Data collection instrument

As stated in Polit, “a researcher collecting self-report data for a quantitative study almost always uses a formal written instrument” (Polit et al. 2004:349). In this case, the instrument selected was a self-administered questionnaire. The questionnaire was theoretically based and designed specifically for this study. Self-administered questionnaires were used in this case as they were cost-effective, reduced the risk of interviewer bias influencing the response of participants, and also reduced inadequate responses by nurses seeking social acceptability in some of the sensitive questions.

The questionnaire consisted of both open and closed ended items. It is true that particular care needs to be taken in designing closed ended questions as they need to be comprehensive; however they are then easy to administer. Structured questionnaires result in quantitative data that is easy to analyze (Bowling

2009:283). Open ended questions allow more flexibility to participants but they are less easy to administer and analyze.

The theoretical based questionnaire consists of 5 sections. The first section is designed to elicit responses about general demographic data about the research participants. The second section deals with knowledge, experience and perceptions about children living with HIV. Section three deals with perceptions with HIV/AIDS in general, and pediatric HIV, in specific. The fourth section deals with participants' perception about their role in disclosure to children of their HIV status. The last section was left open ended to elicit any additional views related to the topic that they felt was not adequately addressed by the research questions.

3.5.2.2. Pre-testing of data collection tool

Pre-testing is important in checking the scale's ability to measure whether it is relevant to the construct and its ability to discriminate, as well as for checking understandability, and appropriateness, both linguistically and culturally (Polit et al. 2008:481). The average time taken to fill in the questionnaire was also assessed for inclusion in the informed consent form. The questionnaire was pre-tested on seven nurses outside of the research area, and modified according to the findings.

The question 1.6 was phrased originally as "Working as .." and left open ended but changed to specifically ask for what department they are currently working in as the initial one was not specific or clear enough and was misunderstood. Initially, in the demographic data section, after question 1.7, there was just one open ended question asking participants about any HIV/AIDS related training that they have received. This resulted in a lot of answers that were not related to the research topic e.g. monitoring and evaluation. After the pre-test, this was changed to specific close ended questions about specific training on pediatric HIV/AIDS, counselling and disclosure. The question in 2.8 about what type of health care provider should be involved in child disclosure was open ended but no specific answer was given in terms of type of health care worker. To the question about what they do you feel is an important reason that parents don't want to disclose to their children their HIV status that needs to be addressed in discussing disclosure,

before the pre-test, the question was stated as the most important reason and only one answer was expected but as participants were choosing different options, this was changed to a multiple answer question. The last section was added after pre-test to allow participants to add any additional comments or suggestions. After modification, data collection proceeded using the modified questionnaire.

The supervisor of this research was also involved in discussion about the questionnaire.

3.5.2.3. Data collection process

The advantage of using a questionnaire rather than interview is due to the lower cost and the anonymity it offers, which leads to more open responses, especially in sensitive areas, and avoidance of interviewer bias. On the other hand, interviews have a number of advantages, in that they would result in higher response rates, more clarity provided to the questions, less missing information, more depth to the information, addressing the right participants as sampled, and getting additional information about the participants through observation as needed (Polit 2004:350).

Therefore, the design of this study strove to benefit from some of the advantages of interviews by using two skilled nurse research assistants who were trained to establish rapport with participants, and hand out the questionnaires to improve the response rate. They used the same prepared description of the study to ensure reliability and emphasize the importance of each participant's genuine and complete participation. Confidentiality was ensured by separating the questionnaire from the initial informed consent/identification page (Mouton 1996; 157, 158). The research assistants ensured that each questionnaire was filled in completely upon receipt. Data collection was conducted accordingly from October 28th to November 19th, 2010.

3.5.3. Validity and reliability

Threats to validity and reliability need to be addressed early in the research design to ensure that reliable data is obtained, with two types of general validity looked into, namely internal and external. For Creswell, “Internal validity threats are experimental procedures, treatments or experiences of the participants that threaten the researcher’s ability to draw correct inferences from the data of the population in an experiment” (2009:162), while Mouton states that the threat to objectivity and validity “...would include vague research questions, biased instruments, biased sampling, samples that are too small and conclusions that are not supported by the evidence” (1996:112,113). In this study, careful definition of the key concepts was given on the overview of the study and included in the introduction given by data collectors handing out the questionnaire. The content validity was ensured through exhaustive literature review to make sure that all aspects of construct are covered in the research instrument. The designed instrument was pretested and, according to the findings, the questionnaire modified to address the shortcomings identified.

As the main purpose of descriptive research is to describe characteristics of the population under study, external validity was crucial (Terre Blanche 2006:167). Threats to external validity arise when incorrect inferences are made from the sample data to other persons or situations: “These threats arise because of the characteristics selected for the sample, the uniqueness of the setting and the timing of the experiment” (Creswell 2009:162). External validity is mainly concerned with the representativeness of the sample. In this study, convenience sampling was used to select health centres, followed by a request to all nurses available during the data collection period to fill in questionnaires. To ensure that a representative sample was obtained, the response rate was analyzed and characteristics of the sample compared to available characteristics in the population.

Reliability refers to the ability of valid measurement instruments employed to arrive at the same conclusions, when used on different participants or under different circumstances. As Mouton writes, reliability can be defined by the question: “will the same methods used by different researchers and/or at different times produce

the same results?”, concluding that reliability is about ensuring constancy over time (1996:144).

To measure the internal consistency reliability, Cronbach's alpha (α) was calculated for section 3 and 4 and was found out to be 0.633. Though in general, the best level for alpha coefficient is 0.70 and greater (Nunnally 1978), it is possible to have lower levels in case of different latent constructs or in exploratory studies as in this one. Further, testing will need to be done on future utilization of the tool and additional questions to explore the same construct may need to be added to further improve the alpha coefficient based on the current findings.

3.6. ETHICAL CONSIDERATIONS

Babbie quotes Webster's *New World Dictionary* definition of the word 'ethical' as "conforming to the standards of conduct of a given profession or group". He also states that though all researchers consider themselves to be ethical, in social research, the researcher may not always be aware of ethical considerations (Babbie 2007:61). Hence, it is necessary to be watchful so as to anticipate and address ethical issues in each step of the research, from the selection of an important research topic to the final report writing.

3.6.1. Permission to collect data.

Ethical clearance was obtained from the University of South Africa (UNISA) after a review of the study design. Formal permission for conducting research was obtained from Addis Ababa Health Bureau after review of research proposal by its ethical committee. The informed consent form was translated in Amharic, which is the National language, as per request upon data collection approval by the Addis Ababa Health Bureau. The letter from the Health Bureau was then presented to all the health centres involved in the research, to secure permission in accord with the administrative hierarchy.

3.6.2. The principle of beneficence

No harm (physical, psychological, social or economical) was done to any of the participants through their participation in this study. The information they provided did not or will not, in any way, be used against them. The participants did not get benefit directly from the research in terms of payment, but were told that the benefit was for the health system in general, as children living with HIV should benefit from the research findings and recommendations from interventions thereof.

3.6.3. The principle of respect for human dignity

In keeping with the claim that “Humans should be treated as autonomous agents, capable of controlling their own activities” (Polit 2004:147), participation in the research was voluntary and no coercion of any kind was used. Full disclosure was made with regards to the nature of the study and the participants’ right to refuse participation. No deception was used at any time during data collection, and an informed consent form was signed by the participants to attest their voluntary and informed participation.

3.6.4. The principle of justice

The participants’ right to fair treatment and privacy was maintained during this research, and confidentiality was ensured through the use of a top page on the questionnaire containing the name and signature of participants, stating their informed consent. This page was then removed to ensure confidentiality. (Polit 142-149). Confidentiality was also ensured throughout the data analysis part and no identifying information was provided in the dissertation when comments were discussed.

Before conducting the study, appropriate review of the study design was provided at UNISA, with appropriate review and approval provided by the Addis Ababa Health Bureau ethical committee.

Ethics is also considered in proper analysis and reporting of the actual findings of the study.

3.7. DATA ANALYSIS

The data from the completed questionnaires was coded, entered, checked and then analyzed using SSPS. Descriptive statistics were used to summarize and analyze the data.

3.8. CONCLUSION

This Chapter described the research design and methodology, including population and sampling, ethical considerations, validity and reliability, and data collection and analysis. Chapter Four discusses the data analysis and interpretation.

CHAPTER 4

ANALYSIS, PRESENTATION AND DESCRIPTION OF THE RESEARCH FINDINGS

4.1. INTRODUCTION

In the previous chapter, the research design and methodology were discussed. The main purpose of this chapter is to discuss the data analysis, interpret the data and describe the research findings. The sample consisted of 100 nurses working in six health centres in Addis Ababa, Ethiopia. The total number of nurses in the six health centres was 195. The response rate was 93%.

4.2. DEMOGRAPHIC DATA

The first section of the questionnaire covered the respondents' demographic data and previous training information.

4.2.1. Gender

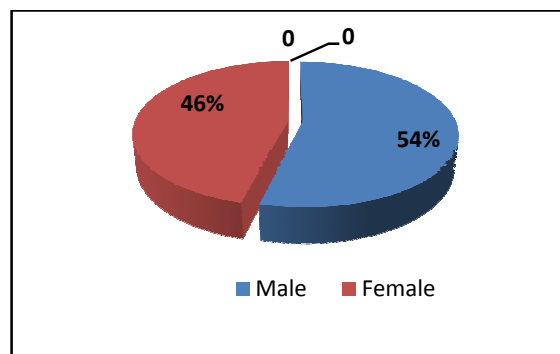


Figure 4.1 Respondents' gender (n=100)

Of the respondents, fifty four (54%) were male and forty six (46%) female. From unpublished data obtained from Addis Ababa Health Bureau's human resource information officer on November 30, 2010, the percentage of female nurses working under the Health Bureau, excluding those working in hospitals, was

59.8%. The percentage of males in the sample was higher than in the actual population.

4.2.2. Age

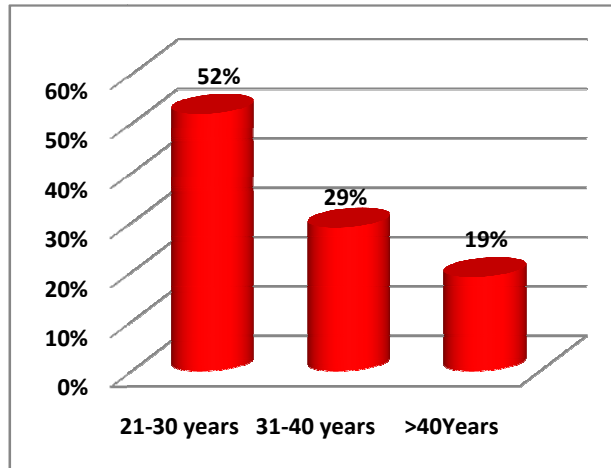


Figure 4.2 Respondents' age (n=100)

Fifty two percent (52%) of the respondents were between the ages of 21 and 30 years, twenty nine (29%) between 31 and 40 years, while nineteen (19 %) were above 40 years of age.

4.2.3. Work experience

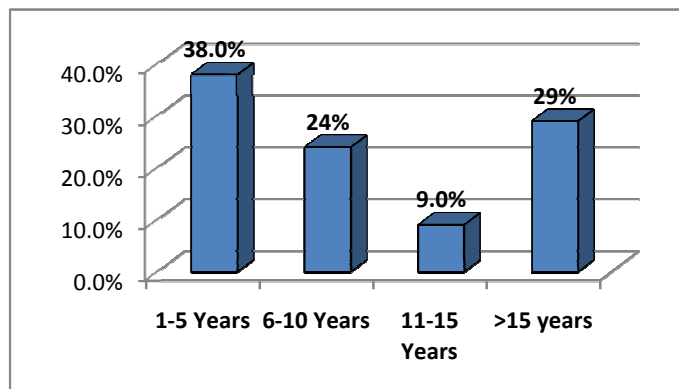


Figure 4.3 Respondents' work experience (n=100)

Thirty eight (38 %) of the respondents had 1-5 years of work experience as nurses, 24% 6 to 10 years, and 9% 11-15 years, while 29% had been working for more than 15 years.

4.2.4. Educational qualification

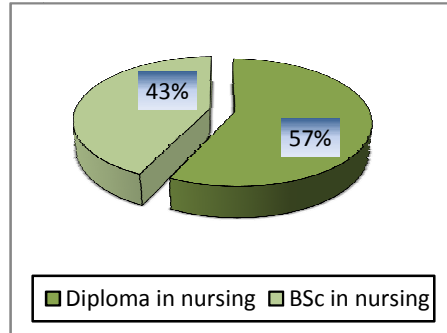


Figure 4.4 Respondents' educational qualifications (n=100)

Fifty seven percent (57%) of the respondents had a diploma in Nursing, while 43% had a bachelor's degree. Although the questionnaire included master's degree, none of the respondents fitted this category, according to the responses. From the unpublished data obtained from Addis Ababa Health Bureau, the percentages of clinical nurses with diploma to nurses with a bachelor's degree were 65% and 35% respectively.

4.2.5 Training institution attended

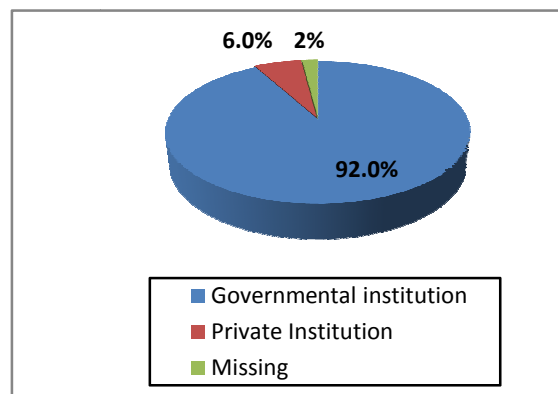


Figure 4.5 Respondents' training institution (n=100)

The majority of the respondents (92%) received their training in nursing from governmental institutions and 6% from private institutions. The data was missing for 2 (2%) respondents.

4.2.6. Department

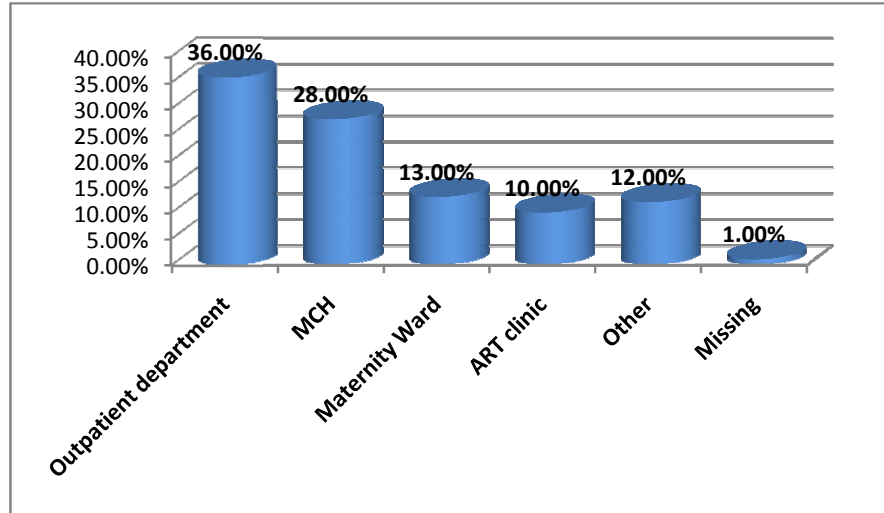


Figure 4.6 Respondents' department (n=100)

Thirty six percent (36 %) of the respondents work in the general Outpatient department, 28% in Maternal and Child Health clinics and 13 % in Maternity ward. 10 % work in the Antiretroviral (ART) clinic. Twelve percent (12 %) selected the response "others", including inpatient, administration, and TB clinic. The data for one respondent was missing.

4.2.7. On Job training on HIV/AIDS

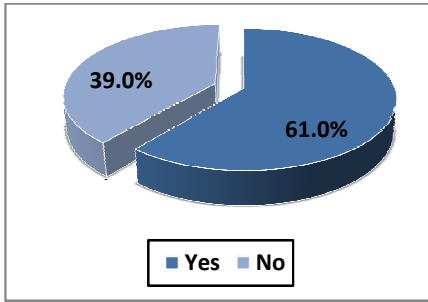


Figure 4.7 Respondents' on job training on HIV/AIDS

Sixty one percent (61%) of the respondents had received on job training on HIV/AIDS, as opposed to 39% who responded that they had not.

Out of the 61 respondents who responded positively to receiving training on HIV/AIDS, the majority (75.8%) had received training on counselling. Thirty seven (60.7%) of the respondents agreed when asked if they had received training on how to disclose their HIV status to adults. Twenty five (41%) responded yes to the question of whether they have received specific training on paediatric HIV and the same number (41%) said they had received specific training on how to disclose to HIV positive children their HIV status. This means that only a quarter (25%) of all respondents had received specific training about paediatric HIV, or how to disclose to HIV positive children their status.

4.2.8. Experience with Children living with HIV/AIDS

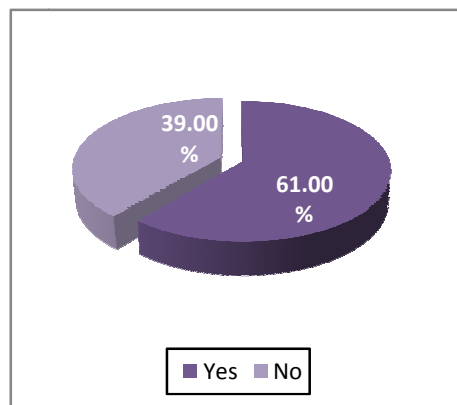


Figure 4.8 Respondents experience with Children living with HIV/AIDS (n=100)

On the question of whether they ever had a Child living with HIV/AIDS as a patient, the majority (61%) responded affirmatively.

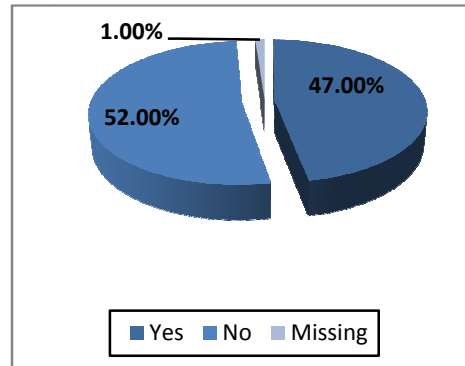


Figure 4.9 Respondents' experience in discussing disclosure with parents (n=100)

The majority of respondents (52%) had never discussed with parents about disclosing to the Child Living with HIV/AIDS his/her HIV status. Similarly, only 41% of respondents had ever helped parents to disclose his status to a child living with HIV/AIDS. In a study conducted by Myers et al. in Cape Town, 50% of the 40 healthcare providers involved had discussed with parents about disclosure, similar to the findings in this study. In contrast, only 18% of parents had been involved in disclosing to a child his/her status, which is a much lower percentage than in this study (Myers et al. 2006:294).

4.3. PERCEPTION AND VIEWS ABOUT HIV/AIDS AND DISCLOSURE OF THEIR HIV POSITIVE STATUS TO CHILDREN

A number of factors were examined in relation to the perception and views of the participants in relation to disclosing to children their HIV positive status.

4.3.1. Respondents' perception on life expectancy of children born with HIV/AIDS

To the question as to whether a child born with HIV virus can live to the age of 10 and beyond, 59 % replied “ Yes”, 13% “ No” , 25 % were unsure .

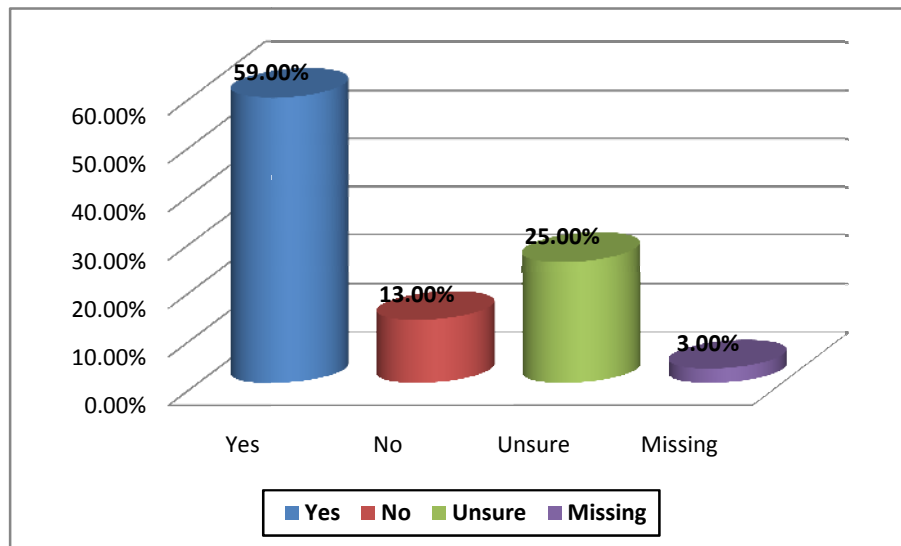


Figure 4.10 Respondents’ reply to possible life expectancy of Child born with HIV (n=100)

One respondent specified “Yes” if the child is on follow up and on ART, unsure if s/he is not on follow up. The data was missing in 3% of the cases.

4.3.2. Respondents’ perception about appropriate age for disclosure

Only 38 of the respondents replied to this question, with a specific age or range of age. Out of the 38, nine (23.7%) suggested disclosing to the child before the age of 10; eleven (28.9%) between the age of 11 and 14 years, and eighteen (47.4%) suggested that disclosure should occur when children are above the age of 15. Amongst the last group, seven (18.4%) suggested disclosure should take place after 18 years of age. This is different from the findings in a study in South Africa where healthcare providers stated that though discussion should be initiated at six years, full disclosure should occur at 10 years of age (Myers et al. 2006:294). In another study, in Zimbabwe, more than 69% of participants were for full disclosure after age 11, with a higher percentage of healthcare providers opting for full

disclosure than community members at any age categories (De Baets et al. 2008:483).

The data was missing for the rest of the respondents on this question, except for a few “unsure”, and “unknown”. Three respondents suggested that it depended on “child maturity”, “development”, and “understanding”. One respondent stated in general that the children would be disturbed, while three respondents replied 18 months and below.

4.3.3. Respondents’ Perception on who should disclose

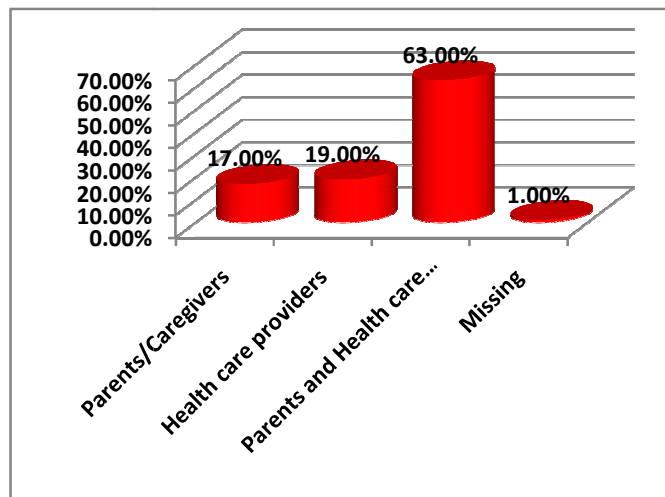


Figure 4.11 Respondents’ perception on who should disclose (n=100)

The majority of respondents (63%) stated that parents and healthcare providers should disclose together. Only 17% said that it was the parents’ responsibility to disclose. This is much lower than the findings in a study in which three quarters of healthcare providers believed that caregivers themselves were the most appropriate people to disclose his/her HIV positive status to the child, but that most would need healthcare providers’ support (Myers et al. 2006:294). On the other hand, 19% gave the responsibility of disclosing to the child his or her HIV positive status, to the healthcare providers.

Out of the 82% who responded that healthcare providers should disclose or be involved when disclosure took place, 35 (43%) replied that nurses should be

involved, 24 (29.6%) paediatricians, two (2.5%) medical doctors and 20 (24.7%) others. Out of these 20 respondents, the majority said that all of them could do it if trained in counselling and child disclosure. One respondent felt that a psychologist and a medical doctor should disclose, while one respondent said that the health worker who was following the child for his previous health-related problems should disclose. Another said that “in health centre, nurse or health officer should be involved but hospital standard medical doctor”. That more than a quarter of the respondents expect a paediatrician should disclose is an issue that needs to be addressed, because of feasibility. Unpublished data from the human resources section in the Addis Ababa Health Bureau reveals that though additional paediatricians are available in Federal hospitals and private clinics, the number of paediatrician under the Addis Ababa Health Bureau was only two as of November 2010.

4.3.4. Respondents’ perception about reasons why parents avoid disclosing

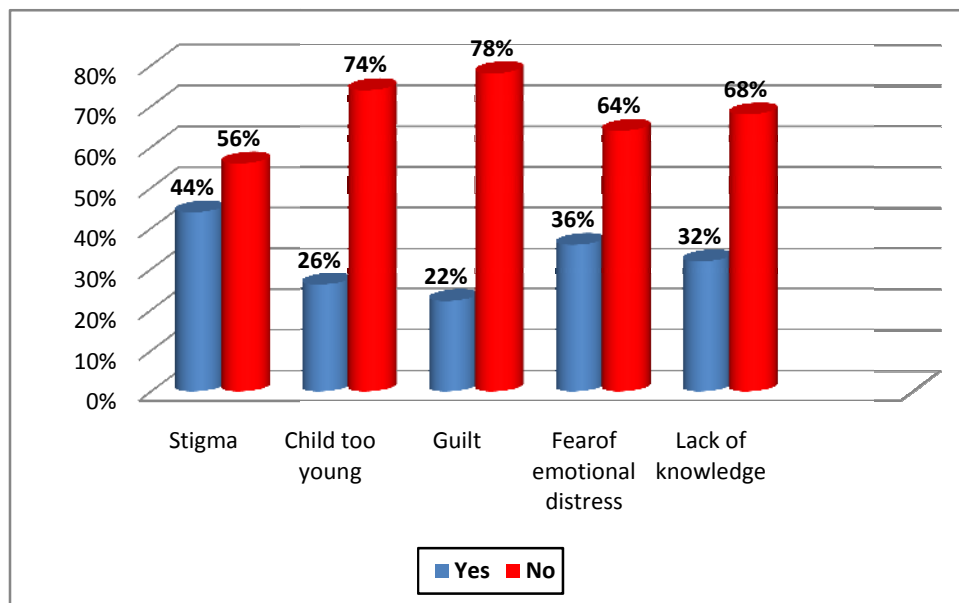


Figure 4.12. Respondents’ perception about reasons why parents avoid disclosing (n=100)

The most important reason parents avoid disclosing to their children, according to respondents, is fear of stigma (44%), followed by fear of emotional distress of the

child (36%), lack of knowledge and skills to disclose (32%), feeling that the child is too young (26%) and guilt (22%). However, the actual reasons parents avoid disclosing to the child his/her HIV positive status needs to be validated by another study of the parents/caregivers. This response only indicates the respondents' perception, which is important in that these perceptions will guide the nurses' actions towards improving disclosure to children.

4.3.5. Respondents' views and perception on HIV/AIDS in general

Table 4.1 Respondents' views and perceptions on HIV/AIDS (n=100)

Serial Number	Statement	Strongly agree (%)	Agree (%)	Neutral/ Unsure (%)	Disagree (%)	Strongly Disagree (%)
3.1.	Most people with AIDS have only themselves to blame	19.6	23.9	14.1	28.3	14.1
3.2.	It is especially important to work with patients with AIDS in a caring manner	47.3	30.1	5.4	11.8	5.4
3.3.	HIV+ women should not have children	6.3	4.2	12.5	42.7	34.4
3.4.	A child born to an HIV positive woman who didn't take Nevirapine to prevent MTCT will be born HIV positive	11.2	25.5	20.4	24.5	18.4
3.5.	Children who get AIDS from their mothers are more deserving of treatment than people who get AIDS through sexual promiscuity	14.0	28.0	18.3	29.0	10.8
3.6.	Patients with AIDS should be treated with the same respect as any other patient	45.4	24.7	1.0	17.5	11.3
3.7.	You would like to do something to make life easier for children with AIDS	57.3	27.1	6.3	7.3	2.1
3.8.	You would do everything you could to give the best possible care to children with AIDS	65.3	27.4	4.2	3.2	0.0

As shown in the Table 4.1 (above), 43.5% of the respondents agreed with the statement that "Most people with AIDS have only themselves to blame", but

nonetheless, 77.4% agreed that it is especially important to work with patients with AIDS in a caring manner. The responses to the same questions were 45.6% and 96.7% respectively in research conducted in Tanzania to evaluate knowledge, attitude and practices of healthcare providers towards HIV positive patients (QAP 2007:9). More than seventy five percent (77.1%) disagreed with the statement that women living with HIV should not have children. More than a quarter (36.7%) believed that a child born to an HIV positive woman who has not taken *Nevirapine* will automatically be positive.

Forty two percent (42%) of the respondents believed that “Children who get AIDS from their mothers are more deserving of treatment than people who get AIDS through sexual promiscuity”. This is especially important when compared to the data obtained earlier; that only 59% believed a child born with HIV could live to the age of 10 or beyond. It may mean that 11 and 12 year olds with HIV may be considered by a more substantial percentage as less deserving of treatment than those who are less than 10 years old.

Seventy percent (70.1%) replied that “Patients with AIDS should be treated with the same respect as any other patient”. The majority, 84.4 % and 92.7%, respectively, replied that they would like to do something to make life easier for children with AIDS and would do everything they could to give the best possible care to children with AIDS.

4.3.6. Respondents’ views on disclosure to children of their HIV status

Table 4.2 Respondents' views on disclosure to children of their HIV status

Serial Number	Statement	Strongly agree (%)	Agree (%)	Neutral/ Unsure (%)	Disagree (%)	Strongly Disagree (%)
3.9.	Children have the right to know about any illness they have	36.7	37.8	8.2	14.3	3.1
3.10.	Children have the right to know their HIV status	31.2	34.4	14.0	16.1	4.3
3.11.	Children have the right to participate in decisions regarding their treatment	33.0	38.1	8.2	14.4	6.2
3.12.	Children who know their status have better adherence to ART than children who don't know their status	35.4	35.4	10.4	16.7	2.1
3.13.	Children who know their HIV status are more exposed to stigma than children who don't know their status	25.5	40.8	9.2	21.4	3.1
3.14.	I feel that parents shouldn't tell their children that they are HIV positive as the children will be depressed	30.8	34.0	11.3	19.6	4.1
3.15.	There are support groups children can access if they are aware of their status	27.6	49.0	14.3	5.1	4.1
3.16.	A child can find out his HIV positive status accidentally	9.6	30.9	11.7	37.2	10.6
3.17.	A child can find out his HIV positive status accidentally in a health centre	9.5	25.3	13.7	41.1	10.5
3.18.	It is better to tell children that they are HIV positive at one session to make it easier on them	11.2	26.5	16.3	27.6	18.4

More than seventy percent (74.5 %) of the respondents stated that children have a right to know about their illness. When it comes to specific HIV status knowledge the percentage is a bit smaller but still the majority believe that children have the right to know their HIV status (65.6%). But this seems to be in contradiction with the findings stated earlier on that the highest percentage of 38 respondents' state that disclosure should happen after 15 years of age. The majority (70.8 %) agreed to the statement that children will have better adherence if they know their status.

On the other hand, 66.3 % feel that children who know their status are more exposed to stigma and 64.8 % feel that parent should not tell children their HIV positive status as the children will be depressed. This perception is different from findings in other studies that state no depression or mental health problem has significantly increased due to disclosure. They were even found to be less depressed in one study ((Mellins et al. 2002: 101; Menon et al. 2007:349).

The majority (76.6 %) agree that if disclosed to, there are support groups children can access. Amongst the respondents, 40.5 % and 34.8 % agree to the statement that a child can find his status accidentally in general and in a health facility respectively. The possibility of accidental disclosure has also been described in different studies even in Health care facilities (Mighten 2009:14; Oberdorfer et al. 2006: 285; Pfaff 2004:35). 46 % disagree with the statement that disclosure in one session is the best. Domek also emphasizes the importance of gradual discussion rather than a single revelation (2006:1368). Disclosure is supposed to be a process that needs planning and a lot of discussion with parents (Pfaff 2004:46; Naeem-Sheik 2005:47).

4.3.7. Respondents' perception of their own involvement in the disclosure process

Table 4.3 Respondents' perception of their own involvement in the disclosure process

Serial Number	Statement	Strongly agree (%)	Agree (%)	Disagree (%)	Strongly Disagree (%)
4.1	I feel I have enough training to help a parent disclose HIV status to a child living with HIV	16.7	27.1	41.7	14.6
4.2.	I feel that taking part in HIV disclosure is stressful as it consists of giving bad news to children	20.6	52.6	22.7	4.1
4.3.	I feel that health care providers need to discuss the issue of disclosure of the child 's HIV status only if his parents/guardians asks advise about it	21.6	37.1	32	9.3
4.4.	I would try to avoid being part of disclosing to a child his/her HIV status	13.5	32.3	37.5	16.7
4.5.	I know of a guideline that I can access that can help me disclose his HIV status to a child	18.8	40.6	29.2	11.5
4.6.	If a child below 15 years ask me directly if he is HIV positive and his parent doesn't want him to know his status, I would lie to keep the secret safe.	15.6	46.9	20.8	16.7

According to Table 4.3 (above), the majority of the respondents (56.3 %) disagreed with the statement that they had sufficient training to disclose to a child, but 59.4% stated that they knew of a guideline they could access to help them disclose to a child his or her HIV positive status. The results differ from another study, in South Africa, in which 98% of the participants felt the need for formal recommendations or guidelines to help them and the parents to disclose (Myers et al. 2006:294). The majority (73.2%) stated that taking part in the disclosure process with a child was stressful, and 45.8% would avoid taking part in it. As quoted in an article by Fallowfield et al.:

In one US study of physicians working in five hospices, even if patients requested survival estimates, physicians said that they would provide frank disclosure only around 37% of the time, favouring instead either no disclosure or a conscious overestimate.

This illustrates that fear of communicating “bad news” could be a common challenge among healthcare providers (2004:313).

The majority (58.7%) will wait until the parents ask advice about the issue before discussing disclosure to the child. In a study in South Africa, the majority of caregivers believed that it was their responsibility to disclose, but only 25 % raised the issue with healthcare providers, leading to the conclusion that paediatric HIV disclosure needs to be given greater attention in clinical consultations (Moodley et al. 2006:202). More than half (62.5%) would lie to keep the secret safe if a child below 15 years asked them directly if he or she was HIV positive and the parent does not want him or her to know the status.

4.3.8. Additional comments by respondents

In the last section of the questionnaire, respondents were asked to feel free to give comments about any of the research’s main topics that they felt had not been addressed. A great majority left this section blank, or commented that the topic had been sufficiently covered. Amongst those who responded in this section, most emphasized the importance of the topic but stressed that training was needed in the area.

A few of the pertinent comments given were:

- “Nurses and any parents/caregiver avoid the disclosure of their HIV positive status to children but it should happen after appropriate training about disclosure.”
- “In my point of view, having children disclosed HIV status for better management is important and especially nurses participating in such cases

must be encouraged through many trainings and supporting guidelines must be addressed.”

- “There should be enough training on HIV/AIDS and any health professional has to know about it.”
- “I think a nurse is better to disclose than any other professional.”
- “Disclosing HIV status for pediatric children is very difficult so that collaborative [effort] should be done for the sake of good result.”
- “In fact children ... [have] the right to know their status in my opinion but at this time for children, they don't know their status. Even, there is no counselling method for children in our context. So we must do so much more.”
- “HIV positive children need disclosure of their HIV status accordingly based on the health status of the children and academic background including their parents'. Then the disclosure should be supported by follow up of the consequences of the disclosure.”
- “Disclosure issue very important and difficult but can make it easy way.... if child knows his status and know why he takes the drug, we can cut the question why?”
- “ ... I think and believe that depending on his/her maturity, this is important for treatment and control.”

One respondent stated the challenge as being one of children coming with grandparents and other relatives, and expressed fear that grandparents especially might not understand the disease well, or care for the child adequately. He then stated that “The parents living with HIV discuss the disclosure of their child HIV status with other parents living with HIV sharing knowledge about disclosure (the benefit of disclosure). All health care providers must have training to help a parent with disclosure HIV status”.

4.4 CONCLUSION

This chapter discussed the data analysis and interpretation of the findings of the research obtained through a self-administered questionnaire administered to 100 Nurses in six health centres in Addis Ababa, Ethiopia. Data was analysed using the Statistical Package for Social Sciences.

Chapter Five concludes the study, discusses its limitations, makes recommendations for improving disclosure to children of their HIV positive status and makes suggestions for further research.

CHAPTER 5

CONCLUSIONS AND RECOMMENDATIONS

5.1. INTRODUCTION

In the previous chapter, data obtained from the self-administered questionnaire gathered from 100 Nurses located in six health centres in Addis Ababa were analyzed, interpreted and presented graphically.

In this chapter, the research findings, limitations of the research and conclusions from the research findings are discussed. Recommendations in order to improve disclosure practice of their HIV status to HIV positive children based on the research findings, and also recommendations for future study areas on the topic are made.

5.2. RESEARCH DESIGN AND METHOD

The aim, design and methods of the research are briefly summarised here.

5.2.1. Aim of the study

Though deemed to be very important in many studies, disclosure of their HIV status to infected children has been found to be low in different countries. For instance, in a study in Ethiopia aimed at estimating the adherence of paediatric patients to ART, only 21% were aware of their HIV status (Biadgilign et al. 2008:1).

As nurses play an important role in the treatment and follow-up of HIV positive children, their perception with regards to the importance of and their role in disclosure of HIV status to children is important in supporting caregivers through the process of disclosure. Different studies mention the need for professional support to caregivers with regards to disclosure (Kouyoumdjian et al. 2005:285,

Lee et al. 2002 :2201, Moodley et al 2006 :201, Myer et al. 2006 :293, Oberdorfer et al 2006:283, the devastating...2006: 424).

The main purpose of this study was to explore and describe nurses' perception about the disclosure of their HIV positive status to children in different health centres in Addis Ababa.

5.2.2. Research objectives

The objectives of the study were to:

1. Explore and describe nurses' perceptions about the importance and implications of disclosing to children their HIV status
2. Explore and describe the perceptions of nurses about their role in disclosing to children their HIV status

5.2.3. Research methodology

A descriptive, exploratory non-experimental quantitative design was used to address the research problem in this case. The research population included all nurses working in health centres in Addis Ababa, Ethiopia. Convenience sampling was used and 100 nurses were recruited to participate in the research in six health centres. Consent for the research was first obtained from UNISA, the Addis Ababa Health Bureau and respective health centre administrations.

A theoretical self-administered questionnaire was prepared and pre-tested with some modifications following pre-testing. After signing an informed consent form, the nurses were asked to fill in the questionnaire by two trained nurse data collectors, and the data was analyzed using SPSS.

5.3. SUMMARY AND INTERPRETATION OF THE RESEARCH FINDINGS

A number of findings emerged from the findings, which are interpreted here.

5.3.1. Demographic Data

The majority of the participants in the research were male (54%). 57% of the respondents had a diploma in nursing, and 61% replied that they had received on the job training on HIV. Out of these, 25 (41%) confirmed that they had received specific training on paediatric HIV, and the same number (41%) that they had received specific training on how to disclose to Children living with HIV their HIV status. This means that only a quarter of all the respondents (25%) had received specific training in paediatric HIV, or how to disclose their status to HIV positive children.

Sixty one (61%) said that they had, or had previously had a Child Living with HIV virus as a patient. Though 39 % of the respondents had not had a Child Living with HIV as a patient this was not considered as an exclusion criterion since they might be involved in treatment and care of a Child Living with HIV at any time and it is also important to assess and address their perception about disclosure about children's HIV positive status. The majority of respondents (52%) had never discussed with parents about disclosing to the Child Living with HIV/AIDS his/her status. Forty one (41%) of the respondents had never helped parents disclose his/her status to a child. In another study in South Africa, 50% of different types of healthcare providers had the discussion and only 18% had been involved in disclosure (Myers et al. 2006:294).

5.3.2. Perception and views about HIV/AIDS and disclosure of their HIV/AIDS Status to Children

A number of perceptions were found on HIV/AIDS, and on disclosure. These two are discussed below.

5.3.2.1. Perceptions and views about HIV/AIDS

The majority (59%) of respondents believe that a child born with HIV virus can live up to 10 years, while 43.5% agreed with the statement that “Most people with AIDS have only themselves to blame”. The fact that 39% had no experience working with Children living with HIV and only 25% have received specific training on pediatric HIV could explain the fact that only 59% answered “Yes” to the question as to whether a child born with HIV virus can live to the age of 10 and beyond. However, 77.4% agreed that it was especially important to work with patients with AIDS in a caring manner. The responses to the same questions were 45.6% and 96.7% respectively, in research carried out in Tanzania (QAP 2007:9). More than seventy five percent (77.1 %) disagreed with the statement that women living with HIV should not have children. Forty two (42%) of the respondents believed that “Children who get AIDS from their mothers are more deserving of treatment than people who get AIDS through sexual promiscuity”. This is especially important when compared to the data obtained earlier that only 59% believe that a child born with HIV could live to the age of 10 and beyond. It may mean that 11 and 12 year olds with HIV may be considered to be less deserving of treatment by a more substantial percentage than those who are less than 10 years old. Assessing possible stigma in healthcare settings is especially important, as attitudes by nurses towards HIV patients will also affect their care and support, including disclosure of HIV status. In this case, there is some blame placed on patients living with HIV, and the assumption that children who received the disease from their mother are more deserving of treatment may lead to some reservations towards children assumed to have acquired HIV infection in another way. The majority i.e. 70.1%, 84.4% and 92.7% agreed, respectively, that “Patients with AIDS should be treated with the same respect as any other patient”, that they would like to do something to make life easier for children with AIDS and would do everything you could to give the best possible care to children with AIDS.

5.3.2.2. Perceptions and views about disclosure

The following perceptions were held on disclosure.

- Appropriate age for disclosure

Only 38 % of the respondents replied with a specific age or range to the question about the appropriate age to disclose to a child his/her HIV status, but amongst those who responded, 47.4% felt that disclosure should occur above 15 years of age. This is much higher than the age for disclosure suggested by healthcare providers in other studies (for instance, Myers et al. 2006:294; De Baets et al. 2008:483). This especially needs following up as in an *HIV/AIDS Behavioral Surveillance* survey in Ethiopia in 2002, it was stated that “Of those that had ever had sex, 40.6% had had sex at or before the age of 15. Amongst those who had ever had sex, more males than females (44.5% vs. 30%) were sexually active at or before the age of 15. The median age of sexual debut (first sex) among those who were sexually active was 16 years for both sexes” (Mitike et al. 2005:58). Waiting for the age of 15 and above to disclose HIV status could expose others to infection. However, the very low response rate for this specific question as opposed to an overall good response rate to other questions needs to be looked into. The question may need to be modified in future studies to elicit better response rates.

- Role of nurses in disclosure

As opposed to other studies that emphasize the role of caregivers in the disclosure process, the majority of respondents (63%) stated that parents and healthcare providers should disclose together. In previous studies, one involving healthcare providers and the other caregivers, the majority stated that parents/caregivers should be the ones to disclose (Moodley et al. 2006:202; Myers et al. 2006:294). Out of the 82% who responded that healthcare providers should disclose or be involved when disclosure to the child of HIV status takes place, 35(43%) replied that nurses should be involved, 24 (29.6%) paediatricians, 2 (2.5%) medical doctors, and 20 (24.7%) others. The answer to others was specified to be all of them or any if trained psychologists, counsellors and a combination of nurse and paediatricians. It is important to emphasize the important role of nurses in the disclosure process,

and the assumption by more than a quarter that paediatricians need to be involved should be addressed, due to feasibility.

- Importance of disclosure

The majority (65.6 %) of the participants responded that children have the right to know their HIV status, and 70.8% believed that children will have better adherence if disclosed to. This shows the importance of the issue, though the age of disclosure discussed earlier remains an issue. At the same time, the majority (66.3%) felt that children who know their status were more exposed to stigma, and 64.8% felt that parent should not tell their children their HIV positive status as the children will be depressed though different studies stated that disclosure will not lead to depression or mental health problems by itself (Mellins et al 2002: 101; Menon et al 2007:349).

The majority (56.3%) of participants disagree to the statement that they have enough training to help parents disclose to a child but 59.4 % states they at least know of a guideline that can help them disclose to children their HIV status. Most (73.2%) felt that taking part in a disclosure process was stressful, and 45.8% would avoid being part of it. That the majority (58.7%) would wait until the parents asked advice about the issue before discussing disclosure to the child, rather than initiate disclosure, needs to be addressed, as in some studies, discussion with healthcare providers is one of the factors that would make disclosure happen. This is especially important since even though parents want to disclose, they will need support from healthcare providers to support them (Moodley et al. 2006:202; Myer 2006: 293; Oberdorfer et al. 2006:283).

- Disclosure process

46% disagreed with the statement that disclosure in one session is the best. Domek also emphasizes the importance of gradual discussion rather than a

single revelation (2006:1368). Disclosure is supposed to be a process that needs planning and much discussion with parents (Naeem-Sheik 2005:47; Pfaff 2004:46).

5.4. CONCLUSIONS

The majority of the participants stated that children have the right to know about their HIV status and to participate in their own treatment, and that disclosure is important for adherence. They give the highest responsibility of disclosure to Parents/caregivers and healthcare providers (more importantly nurses), but more than a quarter believed that paediatricians should be involved. Most perceived disclosing their HIV status to children was stressful and some would want to avoid being part of it. This could be because 56.3% did not believe that they had received sufficient training to be able to disclose, and only a quarter of the respondents had received training specifically on paediatric HIV in general or disclosing to children in particular.

5.5. RECOMMENDATIONS

The following recommendations can be made based on the research findings:

5.5.1. Recommendations for Nursing practice

- In order to improve the care and support of children living with HIV virus, training in paediatric HIV care, including disclosure needs to be more widely available. The training can be included in already existing programmes, but designed to reach a wider audience.
- Internalization of the already existing guidelines would help improve the practice of disclosure of HIV status to children. This could be done through training but also coaching and mentoring

- Emphasis should be placed on the importance of the role of nurses in paediatric HIV care and disclosure, and they should be empowered to act accordingly rather than to expect medical doctors or paediatricians to take the lead. This can be done through provision of required skill and supportive supervision.
- The issue of stigma in general, especially in healthcare settings, still needs to be addressed through raising awareness of health workers about the detrimental effect of stigma and discrimination in prevention and control of HIV but also about their role in reducing stigma in the health care settings and community.
- That gradual disclosure, based on the child maturity level, will not result in depression of the child needs to be stressed.
- Parents/caregivers need to be empowered and supported so that they can be the ones to disclose to their children. Healthcare providers need to be more proactive in discussing issue of disclosure with parents/caregivers at a younger age, depending on the maturity level of the child, rather than waiting for parents to ask for advice.

5.5.2. Recommendations for future research

More research is needed to address the issue of disclosure of their HIV status to children:

- This research explored the nurses' perception on disclosure, the perspective of parents/caregivers and also that of children/adolescents with regards to the issue to be explored in Addis Ababa, Ethiopia.
- The research can also be conducted amongst other professionals, e.g. medical doctors and paediatricians, to assess perception on disclosure of their HIV status to children and assess the different understandings of the importance and role.

- Research needs to be conducted into different regions of Ethiopia, so as to assess and address the different cultural challenges to child rights, especially disclosure of HIV status in different contexts.

5.6. LIMITATIONS OF THE STUDY

The study has a number of limitations:

- Though six of the 24 health centres (25%) available at the time of the research design were sampled, the results cannot be applied to the rest of the country. However, there is no reason that the findings could not be generalized to other nurses in similar areas.
- The information gathered relied on self report of the research participants and though all care was taken to ensure confidentiality, the need for social acceptability affecting some of the responses cannot be fully ruled out.

5.7. CONCLUDING REMARKS

This chapter provided a summary of the study, its limitations, conclusions and recommendations for future intervention.

This study is crucial because as children living with HIV live longer in the era of HIV/AIDS, disclosure of their HIV status is an important part of the care and support that they receive. This has an impact on their quality of life, but is also important to prevent them transmitting the virus to others, as they are unaware of their status. As nurses play an important role in the care of children living with HIV virus, assessing their perception is important.

LIST OF REFERENCES

- Abadia-Barrero, CE & LaRusso, MD. 2006. The Disclosure Model versus a Developmental Illness Experience Model for Children and Adolescents Living with HIV/AIDS in São Paulo, Brazil. *AIDS Patient Care and STDs* Volume 20, Number 1, pp36-43
- Addis Ababa City administration Health Bureau. 2007. Available online at http://www.addisababacity.gov.et/index.php?option=com_content&view=article&id=108&Itemid=105
- Aga, F, Kylvä, J & Nikkonen, M. 2009. Sociocultural factors influencing HIV/AIDS caregiving in Addis Ababa, Ethiopia. *Nursing and Health Sciences* (2009), 11, 244–251
- Aiges, J. 2008. Factors related to caregivers disclosure of the diagnosis to HIV infected children. Doctor of Social work. Dissertation. Adelphi University School of social work. Garden City, NY.
- American Academy of Pediatrics (AAP) Committee on Pediatric AIDS. 1999. Disclosure of Illness Status to Children and Adolescents with HIV Infection. *Pediatrics* 1999; 103; 164-166
- Arun, S, Singh, AK, Lodha, R& Kabra SK. 2006. Disclosure of the HIV infection status in children. *AIDS And Behavior*. Jul 2006; Vol. 10 (4 Suppl), pp. S85-93
- Arun, S, Singh, AK, Lodha, R& Kabra SK.2009. Disclosure of the HIV infection status in children. *Indian Journal Of Pediatrics* Vol. 76 (8), pp. 805-8. *Date of Electronic Publication: 2009 Sep 04.*
- Babbie, E. 1998. *Survey of research methods. Second edition.* California: Wadsworth Publishing Company.
- Babbie, ER & Mouton, J. 2007. *The practice of social research. 11th edition.* Cape Town: Oxford University Press

- Bachanas, PJ, Kullgren, KA, Schwartz, KS, Lanier, B, McDaniel, JS, Smith, J & Nesheim, S. 2001. Predictors of Psychological Adjustment in School-Age Children Infected With HIV. *Journal of Pediatric Psychology*, Vol. 26, No. 6 pp. 343-352
- Batavia, M. 2001. *Clinical research for health professionals: A user Friendly guide*. USA: Butterworth Heinemann Publishing
- Battles, HB & Wiener, L. 2002. From Adolescence Through Young Adulthood: Psychosocial Adjustment Associated With Long-Term Survival of HIV. *Journal of Adolescent Health* 2002;30:161–168
- Berrien, VM, Salazar, J, Reynolds, E & McKay K. 2004. Adherence to Antiretroviral Therapy in HIV-Infected Pediatric Patients Improves with Home-Based Intensive Nursing Intervention. *AIDS Patient Care and STDs* Volume 18, Number 6
- Biadgilign, S, Deribew, A, Amberbir, A and Deribe, K .2008. Adherence to highly active antiretroviral therapy and its correlates among HIV infected pediatric patients in Ethiopia. *BMC Pediatrics*. 8 :53 available online at <http://www.biomedcentral.com/1471-2431/8/53>
- Blasini, I, Chantry, C, Cruz, C, Ortiz, L, Salabarria, I & Scalley N. 1998. Disclosure model for pediatric patients living with HIV. International Conference on AIDS. Int Conf AIDS. 1998; 12: 233 (abstract no. 14255).
- Blasini, I, Chantry, C, Cruz, C, Ortiz, L, Salabarría, I, Scalley, N, Matos, B, Febo, I & Díaz C. 2004. Disclosure model for pediatric patients living with HIV in Puerto Rico: design, implementation, and evaluation. *J Dev Behav Pediatr*. 25(3):181-9
- Boon-Yasidhi, V, Kottapat, U, Durier, Y, Plipat, N, Phongsamart, W, Chokeyhaibulkit, K & Vanprapar N. 2005. Diagnosis disclosure in HIV-infected Thai children. *J Med Assoc Thai*.; 88 Suppl 8:S100-5.

- Bowling, A. 2009. *Research methods in Health: Investigating health and health services. Third edition.* Berkshire: Open University Press
- Bowling A. & Ebrahim S (eds) 2005. *Handbook of health research methods. Investigation, measurement and analysis.* Berkshire: Open University Press
- Brackis-Cott, E, Mellins, CA, Abrams, E, Reval, T & Dolezal, C.2003. Pediatric HIV Medication Adherence: The Views of Medical Providers From Two Primary Care Programs. *J Pediatr Health Care* 17,252-260.
- Burns N & Groove SK. 2009. *The Practice of Nursing research. Appraisal, Synthesis and generation of evidence.* Sixth edition. Missouri: Saunders Elsevier
- Butler AM., Williams PL, Howland LC, Storm D, Hutton N, Seage GR, III and for the Pediatric AIDS Clinical Trials Group 219C Study Team. 2009. Impact of Disclosure of HIV Infection on Health-Related Quality of Life among Children and Adolescents with HIV Infection. *Pediatrics* 123; 935-943
- Butler,AM, Williams,PL, Howland,LC, Storm,D, Hutton,N,. Seage,GR III and for the Pediatric AIDS Clinical Trials Group 219C Study Team. Impact of Disclosure of HIV Infection on Health-Related Quality of Life Among Children and Adolescents With HIV Infection. *Pediatrics* 2009;123;935-943 available online at <http://www.pediatrics.org/cgi/content/full/123/3/935>
- Cambridge Advanced Learner Dictionary. 2003. Cambridge University Press
- Chinouya, M.2006. Telling children about HIV in transnational African families: tensions about rights.Diversity in Health and Social Care, Volume 3, Number 1, pp. 7-17(11)
- Collins English Dictionary. 1991. 3rd Edition. Glasgow: HarperCollins
- Convention on the rights of the Child, 1990
- Corneli , A, Vaz, L, Dulyx, J, Omba, S, Rennie, S& Behets, F.2009. The role of disclosure in relation to assent to participate in HIV-related research among

- HIV-infected youth: a formative study. *Journal Of The International AIDS Society* Vol. 12 (1), pp. 17
- Cramer, D.2003. *Advanced Quantitative data analysis*. Maidenhead. Philadelphia: Open University Press.
- Creswell, JW. 2009. *Research design: Qualitative, quantitative and mixed Methods approach, third edition*. Los Angeles: Sage publications
- De Baets, AJ, Sifovo, S, Parsons, R & Pazvakavambwa, IE.2008. HIV disclosure and discussions about grief with Shona children: A comparison between health care workers and community members in Eastern Zimbabwe. *Social Science & Medicine* 66 (2008) 479–491
- Deacon, H & Stephney, I. 2005. HIV/AIDS, stigma and children: A literature Review, HSRC Press, Cape town, South Africa
- DeMatteo, D, Harrison, C, Arneson, C, Salter Goldie, R, Lefebvre, A, Read, E & King SM. 2002. Disclosing HIV/AIDS to children: the paths families take to truth-telling. *Psychology, Health & Medicine*, Vol 7 No 3, pp 339-356.
- Domek, GJ. 2006. Social consequences of antiretroviral therapy: preparing for the unexpected futures of HIV-positive children. *Lancet* 367: 1367- 69.
- Fallowfield, L & Jenkins, V. 2004. Communicating sad, bad, and difficult news in medicine. *Lancet* 2004; 363: 312–19.
- Federal Democratic Republic of Ethiopia Ministry of Health Planning and Programmatic Department. 2008. *Health and Health related indicators*.
- Federal HIV/AIDS Prevention and Control Office, Federal Ministry of Health (FMOH). July 2008. Guidelines for Paediatric HIV/AIDS Care and Treatment in Ethiopia.
- Federal Negarit Gazetta of the Federal Democratic Republic of Ethiopia. *The Revised Family Code*, Addis Ababa 4th Day of July, 2000.

Federal Ministry of Health/ National HIV/AIDS Prevention and control office. AIDS in Ethiopia: Sixth Report.

Ferris ,M, Burau, K, Schweitzer, AM, Mihale , S, Murray, N, Preda, A, Ross, M & Kline, M. 2007. The influence of disclosure of HIV diagnosis on time to disease progression in a cohort of Romanian children and teens. *AIDS Care*, October 2007; 19(9): 1088-1094

Gaughan, DM, Hughes, MD, Oleske, JM, Malee ,K, Gore, CA, Nachman, S & for the Pediatric AIDS Clinical trials Group 219C team. 2004. Psychiatric Hospitalizations Among Children and Youths With Human Immunodeficiency Virus Infection. *Pediatrics* 113: e544-e551.

Giacomet, V, Albano, F, Starace, F, de Franciscis , A, Giaquinto, C, Castelli Gattinara , G, Bruzzese, E, Gabiano, C, Galli, L, Viganò, A, Caselli D & Guarino, A. 2003. Adherence to antiretroviral therapy and its determinants in children with human immunodeficiency virus infection: a multicentre, national study. *Acta Paediatr* 92: 1398-1402. Online Publication Date: 01 December 2003

Gibb ,DM, Goodall , RL, Giacomet, V, McGee, L, Compagnucci, A & Lyall ,H, Paediatric European Network for Treatment of AIDS Steering Committee. 2003. Adherence to prescribed antiretroviral therapy in human immunodeficiency virus-infected children in the PENTA 5 trial. *The Pediatric infectious disease journal* Vol 22, Issue 1, pp 56-62.

Grosz, J. 2002. " Invisible Caregivers: Older Adults Raising Children in the Wake of HIV/AIDS, ed. Daphne Joslin (New York: Columbia University Press)

Hammami, N, Nöstlinger, C, Hoérée ,T, Lefèvre, P, Jonckheer ,T & Kolsteren, P. Integrating Adherence to Highly Active Antiretroviral Therapy Into Children's Daily Lives: A Qualitative Study. *Pediatrics* 2004;114:e591-e597

Horwood, C, Voce, A, Vermaak, K, Rollins, N & Qazi, S. 2010. Routine checks for HIV in children attending primary health care facilities in South Africa: Attitudes of nurses and child caregivers. *Social Science & Medicine* 70 ,313–320

- Instone , SL. 2000. Perceptions of Children With HIV Infection When Not Told for So Long: Implications for Diagnosis Disclosure. *J Pediatr Health Care*. 14,235-243.
- Ionescu, C. 2006. Romanian parents keep HIV a secret from infected children. World Report. www.thelancet.com Vol 367 May 13, 2006
- Kmita G & Baranska M. 2004. The process of disclosure of an HIV/AIDS problem in the family to children--an exploratory study *Medycyna Wieku Rozwojowego [Med Wieku Rozwoj]* . English Abstract. Jul-Sep; Vol. 8 (3 Pt 1), pp. 623
- Kothari C.R. 2004. *Research Methodology; Methods & Techniques*. Second edition. New Age International limited Publishers, New Delhi.
- Kouyoumdjian F G., Meyers T& Mtshizana S.2005. Barriers to Disclosure to Children with HIV. *Journal of Tropical Pediatrics* Vol. 51(5):285-287
- Ledlie, SW. 2001. The Psychosocial Issues of Children with Perinatally Acquired HIV Disease Becoming Adolescents: A Growing Challenge for Providers. *AIDS Patient Care and STDs* Volume 15, Number 5,pp 231-236
- Lee, MB& Rotheram-Borus, MJ.2002. Parents' disclosure of HIV to their children. [EPIDEMIOLOGY & SOCIAL]. *AIDS* 16(16):2201-2207
- Lesch, A, Swartz, L, Kagee, A, Moodley, K, Kafaar, Z, Myer, L& Cotton,M. 2007. Paediatric HIV/AIDS disclosure: towards a developmental and process-oriented approach. *AIDS Care*, 19(6): 811-816
- Lester, P, Chesney, M, Cooke, M, Whalley, P, Perez, B, Petru, A, Dorenbaum, A & Wara, D. 2002. Diagnostic Disclosure to HIV-Infected Children: How Parents Decide When and What to Tell. *Clinical Child Psychology and Psychiatry*. Vol. 7(1): 85–99
- Lester, P, Chesney, M, Cooke, M, Weiss, R, Whalley, P, Perez, B, Glidden, D, Petru, A, Dorenbaum, A & Wara, D.2002. When the Time Comes To Talk About HIV: Factors Associated With Diagnostic Disclosure and Emotional

- Distress in HIV-Infected Children. *Journal of Acquired Immune Deficiency Syndromes* 31:309–317
- Lwin, R & Melvin, D. 2001. Annotation: Paediatric HIV Infection. *Journal of Child Psychology and Psychiatry*. Vol. 42, No. 4, pp. 427-438
- Marhefka, SL, Tepper, VJ, Brown, JL & Farley, JJ. 2006. Caregiver Psychosocial Characteristics and Children's Adherence to Antiretroviral Therapy. *AIDS Patient Care and STDs* Volume 20, Number 6, pp 429-437
- Martin, S, Elliott-DeSorbo ,DK, Wolters, PL, Toledo-Tamula, MA, Roby, G, Zeichner, S& Wood LV.2007. Patient, caregiver and regimen characteristics associated with adherence to highly active antiretroviral therapy among HIV-infected children and adolescents. *Pediatr Infect Dis J*. 26(1):61-7.
- Mellins, CA, Brackis-Cott, E, Dolezal, C, Richards, A, Nicholas, SW & Abrams EJ. 2002. Patterns of HIV Status Disclosure to Perinatally HIV-Infected Children and Subsequent Mental Health Outcomes. *Clinical Child Psychology and Psychiatry* Vol. 7(1): 101–114
- Mellins, CA, Brackis-Cott, E, Dolezal, C& Abrams, E J. 2004. The Role of Psychosocial and Family Factors in Adherence to Antiretroviral Treatment in Human Immunodeficiency Virus-Infected Children. *The Pediatric Infectious Disease Journal* Volume 23(11) pp 1035-1041
- Menon, A, Glazebrook, C, Campain, N & Ngoma, M.2007. Mental Health and Disclosure of HIV Status in Zambian Adolescents With HIV Infection Implications for Peer-Support Programs. *J Acquir Immune Defic Syndr* ;46:349–354
- Merzel, C, VanDevanter, N & Irvine, M. 2008. Adherence to Antiretroviral Therapy among Older Children and Adolescents with HIV: A Qualitative Study of Psychosocial Contexts. *AIDS Patient Care and STDs* Volume 22, Number 12, pp 977-987

- Mialky, E, Vagnoni, J & Rutstein, R. 2001. School-Age Children with Perinatally Acquired HIV Infection: Medical and Psychosocial Issues in a Philadelphia Cohort. *AIDS Patient Care and STDs* Volume 15, Number 11, pp 575-579
- Mighten, J. 2009. Confidentiality and Children with HIV. *Pediatric Nursing*. Vol 21, No 5, pp 14-18.
- Missmer, SA, Spiegelman, D, Gorbach, SL & Miller TL. 2000. Predictors of Change in the Functional Status of Children With Human Immunodeficiency Virus Infection. *Pediatrics*. 106; e24 1-7
- Mitike, G, Tesfaye, M, Ayele, R, Gadissa, T, Enqusillasie, F, Lemma, W, Berhane, F, Yigezu, B and Woldu, A. 2005. HIV/AIDS *Behavioral* Surveillance Survey (BSS). Ethiopia 2005 Round Two.
- Moodley K., Myer L, Michaels D & Cotton M. 2006. Paediatric HIV disclosure in South Africa – caregivers’ perspectives on discussing HIV with infected children. *South African Medical Journal*, Vol. 96, No. 3: 201-204
- Mouton, J. 1996. *Understanding social research*. Pretoria : Van Schaik Publishers
- Myer L, Moodley K, Hendricks F and Cotton M. 2006. Healthcare Providers’ Perspectives on Discussing HIV Status with Infected Children. *Journal of Tropical Pediatrics* Vol. 52, No. 4: 293-295
- Naeem-Sheik, A & Gray, G. November 2005. HIV disclosure in children. *The Southern African Journal of HIV Medicine*: 46-48
- Nam, SL, Fielding, K, Avalos, A, Gaolathe, T, Dickinson, D & Geissler, PW. 2009. Discussing matters of sexual health with children: what issues relating to disclosure of parental HIV status reveal. *AIDS Care* Vol. 21 (3), pp. 389-95.
- Nehring, WM, Lashley, FR & Malm, K. 2000. Disclosing the Diagnosis of pediatric HIV Infection: Mothers’ Views.. *J S P N* Vol. 5, No. 1, pp 5-13
- Nöstingler, C, Jonckheer, T, De Belder, E, Van Wijngaerden, E, Wylock C, Pelgrom, J & Colebunders R. 2004. Families affected by HIV: parents’ and

- children's characteristics and disclosure to the children .*AIDS Care* Vol. 16, No. 5, pp. 641-648
- Nöstlinger, C& Colebunders, R. 2006. Informing children of their HIV status. *www.thelancet.com* Vol 368 August 5, 2006: 447
- Nunnaly, J. (1978). Psychometric theory. New York: McGraw-Hill.
- Oberdorfer, A, Akarathum, N, Charmsil, C, Louthrenoo , O, Tangsongsakkul, T, Puthanakit, T, Sirisanthana, V& Sirisanthana T . 2004. Disclosure patterns of HIV/AIDS status among school children receiving HAART: A Thai situation. Int Conf AIDS 2004 Jul 11-16; 15:(abstract no. TuPeB4417)
- Oberdorfer, P, Puthanakit, T, Louthrenoo, O, Charmsil C, Sirisanthana V & Sirisanthana T. 2006. Disclosure of HIV/AIDS diagnosis to HIV-infected children in Thailand. *Journal of Paediatrics and Child Health* **42** (2006) 283–288
- Ostrom, RA, Serovich, JM, Lim, JY & Mason, TL.2006. The role of stigma in reasons for HIV disclosure and non-disclosure to children. *AIDS Care* 18(1): 60–65.
- Oxford Advanced Learner's Dictionary of Current English. 2000. Oxford: Oxford University Press
- Pfaff, C. 2004. Telling a child he is HIV positive. *SA Fam Pract*;46(9): 35-40
- Polit, BL & Beck, CT. (Eds) 2004. *Nursing research: Principles and methods*, 7th edition, Philadelphia: JB Lippincott
- Polit, DE & Beck CT. 2008. *Nursing research; generating and assessing evidence for nursing practice*.8th edition. Philadelphia: JB Lippincott
- Pontali, E . May-June 2005. Facilitating adherence to highly active antiretroviral therapy in children with HIV infection: what are the issues and what can be done? (Current Opinion). *Pediatric Drugs* 7.3 p137 (13)

- Prendergast, A, Tudor-Williams, G, Jeena, P, Burchett, S & Goulder, P. International perspectives, progress, and future challenges of paediatric HIV infection. *Lancet*; 370: 68–80
- Punpanich, W. 2009. Development of a Culturally Appropriate Health-Related Quality of Life Measure for HIV-infected Children in Thailand. Doctor of Philosophy in epidemiology. University of California, Los Angeles.
- QAP Tanzania HIV Stigma Study Team. 2007. Evaluation of Knowledge, Attitudes, and Practices of Health Care Providers toward HIV-positive Patients in Tanzania. *Operations Research Results*. Published for the U.S. Agency for International Development (USAID) by University Research Co., LLC, Bethesda, MD.
- Reuter, H. 2006. *Editorial: HIV care beyond garlic, beetroot and olive oil.* *updAIDS in SA Family Practice*. *SA Fam Pract* ;48(8):55-60
- Rwemisisi J, Wolff B, Coutinho A, Grosskurth H & Whitworth J. 2008. 'What if they ask how I got it?' Dilemmas of disclosing parental HIV status and testing children for HIV in Uganda, *Health Policy and Planning* 2008;23:36–42
- Seyoum, E, Mekonen, Y, Kassa, A, Eltom, A, Damitew, T, Lera, M, Felema B & Assefa Y. 2009. ART Scale up in Ethiopia: Successes and challenges. Ethiopia HIV/AIDS Prevention and Control Office (HAPCO) plan, monitoring & Evaluation Directorate.
- Simoni, JM, Montgomery, A, martin, E, New, M, Demas, PA & Rana ,S. 2007. Adherence to antiretroviral Therapy for Pediatric HIV infection: A qualitative systematic Review With recommendations for Research and Clinical management. *Pediatrics* 119: e1371-e1383; originally published may 28, 2007
- Steele, RG, Nelson, TD & Cole, BP. 2007. Psychosocial functioning of children with AIDS and HIV infection: review of the literature from a socioecological framework. *Journal Of Developmental And Behavioral Pediatrics* Vol. 28 (1), pp. 58-69F

Sutcliff, CG, van Dijk, JH, Bolton, C, Persaud, D & Moss WJ. 2008. Effectiveness of antiretroviral therapy among HIV-infected children in sub-Saharan Africa. *The Lancet Infectious Diseases*, Volume 8, Issue 8, Pages 477 – 489

Suzuki, C, Mishra, V, Govindasamy, P, Hong, R & Gu, Y.2008. Changes in HIV-Related Knowledge and Behavior in Ethiopia, 2000-2005: Further Analysis of the 2000 and 2005 Ethiopia Demographic and Health Surveys. Calverton, Maryland, USA: Macro International Inc.

Teenagers HIV and AIDS: Insights from youths living with the virus. 2006. Praeger Publishers, 88 Post Road West, Westport.

Terre Blanche, M, Durrheim, K & Painter, D. 2006. *Research in Practice: applied methods for the social sciences*.2nd edition. Cape Town: University of Cape Town Press

The American Heritage® Stedman's Medical Dictionary. Retrieved October 09, 2011, from Dictionary.com website: <http://dictionary.reference.com/browse/caregiver>

The devastating effects of HIV/AIDS on children.2006. *The Lancet*. 368:424

Thorne, C, Newell, ML, Botet, FA; Bohlin, AB, Ferrazin, A, Giaquinto, C, de José Gomez, I, Mok, JYQ, Mur, A & Peltier, A, European Collaborative Study. 2002.Older Children and Adolescents Surviving With Vertically Acquired HIV Infection. *Journal of Acquired Immune Deficiency Syndromes* Volume 29 - Issue 4 - pp 396-401

UNAIDS. 2008. Report on the global epidemic update.

UNAIDS. 2009. AIDS epidemic update

- Vaz, L, Corneli, A, Dulyx, J, Rennie, S, Omba, S, Kitetele, F, the AD Research Group, Behet, F. 2008. The process of HIV status disclosure to HIV-positive youth in Kinshasa, Democratic Republic of the Congo. *AIDS Care*. Vol. 20, No. 7, 842- 852
- Vreeman ,RC, Wiehe ,SE, Pearce, EC & Nyandiko WM. 2008. A systematic review of pediatric adherence to antiretroviral therapy in low- and middle-income countries. *Pediatr Infect Dis J*. 2008 Aug;27(8):686-91
- Wariua ,G, Wamalwa ,D, Obimbo, E, Farquhar ,C & John-Stewart,G. Disclosure of HIV diagnosis to HIV-infected children in Nairobi, Kenya – Abstract
- Waugh S. 2003. Parental views on disclosure of diagnosis to their HIV-positive children. *AIDS Care*, Volume 15, No 2, p169-176.
- Webster Dictionary available at: <http://www.webster-dictionary.net/definition/Disclosure>
- Weigel, R, Makwiza, I, Nyirenda, J, Chiunguzeni, D , Phiri, S& Theobald, S. 2009. Supporting children to adhere to anti-retroviral therapy in urban Malawi: multi method insights. *BMC Pediatrics* 2009, 9:45 available online at <http://www.biomedcentral.com/1471-2431/9/45>
- Wiener, LS & Battles, HB. 2006. Untangling the web: A close look at diagnosis disclosure among HIV infected adolescents. *Journal of Adolescent Health* 38 (2006) 307–309
- Wiener, L, Mellins, CA, Marhefka, S & Battles, HB. 2007. Disclosure of an HIV diagnosis to Children: History, Current Research, and Future Directions. *J Dev Behav Pediatr*. 2007 April; 28(2): 155–166.
- Williams, PL, Storm, D, Montepiedra, G, Nichols, S, Kammerer, B, Sirois, PA, Farley, J & Malee, K and for the PACTG 219C Team. 2006. Predictors of Adherence to Antiretroviral Medications in Children and Adolescents With HIV Infection. *Pediatrics* 2006:118;e1745-e1757

**UNIVERSITY OF SOUTH AFRICA
Health Studies Higher Degrees Committee
College of Human Sciences
ETHICAL CLEARANCE CERTIFICATE**

HS HDC/47/2012

Date of meeting: 7 May 2012 Student No: 3570-088-2

Project Title: Perceptions of nurses on disclosure of their HIV positive status to children in Addis Ababa, Ethiopia

Researcher: Dr Yenealem Tadesse Woldemariam

Degree: Masters in Public Health Code: MPHPR09

Supervisor: Prof SP Human
Qualification: D Cur (Community Health)
Joint Supervisor: -

DECISION OF COMMITTEE

Approved

Conditionally Approved

E Potgieter
Prof E Potgieter
CHAIRPERSON: HEALTH STUDIES HIGHER DEGREES COMMITTEE

Dr MM Moleki
Dr MM Moleki
ACTING ACADEMIC CHAIRPERSON: DEPARTMENT OF HEALTH STUDIES

PLEASE QUOTE THE PROJECT NUMBER IN ALL ENQUIRES

September 28, 2010

UNISA-ET/KA/ST/29/28-09-10

Addis Ababa City Administration Health Bureau

Addis Ababa

Dear Madam/Sir,

This is to certify that Dr. Yenealem Tadesse WoldeMariam (student number 35700882) is a Master of Public Health student at the University of South Africa (UNISA). Currently, she has finished her Master's proposal entitled "Disclosure of their HIV Positive Status to Children in Addis Ababa, Ethiopia: Nurses' Perception." She has now intended to collect data in some Health Centres in Addis Ababa.

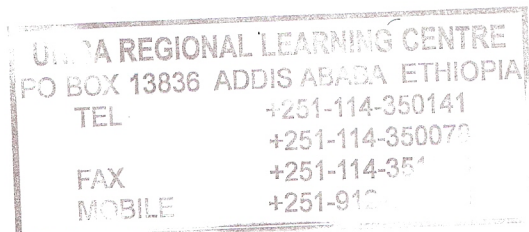
This is therefore to ask your esteemed bureau to assist her endeavour in every possible way.

Thanking you in advance for your cooperation,


Aberra, Tsige

Deputy Director – Facilitation of Learning and ICT Support

UNISA – Ethiopia Regional Learning Centre



ETHICAL REVIEW COMMITTEE

ETHICAL REVIEW FORM

Tel: + 251 115 513911

P.O. Box 30738

Fax No. +251 115 515689

Research Project: *“Disclosure of their HIV Positive status to children in Addis Ababa, Ethiopia; Nurse’s Perception”*

Principal Investigator: Yenealem Tadesse

CRITERIA/ITEM	RATING
1. consent form	<input checked="" type="checkbox"/> Yes
2. Does the consent contain all the necessary information that the subject should be aware of?	<input type="checkbox"/> Requires revision <input type="checkbox"/> No <input type="checkbox"/> Not applicable <input type="checkbox"/> Not attached
3. Are the objectives of the study clearly stated?	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No
4. Are provisions to overcome risks well described and accepted? a. Justice b. Beneficence c. Respect for a person	<input type="checkbox"/> Yes <input type="checkbox"/> Not well described <input type="checkbox"/> No <input checked="" type="checkbox"/> Not applicable
5. Are the safety procedures in the use of vaccines, drugs and other biological products acceptable?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input checked="" type="checkbox"/> Not applicable
6. Are the procedures to keep confidentiality well described?	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable
7. Are the proposed researchers competent to carry out the study in a scientifically sound way?	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable <input type="checkbox"/> Unable to assess
8. Does it have material transfer agreement?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input checked="" type="checkbox"/> Not applicable
9. Recommendation	<input checked="" type="checkbox"/> Approved <input type="checkbox"/> Approved on condition <input type="checkbox"/> Not approved
10. Remarks	

Ethical Clearance Committee Members:

Name

Signature

Name

Signature

1. Ato Alemu Haile mariam
2. Dr. Addis Akalu
3. Ato Ezra Muluneh





ቁጥር 2/2/1m/1751/227

ቀን 5/2/2003

የኢትዮጵያ ጤና ሚኒስቴር ሪፐብሊክ
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The Addis Ababa City Administration
Health Bureau

- ለ ልደታ ጤና ጣቢያ
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አዲስ አበባ

ጉዳይ የጥናት ትብብር ስለመጠየቅ

በ UNISA የህብረተሰብ ጤና ሳይንስ ተማሪ የሆኑት የኔግላም ታደሰ በ Disclosure of their HIV Positive status to children in Addis Ababa, Ethiopia; Nurse's Perception በሚል ርዕስ ያቀረቡት የጥናት ሰነድ ለአዲስ አበባ ጤና ቢሮ ኤተካል ኮሚቴ ቀርቦ የታየና የጸደቀ መሆኑን እያሳወቅን አመልካቹ ለጥናታቸው የሚያስፈልገውን መረጃ ማግኘት እንዲችሉ ትብብር እንዲደረግላቸው እንጠይቃለን።



ከሀላግምታ ጋር

አዲስ አበባ (ዶር)
የኤተካል ኮሚቴ ጸሃፊ

ግልጻጭ :-

- ለ የኔግላም ታደሰ
- አዲስ አበባ
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TRUST COMPUTER & TRANSLATION OFFICE

Header Seal

The Addis Ababa City Administration Health Bureau

Ref: 2/2/M/1751/227

Date: 15/10/2010

To: Lideta Health Center
Beletshachew Health Center
Teklehimanot Health Center
Nifas Silk Number 1 Health Center
Nifas Silk Number 2 Health Center
Kirkos Health Center
Meshwalekia Nifas Health Center

Addis Ababa

Subject: Request for Cooperation

This is to notify that the research proposal "Disclosure of their HIV Positive status to children in Addis Ababa, Ethiopia; Nurse's Perception" submitted by Yenealem Tadesse, student of Public Health at UNISA has been seen and approved by the Addis Ababa Health Bureau Ethical Committee. Hence, this is to kindly request for cooperation to be made for the applicant to be able to obtain the necessary information for her research.

Regards

Signed & Sealed

Addis Akalu (Dr.)

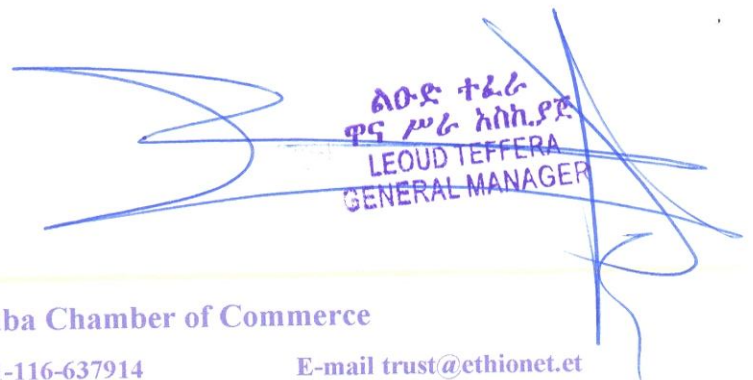
Secretary, Ethical Committee

CC

To: Yenealem Tadesse

To: Ethical Committee

Addis Ababa


ለዐድ ተፈሪ
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LEOUD TEFFERA
GENERAL MANAGER



Tel.

0911-609028/0911-951631

Trust Computer & Translation office

Fax. 251-116-637914

E-mail trust@ethionet.et

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QUESTIONNAIRE to ASSESS THE PERCEPTION OF NURSES
ON DISCLOSURE OF THEIR HIV POSITIVE STATUS TO CHILDREN

SECTION 1: DEMOGRAPHIC DATA

Please tick the relevant information

- 1.1. Gender
- a. Male
 - b. Female
- 1.2. Age in years
- a. 15-20 years
 - b. 21-30 years
 - c. 31-40 years
 - d. >40 years
- 1.3. Years of experience as nurse
- a. 1-5 years
 - b. 6-10years
 - c. 11-15 years
 - d. >15 years
- 1.4. Educational qualification
- a. Diploma in nursing
 - b. BSc in nursing
 - c. Masters degree

1.5. Training received at

- a. Governmental institution
- b. Private institution

1.6. What department/ward are you working in?

- a. Outpatient department
- b. MCH
- c. Maternity ward
- d. ART clinic
- e. Other, please specify _____

1.7. Have you received specific on the job training on HIV/AIDS?

- a. Yes
- b. No

If you have responded No to No 7, please proceed to the next section. Please answer the following questions only if you have answered Yes to No 7.

1.8. Have you received specific on the job training on Pediatric HIV/AIDS?

- a. Yes
- b. No

1.9. Have you received specific on the job training on counseling?

a. Yes

b. No

1.10. Have you received specific on the job training on disclosure of HIV status?

a. Yes

b. No

1.11. Have you received specific on the job training on disclosure of their HIV positive status to children living with HIV/AIDS?

a. Yes

b. No

SECTION 2:

Please tick the appropriate box for the following questions

The term child for the purpose of this research is defined as any child between the ages of 10 and 15 years of age.

2.1. Have you ever had a child living with HIV virus as a patient?

a. Yes

b. No

2.2. Have you ever discussed with parents about disclosure of his/her status to the child living with HIV?

a. Yes

b. No

2.3. Have you ever helped parents disclose his HIV positive status to a child?

a. Yes

b. No

2.4. A child born with HIV can live to age 10 and beyond

a. Yes

b. No

c. Unsure

2.5. What do you feel is the appropriate age for a child living with HIV to know his status _____

2.6. Who should disclose their HIV positive status to children

- a. Parents/ Primary caregivers
- b. Health care providers
- c. Both a and b together
- d. Other please specify _____

2.7. If you have replied , b or c to question number 8 please specify, what type of health care provider should be involved in child disclosure

- a. Nurse
- b. Pediatrician
- c. Medical doctor
- d. Other, please specify_____

2.8. What do you feel is an important reason that parents don't want to disclose to their children their HIV status that needs to be addressed in discussing disclosure

- a. Stigma
- b. Their belief the child is too young
- c. Guilt
- d. Fear of emotional distress
- e. Lack of knowledge and skill
- f. Other , please specify

SECTION 3: *Please rate the degree to which you agree with each statement below by ticking the box*

Serial Number	Statement	Strongly agree	Agree	Neutral/ unsure	Disagree	Strongly disagree
3.1	Most people with AIDS have only themselves to blame					
3.2.	It is especially important to work with patients with AIDS in a caring manner					
3.3.	HIV+ women should not have children					
3.4	A child born to an HIV positive woman who didn't take Nevirapine to prevent MTCT will be born HIV positive					
3.5.	Children who get AIDS from their mothers are more deserving of treatment than people who get AIDS through sexual promiscuity					
3.6.	Patients with AIDS should be treated with the same respect as any other patient					
3.7.	You would like to do something to make life easier for children with AIDS					
3.8.	You would do everything you could to give the best possible care to children with AIDS					
3.9.	Children have the right to know about any illness they have					
3.10.	Children have the right to know their HIV status					
3.11.	Children have the right to participate in decisions regarding their treatment					
3.12	Children who know their status have better adherence to ART than children who don't know their status					
3.13	Children who know their HIV status are more exposed to stigma than children who don't know their status					
3.14	I feel that parents shouldn't tell their children that they are HIV positive as the children will be depressed					
3.15	There are support groups children can access if they are aware of their status					
3.16	A child can find out his HIV positive status accidentally					
3.17	A child can find out his HIV positive status accidentally in a health center					
3.18	It is better to tell children that they are HIV positive at one session to make it easier on them					

SECTION 4:

Please rate the degree to which you agree with each statement below and tick the appropriate box

Serial Number		Strongly Agree	Agree	Disagree	Strongly disagree
4.1	I feel I have enough training to help a parent disclose HIV status to a child living with HIV				
4.2.	I feel that taking part in HIV disclosure is stressful as it consists of giving bad news to children				
4.3.	I feel that health care providers need to discuss the issue of disclosure of the child 's HIV status only if his parents/guardians asks advise about it				
4.3.	I would try to avoid being part of disclosing to a child his/her HIV status				
4.4.	I know of a guideline that I can access that can help me disclose his HIV status to a child				
4.5.	If a child below 15 years ask me directly if he is HIV positive and his parent doesn't want him to know his status, I would lie to keep the secret safe.				

SECTION 5: You are invited to share any additional views on the topic of disclosure of their HIV positive status to children focusing on the importance of disclosure and nurses' role that you feel have not been sufficiently covered by the above questions.

THANK YOU FOR COMPLETING THE QUESTIONNAIRE

INFORMED CONSENT FORM

Dear Research participant,

You are invited to participate in a research study entitled: **“Disclosure of their HIV positive status to children in Addis Ababa, Ethiopia: Nurses’ perception.”** You were selected as possible participant as part of a sample including nurses from health centers in Addis Ababa. This research is being conducted as part of the requirements towards the degree of Masters in Public Health from the University of South Africa (UNISA).

The purpose of the study is to explore and describe nurses’ perception about their HIV status to Children living in Addis Ababa. The results of this study might contribute to the design of further interventions to improve the care of Children living with HIV virus. If you agree to participate, you will be asked to complete a self administered questionnaire that will take 15-20 minutes of your time. There is no financial compensation for your participation in this research.

The records from this study will be kept as confidential as possible and your name will not be included in any publications or reports.

Participation in this study is voluntary. If you decide to participate, you are free to withdraw at any time. Your participation in this study will be highly appreciated.

The researcher in this study is Dr Yenealem Tadesse WoldeMariam and can be contacted at 0911406151 if you have any further question.

Statement of Consent

I have read the above information. I consent voluntarily to participate in the study.

Participant’s Name:

Participant’s Signature:

Signature of Data Collector: