

**KNOWLEDGE AMONG PARENTS/GUARDIANS ON THE
PRESENTATION OF PAEDIATRIC HIV/AIDS AND RELATED
FACTORS.**

By DR. NAMWINGA CHINTU

THESIS
M.MED
CHI
2005

*Dissertation submitted in Partial Fulfilment of the requirement for the Degree of
Masters of Medicine in Paediatrics*



Table of contents

| | Page |
|--|----------|
| Table of contents ----- | i |
| List of tables and figures----- | iv |
| Acknowledgements ----- | v |
| Copyright ----- | vi |
| Declaration ----- | vii |
| Approval ----- | viii |
| List of abbreviations ----- | xi |
| Abstract ----- | x |
| | |
| Chapter 1 Introduction----- | 2 |
| 1.1 Main objective ----- | 4 |
| 1.2 Specific objectives ----- | 4 |
| | |
| Chapter 2 Literature Review----- | 5 |
| 2.1 HIV Transmission ----- | 5 |
| 2.2 Mother to Child Transmission of HIV----- | 6 |
| 2.2.1 Perinatal transmission of HIV----- | 6 |
| 2.2.2 Post natal transmission of HIV through breastfeeding ----- | 7 |
| 2.2.3 Duration of breastfeeding in relation to MTCT ----- | 7 |
| 2.2.4 Form of breastfeeding and HIV ----- | 8 |
| 2.3 The Zambian situation ----- | 9 |
| 2.3.1 HIV Prévalence in Zambia ----- | 9 |
| 2.3.2 Impact of paediatric HIV/AIDS on infant morbidity and mortality--- | 10 |

| | |
|--|-----------|
| 2.4 Strategies to reduce mother to child transmission in Zambia ----- | 11 |
| 2.4.1 Voluntary testing and counselling services ----- | 11 |
| 2.4.2 Prevention of Mother to child Transmission HIV pilot sites ----- | 12 |
| 2.4.3 Print and electronic media ----- | 12 |
| 2.5 Signs and symptoms of HIV/AIDS infection in children ----- | 13 |
| 2.5.1 WHO staging system for HIV Infection and Disease in Children----- | 13 |
| 2.5.2 Modified Zambian Criteria ----- | 14 |
| 2.5.3 Centres for Disease Control HIV/AIDS Criteria in Children ----- | 15 |
| 2.5.4 HIV Progression in children ----- | 16 |
| 2.6 Local knowledge on signs and symptoms of HIV ----- | 17 |
| Chapter 3 Methodology ----- | 19 |
| 3.1 Study design ----- | 19 |
| 3.2 Study site ----- | 19 |
| 3.3 Study population ----- | 19 |
| 3.4 Sampling procedure ----- | 20 |
| 3.5 Inclusion criteria ----- | 20 |
| 3.6 Exclusion Criteria ----- | 20 |
| 3.7 Sample size ----- | 20 |
| 3.8 Data collection ----- | 21 |
| 3.9 Data analysis ----- | 21 |
| 3.9.1 Ethical consideration ----- | 21 |
| Chapter 4 Results ----- | 22 |
| 4.1 Social Demographic data ----- | 22 |
| 4.2 Reasons for referral to hospital ----- | 26 |
| 4.3 Knowledge on possibility of HIV infection in children ----- | 26 |
| 4.3.1 Educational level and knowledge of HIV infection in children ----- | 27 |
| 4.4 Knowledge on modes of MTCT ----- | 28 |
| 4.5 Health status of child in relation to HIV status ----- | 29 |

| | |
|--|-----------|
| 4.6 Knowledge of health problems associated with HIV infection ----- | 30 |
| 4.6.1 Major signs of HIV Infection ----- | 30 |
| 4.6.2 Minor signs of HIV Infection ----- | 31 |
| 4.7 Knowledge on availability of antiretroviral drugs ----- | 31 |
| 4.8 Attitudes on HIV and breastfeeding----- | 33 |
| 4.8.1 Feasibility of exclusive breastfeeding----- | 34 |
| 4.9 Knowledge on availability of VCT services ----- | 34 |
| 4.9.1 Willingness for VCT ----- | 35 |
| 4.9.2 Preferred sites for VCT ----- | 35 |
| Chapter 5 Discussion----- | 36 |
| 5.1 Socio demographic data for parents /guardians ----- | 36 |
| 5.2 Infant data ----- | 37 |
| 5.3 Referrals to UTH ----- | 37 |
| 5.4 Knowledge on Paediatric HIV ----- | 37 |
| 5.5 Knowledge on availability of ARV's ----- | 38 |
| 5.6 HIV and breastfeeding ----- | 39 |
| 5.7 VCT services ----- | 39 |
| Chapter 6 Conclusions and recommendations----- | 40 |
| 6.1 Conclusions ----- | 40 |
| 6.2 Recommendations ----- | 41 |
| 6.3 Study limitations ----- | 42 |
| References ----- | 43 |
| Appendices | |
| Questionnaire ----- | 48 |
| Consent form ----- | 51 |

List of Tables and Figures

| | |
|----------|---|
| Table 1 | Sex distribution of children |
| Table 2 | Relationship of care givers interviewed |
| Table 3 | Distribution of deceased parents |
| Table 4 | Can children get HIV |
| Table 5 | Educational level and knowledge of HIV in children |
| Table 6 | Modes of HIV transmission as given by respondents |
| Table 7 | Minor signs of HIV infection |
| Table 8 | HIV and Breastfeeding |
| Table 9 | Feasibility of exclusive breastfeeding |
| Table 10 | Willingness for VCT according to site |
| Table 11 | Preferred site for VCT |
| | |
| Figure 1 | Sex distribution of Parents /caregivers |
| Figure 2 | Educational background of parents interviewed |
| Figure 3 | Reasons for referral to hospital |
| Figure 4 | HIV-ve child = healthy parents? |
| Figure 5 | Major signs of HIV infection |
| Figure 6 | Knowledge on availability of ARV's |
| Figure 7 | Knowledge on availability of VCT services at local clinic |

AKNOWLEDGEMENTS

I am deeply grateful for the support and encouragement given by Dr C. Kankasa Consultant paediatrician, Dr MPS Ngoma Head of Department Paediatrics and Child Health, and Dr I M Nalubamba to complete this dissertation. I also remain indebted to Mrs Lungowe Chitembo for her unwavering support and her untiring efforts to complete data collection for this dissertation.

COPYRIGHT

Dr Namwinga Towela Chintu

2004

All rights reserved; no part of this dissertation may be produced, stored in a retrieval system or transmitted in any form or by other means, electronic, mechanical, photocopying or recording without the prior consent of the author.

DECLARATION

I hereby declare that this dissertation represents my own work and has not been presented even in part to any forum or University other than the University of Zambia.

Signed  _____

Namwinga Towela Chintu BSc HB MBChB MTrop Paeds

Supervisor:

Signed  _____

C Kankasa MD MMed Paeds, Consultant paediatrician

APPROVAL

This dissertation of Dr Namwinga Towela Chintu is approved as partial fulfilment of the requirements for the award of the Master of Medicine in Paediatrics and Child Health by the University of Zambia

Signed M Ngoma

Dr M.P.S Ngoma FRCP

Head of Department

Paediatrics and Child Health

University Teaching Hospital

DEPARTMENT OF PAEDIATRICS
AND CHILD HEALTH
UNIVERSITY TEACHING HOSPITAL
HEAD OF DEPARTMENT

Examiners

1. Name PROF YAKUB MULLA

Signature Yr

Date 1/06/2005

2. Name DR. MPS NGOMA

Signature M Ngoma

Date 30.05.05

3. Name DR B.C. AMADI

Signature B Amadi

Date 1/6/05

List of Abbreviations

| | |
|-------|---|
| AIDS | Acquired immunodeficiency Syndrome |
| ARV's | Anti retroviral drugs |
| HIV | Human immunodeficiency virus |
| CBOH | Central Board of Heath |
| CSO | Central Statistical Office |
| MOH | Ministry of Health |
| MTCT | Mother-to-child transmission of HIV |
| PMTCT | Prevention of mother-to-child transmission of HIV |
| VCT | Voluntary counselling and testing |

ABSTRACT

Background

Zambia similar to other sub Saharan countries has high sero prevalence rates of HIV. In spite of several campaigns and strategies to improve HIV/AIDS awareness, paediatric HIV/AIDS cases in Zambia continue to rise. Despite the now available ARV's, few children are brought forward to access care. Possible reasons for this continued rise were explored in this study.

Methods

This quantitative descriptive study aimed to document awareness of parents/guardians of symptomatic paediatric AIDS among children under five years in a primary and tertiary health institution. Knowledge on mother-to-child transmission of HIV, and symptomatology of HIV among 331 parents/guardians attending Kabwata Health Center and University Teaching Hospital was assessed using a structured questionnaire.

Results

Parents/ guardians are aware of mother to child transmission of HIV (MTCT) during pregnancy (36 %), labour and delivery (16%), and through breastfeeding (26%). Of note was that parents thought that HIV can be hospital acquired through use of unsterilised needles and syringes.

Just over 50% of respondents thought that an apparently healthy child was a guarantee that the child's parents were free from HIV infection and this may be a contributing factor to the low utilisation of voluntary counselling and testing (VCT) services.

Signs and symptoms of HIV infection volunteered by parents were non-specific. Specific signs and symptoms only accounted for 16% of the total responses. Half of the respondents were aware of the availability of anti-retroviral drugs for the management of HIV infection as well as for PMTCT. More than 80% of respondents were willing to undergo VCT if they suspected their child of having HIV infection.

Conclusion

Insufficient and inaccurate knowledge among parents and care givers about paediatric HIV/AIDS is one of the important reasons for low VCT uptake and may be indirectly responsible for the increase in infant morbidity and mortality in Zambia. The study has shown the need for sustained aggressive community sensitization on the presentation and management of paediatric HIV/AIDS.

CHAPTER ONE

INTRODUCTION

In 1981, the 1st HIV case was discovered in the United States of America and since then United Nations AIDS program estimates that there are about 32 million people worldwide living with HIV/AIDS (UNAIDS 2000). Since the beginning of the epidemic more than 16 million adults have been infected with HIV in Africa with more than half of them women (Quinn TC 1996). Although the HIV epidemic is centred in developing countries, AIDS has also become a leading cause of death in the United States of America and the developing world (Selik et al 1991).

The steady increase in under five mortality rate from 1985 to 1992 in Zambia appears to be consistent with the impact of AIDS deaths on under five mortality rate (Central Statistics 2001/2002). The major causes of morbidity and mortality among paediatric patients are Gastroenteritis, respiratory tract infections, anaemia, malaria and, malnutrition. All of the above can be worsened by co infection with HIV.

With mother to child transmission rates of HIV in Africa of between 20 – 40% (The Working Group on Mother to Child Transmission of HIV 1995) ways off reducing Mother to Child Transmission (MTCT) and thereby infant morbidity and mortality must be sought. This can be done primarily through voluntary testing and counselling (VCT) as well as community mobilization and behaviour change. Although provision of antiretroviral drugs coupled with avoidance of breastfeeding can reduce MTCT to less than 10%, (Centres for Disease Control and Prevention 1997, 1999). Without VCT it is not possible to know who needs intervention. VCT in Zambia is readily accessible however not much is known in terms of community awareness on where and when to seek VCT in relation to paediatric HIV/AIDS in Lusaka.

This study aims to describe knowledge among parents/guardians about the clinical presentation of paediatric HIV/AIDS, attitudes towards HIV testing and treatment with a view to suggest areas in which paediatric HIV/AIDS awareness may be strengthened.

OBJECTIVES

1.1 MAIN OBJECTIVE

To determine and document the awareness of parents/guardians attending health institutions on the clinical presentation of paediatric HIV/AIDS among children under 5 years of age.

1.2 SPECIFIC OBJECTIVES

To determine the extent awareness of parents/ caregivers in a primary and tertiary health providing institution on

- a) Clinical presentation of paediatric HIV
- b) Routes of mother to child transmission of HIV
- c) Prevention of mother to child transmission of HIV
- d) Awareness of availability/accessibility of antiretroviral therapy
- e) Where to go for tests if HIV/AIDS is suspected

OBJECTIVES

1.1 MAIN OBJECTIVE

To determine and document the awareness of parents/guardians attending health institutions on the clinical presentation of paediatric HIV/AIDS among children under 5 years of age.

1.2 SPECIFIC OBJECTIVES

To determine the extent awareness of parents/ caregivers in a primary and tertiary health providing institution on

- a) Clinical presentation of paediatric HIV
- b) Routes of mother to child transmission of HIV
- c) Prevention of mother to child transmission of HIV
- d) Awareness of availability/accessibility of antiretroviral therapy
- e) Where to go for tests if HIV/AIDS is suspected

CHAPTER TWO

LITERATURE REVIEW

2.1 HIV TRANSMISSION

The majority of HIV infections are transmitted heterosexually, and perinatally from mother to child (Ferdinand et al 1987, Piot et al 1988). In developed countries HIV seropositive women are more likely to be intravenous drug users, partners of drug users or bisexual men, or be involved in sex work (Brotman et al 1993). The situation is very different in developing countries where heterosexual transmission is the predominant mode of spread. Southern Africa is the most affected region in terms of HIV prevalence. In Kenya, Malawi, Namibia, Rwanda, South Africa, Tanzania, Zambia, and Zimbabwe, over 10% of women attending antenatal clinics in urban areas are HIV positive¹ (UNAIDS 1997). While prevalence rates in antenatal women have been taken as a good indicator of the rate of infection in communities, sentinel surveillance at antenatal clinics may under-estimate the population surveillance as shown in a study in Tanzania, where the prevalence in antenatal mothers was below that of the general population by 0.75 (Borgdoff et al 1993). In Zambia, with 98% of women attending antenatal clinics, this can serve as a powerful and appropriate forum to launch the important topic of mother to child transmission of HIV (MTCT). However, a decrease in the fertility of HIV infected women, both from sub fertility and from increased early pregnancy loss, as reported from the Rakai district in Uganda, may exacerbate this underestimation and may thus lead to suboptimal numbers of women being exposed to information about HIV/AIDS in the reproductive period (Gray et al 1998).

2.2 MOTHER TO CHILD TRANSMISSION OF HIV

It is been estimated that 1700 children globally are born with HIV every day. A further 300 children are infected daily with HIV through breastfeeding (De Cock et al 2001).

Reported cases of mother to child transmission range from around 15% - 25% in Europe and USA to 25% - 40% in some African studies (Working Group on Mother to Child Transmission of, HIV 1995, De Cock et al 2000). With the advent of routine antiretroviral therapy in many developed countries, much lower rates, in some cases of less than 2%, are now being described (Lallemant M et 2000 Kind C et al 2000).

2.2.1 Perinatal transmission of HIV

Infected mothers may pass on the virus to their children perinatally during pregnancy and labour. Without intervention studies have shown that transmission rates between 13-28%. Transmission rates were generally shown to be higher in countries where virtually all women breastfed compared to countries where breastfeeding by HIV infected mothers is non-existent.

Transmission of HIV during pregnancy and delivery occurs in about 15% of HIV infected women. Rates have been further reduced with elective caesarean (Mandllebrot L et al 1998). The importance of aggressive VCT was shown by Arbona et al 2001 who showed that there was on-going MTCT in the United States of America due to the fact that not all mothers receive prenatal care or know their HIV status when they deliver. Mothers armed with the knowledge of their HIV status may be able to plan for the delivery and care of their infants.

2.2.2 Post natal transmission of HIV through breastfeeding

Postnatal transmission through breastfeeding is generally assumed to explain most of the differences in transmission rates between developed and developing countries, due to the duration of breastfeeding, which tends to be prolonged in the developing countries.

The first suspected case of transmission of HIV through breastfeeding was reported by Ziegler in 1985 (Ziegler et al 1985). MTCT through breastfeeding was confirmed in 1993 (Palasanthirian et al 1993). The reports described HIV transmission from mothers who had been infected by HIV through postpartum blood transfusions and shared needles for intravenous drug use. Several cases of MTCT through breastfeeding have since been established (Hira et al 1990, Dunn et al 1992, Lapage et al 1993).

Studies to further understand the transmission of HIV through breastfeeding concluded that the cumulative probability of HIV infection at 24 months was higher among breastfed compared to formula fed babies (Nduati et al 2000).

2.2.3 Duration of breastfeeding in relation to MTCT

Studies done in Malawi showed that the cumulative risk of infection for children of HIV positive mothers continuing to breastfeed after 1 month was 3.5% at the end of 5 months, 7.0% at the end of 11 months, 8.9% at the end of 17 months and 10.3% at the end of 23 months (Miotti et al 1999). It was therefore postulated that the longer the duration of breastfeeding, the greater the risk of HIV transmission. Leroy et al in 1998 in a pooled analysis of studies in Rwanda, Ivory Coast and Kenya showed that there was late transmission of HIV from mother to child in 5% of breastfed children. In this study showed the cumulative probability of late postnatal transmission was 0.6% at 6 months of age, 0.95% at 9 months of age, 2.5% at 12 months of age and 7.4% at 24 months of age and 9.6% at 36 months of age.

Though the studies both showed a cumulative increase in late postnatal transmission of HIV with duration of breastfeeding, the differences in the figures was as a result in the

differences in the definition of late postnatal transmission of HIV which was at an earlier age in the Malawian study.

2.2.4 Form of breastfeeding and HIV

In an effort to understand the relationship between mother to child transmission of HIV, studies done in Durban South Africa have shown that mixed feeding may be associated with higher rates of HIV transmission (Coutsoudis et al 1999). Type of breastfeeding in this study was classified either as exclusive or mixed. By 15 months of age children who had ever breastfed were more likely to become HIV infected (31.6%) than those who had never breastfed 19.4% [$p=0.007$]. Those who had exclusively breastfed had lower transmission point estimates than those who had mixed fed. This would imply that rates of transmission could be higher with low rates of exclusive breastfeeding. It was also postulated that fluids and foods given to infants who were mixed feeding damaged the bowel mucosa facilitating entry of HIV-1 into cells.

Use of antiretroviral drug regimes and avoidance of breastfeeding can reduce rates of mother to child transmission of HIV by about 50%.

Postnatal transmission of HIV through breastfeeding is of particular importance in Zambia. Zambia is predominantly a breastfeeding nation with 98% of mothers breastfeeding their infants. The median duration of breastfeeding is 21 months. Exclusive breastfeeding is not commonly practiced in Zambia. Rates of exclusive breastfeeding rose from 13% in 1992 to 26% in 1996 (CSO 1996) and can be attributed to the introduction of the Baby Friendly Hospital Initiative a WHO/UNICEF initiative to protect promote and support breastfeeding in health institutions providing care to mothers and babies.

WHO/UNAIDS recommends that the risk of illness from replacement feeding should be less than the risk of illness through breastfeeding otherwise breastfeeding is recommended. Artificial feeding in Zambia is associated with social stigmatisation as every woman is socially and culturally expected to breastfeed her infant (LINKAGES 2000)

2.3 THE ZAMBIAN SITUATION

2.3.1 HIV Prevalence in Zambia

HIV prevalence in Zambia, with a population of approximately 10.3 million, is 19.7 percent on average. In Lusaka the capital city with a population of 2 million inhabitants, the prevalence of HIV is 27.3 %. In Zambia factors predisposing to high prevalence of HIV infection are urbanisation and poverty. About 43% of the population live in urban areas from which an estimated 70% live below the poverty datum line. Nearly 47% of children under five years of age are stunted as shown by the Zambia Health and Demographic Survey (ZHDS 2001-2002). Mother to child transmission rates of HIV in Zambia are estimated to be between 25-49%. With these statistics it is estimated that 520,000 children were orphaned in 1999 and the number is expected to rise to 895,000 by 2009 as a result of HIV/AIDS which has in addition had social and economic impact on the nation. In the health sector it is estimated that by the year 2005 43% of the bed capacity in hospitals will be occupied by HIV/AIDS patients (Background projections impacts and interventions HIV/AIDS in Zambia. MOH/CBOH 1999)

Studies have been done to assess knowledge attitude and practice concerning adult/adolescent HIV /AIDS (MOH/CBOH 2000). Knowledge of HIV/AIDS is almost universal with 99% of all Men and women having heard of HIV/AIDS (ZDHS 2001-2002). Almost all adolescents had heard about HIV/AIDS but a large proportion of young people did not think that a person could do anything to avoid HIV/AIDS (30% of men and 32% of women aged 15-19).

Eighty two percent of men and 83% of women knew that an infected mother could infect unborn babies with HIV. Most respondents knew that MTCT could occur during pregnancy (94% of men and 93% of women). Seventy seven percent of men and 79 % of women thought that MTCT could occur during breast-feeding (Zambia Sexual Survey 2000).

In the 1998 Zambia Sexual Behaviour Surveillance (ZSBS) 9% of women and 7% of men stated that they had been tested for HIV. In the 2000 ZSBS those who had responded to having taken an HIV test increased to 14% among the men and 12% for the women.

The cause of death most commonly reported for all persons in house holds were tuberculosis, malaria, other infectious diseases and diarrhoea. AIDS was rarely reported as a cause of death implying lack of knowledge on symptomatology of HIV/AIDS or fear of stigmatisation.

Preliminary studies done by MTCT working group formative research (2000) showed that most expectant mothers were aware of MTCT although there were misconceptions and an over exaggeration of the rates of MTCT. The formative research also showed that the community was aware of signs and symptoms of AIDS in adults but nothing was mentioned about signs and symptoms in children. However most individuals in this study were aware of MTCT of HIV.

None of these studies mention awareness of signs and symptoms of paediatric HIV infection nor do they mention knowledge of availability of anti-retroviral in relation to HIV management.

2.3.2 Impact of paediatric HIV/AIDS on infant morbidity and mortality

Paediatric HIV/AIDS is an important cause of morbidity and mortality. A large number of children are infected through perinatal transmission and a smaller number through breastfeeding. More than 25,000 children become infected each year in Zambia (MOH/CBOH 1999). HIV/AIDS in children continues to have a profound effect on under 5 mortality, which is projected to rise from 1/1000 in 1985 to 33/1000 births in 2000. Zambia now ranks 13th highest world wide with an under five-mortality rate of 202/1000 live births. A study done by Chintu et al at the University Teaching Hospital Lusaka Zambia found that the mortality rate for children with HIV was found to be 190 per 1000

children admitted and 100/1000 for those children who were HIV negative (Chintu et al 1993). The life expectancy at birth now stands at 43 years.

2.4 STRATEGIES TO REDUCE MOTHER TO CHILD TRANSMISSION IN ZAMBIA

The National AIDS Surveillance Committee and The Inter sectorial AIDS Health Education Committees were set up in 1986 to coordinate activities for AIDS prevention and control. Other strategies include: -

2.4.1 Voluntary testing and counselling services

By 2000 there are 40 Counselling and testing sites under the Zambia Voluntary Counselling and Testing service. Eight of these sites were located in Lusaka with the rest in the 8 of the remaining provinces of Zambia. A study done in Zambia on voluntary counselling and testing showed that the readiness for voluntary counselling and testing in the general population was low. Provision factors such as concerns about confidentiality and length of time waiting for test results contributed to the low utilisation rate (Fylkessess et al 2001). This sharply contrasted with reported VCT acceptance rates of 70%-90% among women attending antenatal care in Zambian and other African populations. Ministry of Health through the Zambia HIV/AIDS Background and Projections 1999 indicated that 26% of Zambians have been counselled and tested and know their results. A study done to Assess the impact of HIV on childhood morbidity and mortality among under five children hospitalised in UTH Lusaka, Zambia showed acceptance rates for HIV testing of 83% among parents of hospitalised children (Sinyinza 2002).

Individuals are reluctant to go for tests for fear of stigmatisation as well as the feeling of there is nothing to offer once the results are positive.

2.4.2 Prevention of Mother to child Transmission HIV pilot sites

There were 6 sites in three districts (Lusaka, Monze, and Mbala) providing voluntary counselling and testing, antiretroviral drugs to HIV positive women and infant feeding counselling in Zambia at the time of the study. These sites are under the Mother to Child Transmission of HIV Working Group in conjunction with UNICEF. Chipata clinic hosts the Lusaka site for this pilot intervention. With up scaling of sites more health centres will soon be equipped with facilities to implement PMTCT strategies. Since 2000 several other governmental and non governmental institutions provide PMTCT services to mothers and affected children.

2.4.3 Print and electronic media

Print and electronic media provide a valuable source and wide source of information of information on HIV.

2.5 SIGNS AND SYMPTOMS OF HIV/AIDS INFECTION IN CHILDREN

With the wide spectrum of presentation of paediatric HIV/AIDS, a number of criteria have been formulated to identify children who may be infected with HIV. These criteria are mainly used by clinicians, however some signs and symptoms may be recognised and associated with HIV by the general public.

The World Health Organisation formulated a staging system for HIV infection and disease in children. This criterion is helpful as the staging determines the course of management of the affected child. Where HIV testing is unavailable, the criteria is also useful in clinically diagnosing HIV, however HIV testing still remains the gold standard.

2.5.1 WHO staging system for HIV Infection and Disease in Children

Clinical Stage I

1. Asymptomatic
2. Generalised lymphadenopathy

Clinical stage II

3. Unexplained chronic diarrhoea
4. Severe persistent or recurrent candidiasis outside the neonatal period
5. Weight loss or failure to thrive
6. persistent fever
7. Recurrent severe bacterial infections

Clinical stage III

8. AIDS defining opportunistic infections
9. Severe failure to thrive
10. Progressive encephalopathy
11. Malignancy
12. Recurrent septicaemia or meningitis

WHO/ARV Guidelines May 2002 Appendix 2.

A modified criterion for HIV/AIDS infection in children suitable to the Zambian environment has been formed (Chintu et al 1993) and includes the following and applies to children under 13 years of age. Paediatric AIDS is suspected in a child presenting with at least 2 major signs associated with 2 minor signs

2.5.2 Modified Zambian Criteria

Major signs

Recurrent fever at least one month's duration

Recurrent oropharyngeal candidiasis

Recurrent lower respiratory tract infections

Minor signs

Chronic diarrhoea of at least one month's duration

Weight loss or abnormally slow growth

Generalised lymphadenopathy

Persistent cough of at least one month's duration

Extrapulmonary tuberculosis

Pneumocystis carinii pneumonia

Confirmed maternal HIV-1 infection

2.5.3 Centres for Disease Control HIV/AIDS Criteria in Children

The Centres for Disease Control have utilised both clinical and immunological parameters of the classification of HIV in children as listed below

| CATEGORY | CHARACTERISTICS |
|-------------|--|
| N | No signs or symptoms considered to be the result of HIV infection or only 1 condition listed in A |
| A (Mild) | Two or more of the conditions listed below but none from B or C attributed to HIV infection but limited to <ul style="list-style-type: none">▪ Lymphadenopathy (greater or equal to 5mm or at more tha 2 sites ;bilateral, 1 site▪ Hepatomegaly▪ Splenomegaly▪ Parotitis▪ Dermatitis▪ Recurrent or persistent upper respiratory tract infections, sinusitis, or otitis media |
| B (Mild) | Symptomatic conditions other than those from A or C <ul style="list-style-type: none">▪ Anaemia (< 8g/dl) Neutropenia (>1000/mm³) Thrombocytopenia (100,000/mm³ persisting more or equal to 30 days.▪ Bacterial meningitis, pneumonia or sepsis (single episode)▪ Candidiasis, pesisting > 2 months in children > 6 months of age▪ Cytomegalovirus infection onset< 1 year of age▪ Diarrhoea recurrent or chronic▪ Hepatitis▪ Herpes simplex virus stomatitis >2 episodes within a year▪ Herpes simplex bronchitis, pneumonia or oesophagitis with onset< 1 month▪ Herpes zoster more or equal to 2 episodes or > 1 dermatome▪ Leiomyosarcoma▪ Lymphoid interstitial pneumonitis or pulmonary lyphoid hyperplasia complex▪ Nephropathy▪ Norcardiosis▪ Persistent fever> 1 month▪ Toxoplasmosis onset< ! month of age▪ Varicella disseminated |
| C | Any conditions listed below |

| | |
|----------|--|
| (Severe) | <ul style="list-style-type: none"> • Serious bacterial infections, multiple or recurrent episodes of septicaemia, pneumonia, meningitis, bone or joint infection, or abscess of an internal organ or body cavity • Candidiasis (oesophageal or pulmonary) • Coccidiomycosis (disseminated) • Cryptococcosis (disseminated) • Cytomegalovirus disease onset at age > 1 month (at site other than lymph node, spleen, liver) |
|----------|--|

These criteria are of particular importance in settings where laboratory tests are not readily available all the time. However, testing for HIV remains the gold standard. For children below 18 months HIV antibody tests do not give the true picture of the child's HIV status due to the presence of maternal antibodies. Molecular DNA techniques offer accurate diagnosis in babies in this age group.

2.5.4 HIV Progression in children

HIV progression in children is more rapid than in adults and there are three distinct patterns which have been observed (Nelsons Textbook of Paediatrics 2000).

1. Rapidly progressive form: - onset of AIDS occurs within a few months of life. If untreated the mean survival age is between 6 to 9 months. Infection is considered to have occurred in utero.
2. Slow progressive form: - The mean age of survival is 6 years. Infants are considered to have been infected during the intrapartum period.
3. Long term survivors: - Infection is considered to have taken place in the postnatal period.

LOCAL KNOWLEDGE ON SIGNS AND SYMPTOMS OF HIV

A report on formative research done in Chipata Health Centre and its catchment area done by The Mother to Child Intervention Group documented some of the local name denoting HIV/AIDS in adults listed below.

| <u>LOCAL NAME</u> | <u>MEANING</u> |
|-------------------------|--|
| Kalondelonde | Slimming/wasting |
| SIDA | French abbreviation for HIV/AIDS |
| Kavute anoko illness | Go and trouble your mother. Implying long |
| Egesi | Corrupted version of AIDS |
| E 21 | Male medical UTH- reflects high admission rate for HIV related illnesses. |
| Serial killer | One person can kill several others |
| Julia | Promiscuous woman |
| Sepe | A pruritic rash |
| TB | Tuberculosis highly associated with HIV/AIDS |
| Slow puncture | Refers to chronic ill health |

The various local names for HIV/AIDS can be placed in 4 categories as follows

- A. Those that would describe the wasting nature of the illness and the hair changes that go with it.
- B. Those that reflect the burden on mothers to look after HIV/AIDS patients.
- C. Those that describe the “serial” manner in which persons die of HIV/AIDS in the community. The disease manifests the predictable nature in which persons acquire and are subsequently killed by the disease one after the other.
- D. Those which blame the promiscuous woman for spreading HIV/AIDS

Some of the features of HIV/AIDS in adults mentioned by respondents include the following

- Fevers
- Hair changes
- Swollen feet
- Diarrhoea (even when patient laughs)
- Rashes
- Tuberculosis
- Weight loss
- Abscesses
- No energy during delivery
- Swellings
- Cough similar to tuberculosis

This study to showed the level of knowledge of caregivers/ parents with regards to the symptomatology of paediatric HIV/AIDS and factors related to mother to child transmission of HIV.

CHAPTER THREE

METHODOLOGY

3.1 Study design

The study was a cross sectional questionnaire based descriptive study. The principal researcher with the aid of a trained HIV/AIDS counsellor as a research assistant filled in questionnaire according to Parents/caregivers responses.

Information collected focused on social demographic data, and questions related to paediatric HIV/AIDS. The criterion used to define clinical paediatric HIV/AIDS was the Zambian criterion as is was noted to be more user friendly to parents and caregivers.

3.2 Study site

The study was undertaken at the University Teaching Hospital (UTH) Department of Paediatrics Outpatients Department Lusaka and Kabwata under five clinics. Kabwata clinic provides primary health care to a catchment area of approximately 50,000 inhabitants. The UTH is the largest referral hospital in Zambia. UTH outpatients may cater for up to 100 outpatients or more per day. Although primarily a referral hospital, it also provides care to self-referred patients. The site was suitable because it caters for a wide spectrum of patients in terms of social economic status, educational level and disease spectrum. Kabwata clinic provided the opportunity to assess the knowledge of parents/ caregivers of children who were otherwise healthy on the presentation of paediatric HIV/AIDS in a primary health care setup.

3.3 Study population

Parents and guardians of children aged below 5 years were recruited from the under five clinic at Kabwata Health Centre and from the out patients department of the University Teaching Hospital. Interviews of the parents and guardians took place from Monday to Friday.

3.4 Sampling Procedure

Parents and Caregivers were recruited consecutively from the above mentioned clinics.
The interviews did not interfere with patient treatment or management.

3.5 Inclusion Criteria

All parents and caregivers of children below five years who agreed to take part in the study

3.6 Exclusion Criteria

- Parents/guardians of children above five years old.
- Parents/guardians who decline to take part in the study.
- Parents /guardians of children who have come for emergency treatment

3.7 Sample size

The size of population from which sample was selected was calculated from the expected outpatient attendance at UTH and the expected Under five clinic attendance at Kabwata clinic

Parents/guardians were recruited consecutively

Usin Epi Info version 6.0, the minimum sample size was calculated to be **331** subjects.

| | |
|---|-------------|
| Size of the population from which sample to be selected | 2400 |
| Expected frequency | 50% |
| Worst acceptable result | 55% |

At 95% confidence interval the sample size was calculated to be **331** subjects

3.8 Data collection

A structured questionnaire was used as a data collection tool. Information collected included social demographics and details on information pertaining to knowledge on symptoms and signs of paediatric HIV.

The questionnaire was field tested and necessary adjustments made.

3.9 Data analysis

Data was analysed by EPI info Version 6 with the aid of a bio statistician.

3.9.1 Ethical consideration

Ethical approval was sought from the Research and Ethics Committee of the University of Zambia. Permission to conduct the study was given by the Managing Director of The University Teaching Hospital Board of Management, The Head of Department of Paediatrics and Child Health, and the Director Lusaka Urban District Health Management Team. Parents participating in the study gave written signed consent. Those who expressed willingness to undergo voluntary counselling and testing were referred to the counselling centre within the Department of Paediatrics.

CHAPTER FOUR

RESULTS

Data collection took place over a period of four weeks from the last week of August to the third week of September 2002. A total of 331 parents were interviewed. Of the 331 parents, 178 (58%) were interviewed from U.T.H and 153 (46.2%) were interviewed from Kabwata Under five clinic.

4.1 Social demographic data

The ages of the children brought for health attention ranged from between 0 months to 60 months. The mean age was 11 months. Only 2 children were above 4 years of age.

The sex distribution of children brought to the health institutions is shown in the table below.

Table 1

Sex distribution of children

| Sex | Frequency | Percentage |
|--------------|------------|-------------|
| Male | 171 | 51.7% |
| Female | 160 | 48.3% |
| Total | 331 | 100% |

The distribution of relationship of caregivers interviewed is given below

Table 2 Relationship of caregivers interviewed

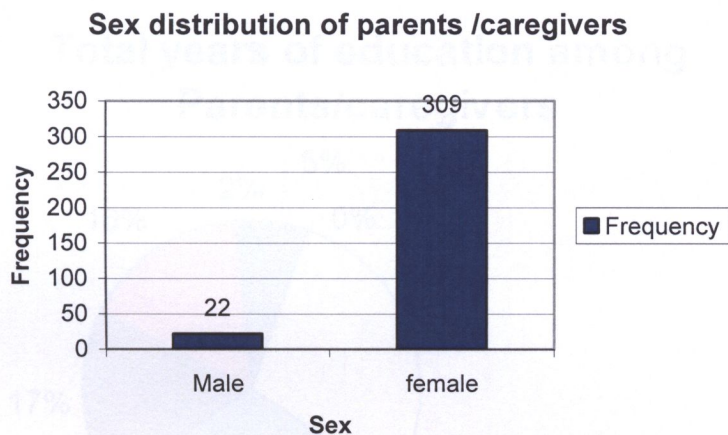
| SITE | RELATIONSHIP | | | |
|----------------|---------------------|------------------|--------------------|-----------------|
| | Mother | Father | Grandparent | Others |
| UTH | 155 | 11 | 8 | 10 |
| Kabwata | 138 | 4 | 1 | 4 |
| TOTAL | 293 (88.5%) | 15 (4.5%) | 9 (2.7%) | 14(4.2%) |

**** OTHERS= Aunts/uncles, siblings, maids**

The average age of the parents/caregivers interviewed ranged between 16 to 68 years with the average age being 27 years. The median age was 25 years.

The sex distribution of parents /caregivers is shown in the following figure

Figure 1 Sex distribution of parents /caregivers



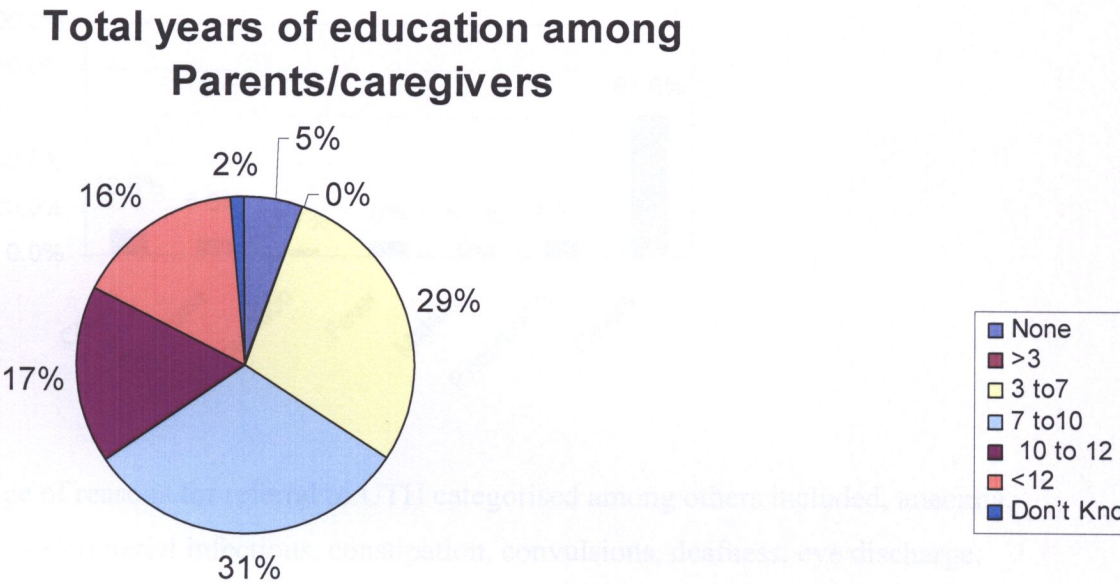
Females 93.4% Males 6.6%

11 (3.32%) respondents having 1 parent of the child as deceased. Of the 11 reported as deceased the sex distribution was: -

Table 3
Distribution of deceased parents

| Sex | Frequency |
|--------|-----------|
| Male | 6 (54.5%) |
| Female | 5 (45.5%) |
| Total | 11(100%) |

Figure 2
Educational background of parents interviewed

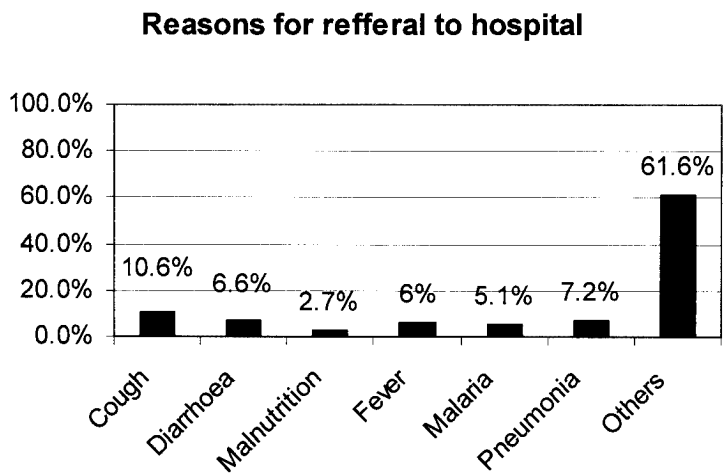


Of those who could not remember their educational level, 4 were over 47years of age and one was 16. The mean educational level was the category between 3 to 7 years of formal education.

4.2 Reasons for referral to hospital

The reasons for referral to hospital are illustrated on the figure below

Figure 3



A wide range of reasons for referral to UTH categorised among others included, anaemia, asthma, ascites, bacterial infections, constipation, convulsions, deafness, eye discharge, ear ache and prematurity.

4.3 Knowledge on the possibility of HIV infection in children

On whether children could acquire HIV, parents /caregivers response was as follows. 93% (308) of respondents were aware that children could contract HIV infection. The breakdown is shown in the table below.

Can children get HIV?

Table 4

| | UTH | KABWATA | TOTAL |
|-------|-----|---------|-----------|
| YES | 166 | 142 | 308 (93%) |
| NO | 12 | 11 | 23 (7%) |
| TOTAL | 178 | 153 | 331 |

4.3.1 Educational level and knowledge of HIV infection in children

When stratified according to educational level the responses as to whether a child can acquire HIV are shown below

Table 5
Educational level and knowledge on HIV infection in children

| EDUCATION Level | YES | NO | |
|--------------------------|------------|-----------|------------|
| None | 13 | 5 | |
| Less than 3 years | 0 | 0 | |
| 3-7 years | 86 | 9 | |
| 7-10 years | 96 | 7 | |
| 10-12 | 51 | 2 | |
| >12 | 57 | 0 | |
| TOTAL | 303 | 23 | 326 |

***** 5 respondents could not recall level of education**

4.4 Knowledge on modes of MTCT

Parents/caregivers interviewed gave the following responses on ways in which children could acquire HIV. Responses given without prompting were ticked on the questionnaire accordingly. 540 responses were given.

Table 6

Modes of transmission of HIV as given by respondents

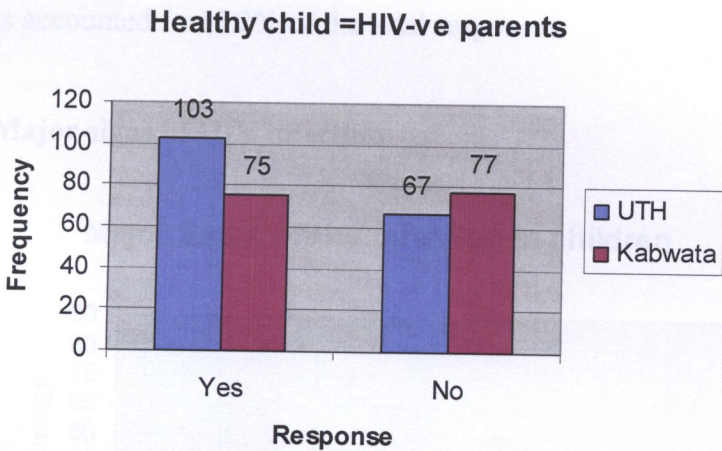
| | |
|---|-------------|
| Don't know | 29 (5.3%) |
| Infected woman during pregnancy | 195 (36.1%) |
| Labour and delivery | 86 (15.9%) |
| Breastfeeding from infected mother | 142 (26.3%) |
| Blood transfusions | 26 (4.8%) |
| Sexual abuse | 6 (1.1%) |
| Blood contact with open wounds | 10 (1.8%) |
| Close contact | 3 (0.5%) |
| Contaminated razors (Tattooing) | 18 (3.2%) |
| Toothbrushes | 1(0.1%) |
| Kissing | 1(0.1%) |
| Sharing meals | 1(0.1%) |
| Contaminated needles (Hospital acquired) | 24 (4.4%) |

4.5 Health status of child in relation to parents HIV status

When asked if an apparently healthy child meant that the child’s parents do not have HIV, the following responses were given

Does healthy child mean parents are HIV free?

Figure 4



Total “yes” responses 55.2%

Total “no” responses 44.7%

9 respondents had no idea

4.6 Knowledge of health problems associated with HIV in children

Seventy four percent (74%) of respondents were aware of problems or illnesses that may be associated with HIV infection in children.

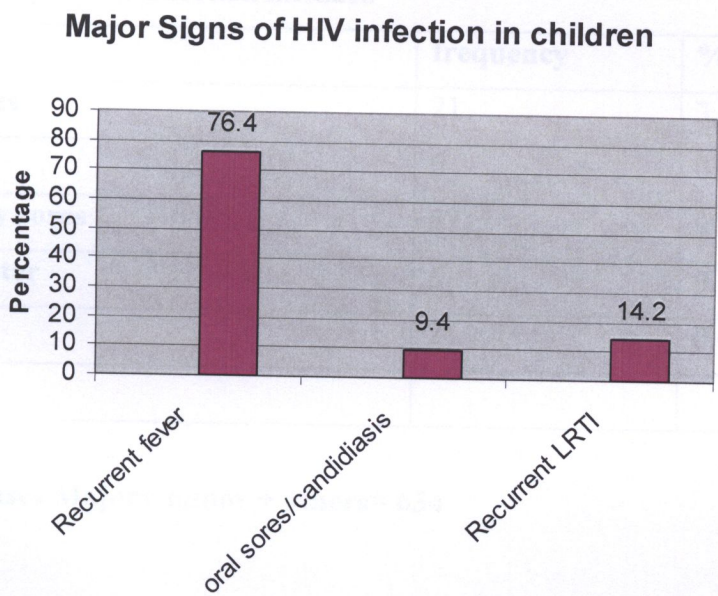
Illnesses associated with HIV infection in children

The problems mentioned as associated with possible infection with HIV in children are given in the figure below. They were divided into major signs and minor signs

4.6.1 Major signs

Major signs accounted for 16.2% of the total responses

Figure 5 Major signs of HIV infection



Recurrent fever

Recurrent fever accounted for 76.4% of the responses in the category of major signs of HIV infection in children.

4.6.2 Minor signs

Minor signs and other signs mentioned accounted for 83.8 percent of the total responses

Table 7

| Minor signs | frequency | % of total responses |
|---------------------------------------|-----------|----------------------|
| Chronic diarrhoea | 142 | 22.4% |
| Weight loss or abnormally slow growth | 125 | 19.7% |
| Generalised lymphadenopathy | 5 | 0.1% |
| Persistent cough | 118 | 18.6% |
| Tuberculosis | 37 | 5.8% |
| Confirmed maternal HIV infection | 10 | 1.6% |

Other signs of possible infection included

| Sign | frequency | %of responses |
|--------------------------|------------------|----------------------|
| Hair changes | 21 | 3.3% |
| Abscesses | 6 | 0.1% |
| Rashes/body sores | 57 | 9% |
| Herpes zooster | 5 | 0.1% |
| Weakness | 2 | 0.05% |
| | | |

Total responses Major+ minor + others= 634

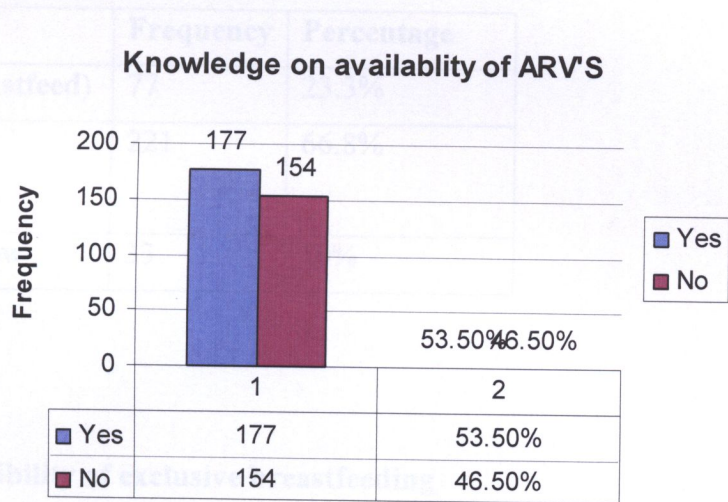
4.7 Knowledge on availability of antiretroviral drugs for PMTCT

Table13

Knowledge on availability of antiretroviral drugs for the management of HIV infection.

Just over 50% of respondents were aware of ARV’s for the management of prevention of HIV infection in children.

Figure 6



173 out of 331 (52.3%) parents/caregivers had received talks on mother to child transmission of HIV during their antenatal period. 142 out of 331 (42.9%) had received no information on prevention of mother to child transmission of HIV with the use of ARV’s during or at the time of delivery. Nine out of 331 (2.7%) were grandparents and question was therefore not applicable.

4.8 Attitudes on HIV and breastfeeding

239 (72.2%) of children whose parents/guardians were interviewed were still breastfeeding.

On the whether HIV+ mothers should breastfeed their infants, the following were the response.

Table 8
HIV and breastfeeding

| | Frequency | Percentage |
|----------------------|-----------|------------|
| Yes (Breastfeed) | 77 | 23.3% |
| No (don't breastfed) | 221 | 66.8% |
| Don't know | 33 | 10% |

4.8.1 Feasibility of exclusive breastfeeding

Responses by parents/caregivers on whether exclusive breastfeeding is possible/feasible up to six are listed in the following table. More than half of the respondents thought that exclusive breastfeeding is not possible.

Table 9

Feasibility of exclusive breastfeeding.

| | Frequency | Percentage |
|-------|-----------|------------|
| Yes | 152 | 46.1% |
| No | 179 | 53.9% |
| TOTAL | 331 | 100% |

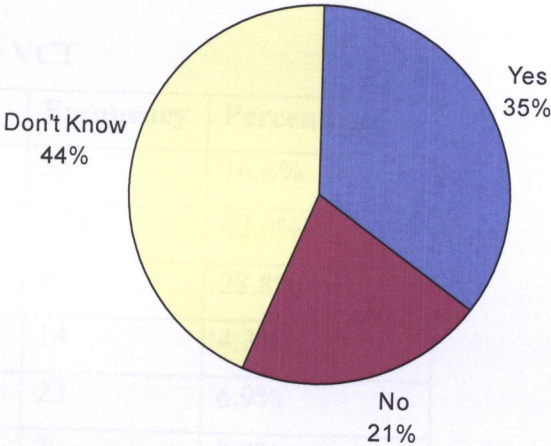
4.9 Knowledge on availability of VCT services

Knowledge by respondents on availability of voluntary counselling and testing services at their respective local clinics is shown in the figure below

Figure

Knowledge on availability of VCT services

Knowledge of availability of VCT services at local clinic



4.9.1 Willingness for VCT

Eighty five percent of respondents were willing to undergo VCT if their child was suspected of having HIV/AIDS.15% were not willing.

Table 10
Willingness for VCT according to site

| Site | Yes | No | Total |
|---------|-----|----|-------|
| UTH | 145 | 33 | 178 |
| Kabwata | 137 | 16 | 153 |
| Total | 282 | 49 | 331 |

4.9.2 Preferred sites for VCT

Preferential sites for VCT by parents/guardians are listed below. Majority of respondents preferred to have VCT at their local health facility.

Table 11
Preferred sites for VCT

| Venue | Frequency | Percentage |
|-------------------|-----------|------------|
| Don't know | 55 | 16.6% |
| Local clinic | 139 | 42.0% |
| Referral hospital | 95 | 28.8% |
| Private clinic | 14 | 4.3% |
| New start centre | 23 | 6.9% |
| Kara counselling | 3 | 0.9% |
| Salvation army | 1 | 0.4% |
| TOTAL | 331 | 100% |

CHAPTER FIVE

DISCUSSION

This study aimed to explore and examine the knowledge of parents and guardians attending health institutions on issues surrounding paediatric HIV/AIDS with emphasis on the presentation of paediatric AIDS, methods of transmission, prevention and availability of ARV's for the management of AIDS. These findings may be useful in strengthening pre existing programmes aimed at prevention HIV/AIDS particularly in the paediatric age group.

5.1 Socio demographic data for parents /guardians

In this study the average age of the parents/caregivers was 27 years the peak of the reproductive age group. This age group would be the primary target for PMTCT programmes even though education on HIV/AIDS including MTCT should have began in primary and secondary schools. However it has been shown that only 27.4 % of adolescents benefited from programmes such as the Anti AIDS clubs in schools (Mwinga 1997). This study also showed that 93.% of children were brought to health facilities by female parents/care givers. This would indicate that female parents/caregivers, particularly mothers who brought 88.5% of children for medical care, are primarily responsible for the health provision of children and in recognising signs and symptoms that may warrant medical attention. Also highlighted, was that males were more likely to accompany a child to a referral centre most likely because of the possible seriousness of the problem warranting medical attention (see table 2). Ninety three percent of parents had received formal education. The majority of parents had received formal education with 59.8% having received 3 to ten years of formal education. Only 16% of parents had received more than 12 years of formal education most likely due to the high school dropout rate after grade nine.

5.2 Infant data

The sex distribution between male and female children brought to the clinic was almost equal (males 51% and females 48.3%). Of note was that only 2 children attending the under five clinic were above 4 years (see 4.1). This is most likely because after booster immunisations at 18 months, parents do not value the necessity of attending under five clinics for growth monitoring. Growth monitoring and immunisation clinics can be used as opportunities to sensitise parents/caregivers of the signs and symptoms of paediatric HIV, voluntary testing and counselling among other topics covered during these visits.

5.3 Referrals to UTH

The disease pattern among the children referred to UTH was similar to those found in other studies with respiratory tract infections being the leading cause of referral (Sinyinza 2003).

5.4 Knowledge on paediatric HIV

Seven percent of parents interviewed thought that children could not get HIV. There was no significant difference between the two sites ($p=0.87$). However, higher level of education was associated with knowledge that children could get the disease ($p=0.00132$).

Infection of the child in utero was the most common response as to the method in which MTCT occurs (36.1% of responses) followed by breastfeeding (26.2%) and labour and delivery (15.9%). This is generally in line with the main mode of transmission being prenatally, intrapartum and postnally through breastfeeding. Of concern the study noted that parents/caregivers thought that spread of HIV can be hospital acquired through the use of contaminated or unsterilised needles in health institutions a situation which is almost non existent as shown by Luo C in a study to determine the diagnosis and risk of transmission of HIV through therapeutic

practices. Tattooing for illnesses in the community is a common practice and the concern about possible transmission through contaminated razors was raised.

Fifty five point two percent of respondents thought that an apparently healthy child meant that the parents were free of HIV. This indicates that parents are using the health of their children as a proxy to their HIV status and this may contribute to under usage of VCT services.

Eighty one parents were able to mention one of the major signs of HIV infection. The most frequently mentioned symptoms of infection with HIV mentioned by parents in order of decreasing frequency were chronic diarrhoea, weight loss or abnormally slow growth, and persistent cough. However, these are minor signs and can easily coexist with malnutrition a leading cause of admission to hospital. Undernourished children and their parents could easily be labelled by the community as being infected with HIV. Confirmed maternal infection with HIV was only mentioned by 10 respondents and therefore did not stand out strongly as a reason to suspect a child born to a mother with HIV of having contracted the disease.

5.5 Knowledge on use of ARV's for PMTCT and for management of AIDS

Only 53% of respondents were aware that there are antiretroviral drugs available to manage HIV. The study therefore showed that there has been ineffective dissemination of the availability and the role of ARV's in the management of HIV. Almost half of the respondents (42.9%) received no information on MTCT during their antenatal period. Considering that all the parents interviewed were parents of children below five years (average age of children was 11 months), with existing PMTCT strategies, most parents should have received some information. Of importance is that Kabwata clinic only provides antenatal care and refers all individuals requiring VCT to either UTH or Kamwala clinic and may explain the lack of knowledge among parents/care givers. However, health facilities providing antenatal services are supposed to cover PMTCT knowledge as well

With a mean age of children whose parents were interviewed of 11 months, 72% of these children were breastfeeding; breastfeeding was shown to be an important source of food security. Nationally the mean age of cessation of breastfeeding is 21 months

5.6 Breastfeeding and HIV

Sixty six percent of respondents thought that HIV positive women should not breastfeed. This highlights some of the difficulties in decision making that HIV positive women who decide to breastfeed have to make. HIV positive women who decide not to breastfeed may be easily stigmatised by the community and this equally highlights the difficult decision HIV positive women who decide not to breastfeed have to make (LINKAGES 2000).

53.9% of respondents thought that exclusive breastfeeding is not feasible. This suggests that methods of reducing MTCT by modified short exclusive breastfeeding may be difficult to achieve.

5.7 Knowledge on VCT services

On whether VCT services were available at respondents respective clinics, 43.9% did not know whether their local clinic provides VCT services yet 42% preferred to attend their local clinic for VCT should they want a test. Parents and guardians may increase usage of VCT if knowledge of services provided by local clinics is disseminated.

Willingness to undergo VCT by respondents if they suspected their children of having HIV was expressed by 85.2%. This is similar to studies that have shown acceptance rates of VCT of 83% among hospitalised children.

CHAPTER SIX

RECOMMENDATIONS AND CONCLUSIONS

6.1 Conclusions

- The commonest symptoms associated with HIV in children mentioned by respondents were;-
Chronic diarrhoea of more than one month's duration
Weight loss or abnormally slow growth
Persistent cough
Signs more specific of HIV were known by very few parents/caregivers.
- Parents/guardians are aware of the routes of MTCT. The commonest routes mentioned were:-
Infection of the fetus in utero and breastfeeding
- There are still some misconceptions about needles and syringes used in the hospital setup and close contact with HIV infected individuals as a means of acquiring HIV in children.
- Knowledge on PMTCT as well as availability of anti retroviral drugs for the management of HIV was below what would be expected with existing anti AIDS programmes and PMTCT.
- About half of respondents are aware of the availability of antiretroviral drugs for the management of HIV/AIDS.
- Parents/guardians prefer to go to their nearest health centres for Voluntary Counselling and Testing Services and are willing to go for VCT if their children are suspected of being infected with HIV.

6.2 Recommendations

- Despite existing programmes to combat HIV/AIDS in Zambia, there is need for sustained aggressive sensitization on the clinical presentation and management of HIV/AIDS particularly paediatric AIDS.
- Existing health education structures such as under five, family planning, antenatal and nutrition clinics can be used as a platform for sensitisation of the community on paediatric HIV/AIDS as well as an entry point for the HIV/AIDS continuum of care.
- Male involvement in the management of childhood illnesses should be encouraged.
- Print and electronic media should be involved in the dissemination of information on paediatric AIDS.
- Health institutions should make known all services provided by the institution and should refer patients requiring services they do not offer, particularly VCT, to facilities providing them. Strategies that can be employed by health include production of brochures, focus group discussions as well as community talks and dramas.

6.3 Study limitations

Use of a structured questionnaire may have resulted in restriction of the responses given by parents/guardians in the study. Focus group discussions with parents could have added more depth to the results of this study.

Parents particularly at the referral site were apprehensive about the health of their children and may have given inaccurate responses.

Filling in the forms for the parents/guardians by the researcher may have resulted in diluted information being collected.

REFERENCES

1. Abrona SI, Melville SK, Hanson C, et al. 2001 Mother-to-child transmission of the human immunodeficiency virus in Texas. *Pediatr. Infect. Dis* 20:602-606.
2. Borgdoff M et al. Sentinel surveillance for HIV-1 infection: how representative are blood donors, outpatients with fever, anaemia or sexually transmitted diseases and antenatal attenders in Mwanza region, Tanzania. *AIDS*, 1993.7 : 567-572.
3. Brotman R et al. Childbearing women at risk for HIV infection in New York City. *AIDS Pub Policy Journal*, 1993 8 (4) :186-193.
4. Central Statistical Office: Ministry of Health: Demographic and Health Survey Chapter 8, P9, 105, 123, 1995.
5. Centres for Disease Control and Prevention: Administration of Zidovodine during late pregnancy and delivery to prevent perinatal HIV transmission, Bangkok Thailand. *Lancet* 1999
6. Centres for Disease Control and Prevention Update: perinatally acquired HIV/AIDS – United States 1997 MMWR Morbidity Mortality Weekly Report 1997;46: 1086 – 1092.
7. Chintu C Malek A: Case definition of paediatric AIDS the Zambian experience: *Int J STD and AIDS* 1993 Vol 4 483-85
8. Coustoudis A, Pillay K, Khun L Spooner E, et al Method of feeding and transmission of HIV-1 from mothers to children by 15 months of age: prospective cohort study from Durban South Africa. *AIDS* 2001,15 :379-387



9. De Cock KM, Fowler MG, Mercier E et al. Prevention of mother to child transmission of HIV in resource poor countries: translating research into policy and practice. *JAMA* 2000 283: 1175-1182.
10. De Cock K. Heterogeneity and Public Health in the Global HIV/AIDS Epidemic. *Top. HIV Med* 2001. 20:602-606.
11. Dunn DT, Newell ML, Ades AE, Peckham CS. Risk of human immunodeficiency virus type 1 transmission through breastfeeding. *Lancet* 1992;340;585-588.
12. Fridland, et al: Transmission of the human immunodeficiency virus. *New England Journal of Medicine*. 317:1125, 1987
13. Fylkessess et al: HIV counselling and testing: Overemphasising high acceptance rates a threat to confidentiality the right not to know *AIDS* 2001,15: 907-916.
14. Gray R H et al. Population based study of fertility in women with HIV-1 infection in Uganda. *Lancet*,1998,351:98-103.
15. Hira SK, Mangrola UG, Mwale C, et al. apparent vertical transmission of human immunodeficiency virus type 1 by breastfeeding in Zambia. *J Pediatr* 1990; 117:421-4.
16. Kind C, Rudin C, Siegrist CA et al. Prevention of vertical HIV transmission: additive protective effect of elective caesarean section and zidovudine prophylaxis. *AIDS* 1998. 12: 205-210.

17. Lallemand M, Jourdain G, Le Coeur S et al. A trial of shortened Zidovudine regimens to prevent mother to child transmission of human immunodeficiency virus type 1. *N. Engl J Med* 2000. 343:982-991
18. Lapage P, Van de Perre P, Sellati P, et al. Mother-to-child transmission of human immunodeficiency virus type-1 (HIV-1) and its determinants: a cohort study in Kigali Rwanda. *Am J Epidemiol* 1993; 137:589-99.
19. Leroy V, Newell ML, Dabis F et al. International multicentre pooled analysis of late postnatal Mother-to-Child Transmission of HIV-1 infection. Ghent International Working Group On Mother-to-Child Transmission of HIV. *Lancet*. 1998;352:597-600
20. LINKAGES. Ndola Demonstration Model Formative Research on Infant feeding methods and HIV. 2000 unpublished.
21. Luo C: HIV infection among hospitalised children at UTH: Diagnosis and Risk of Transmission through therapeutic practices, 1991. Unpublished MMed Dissertation
22. Mandlebrot L, Lechenadec J, Berrebi A, Bongain A, Benifla J, Delfraissy J. Perinatal HIV-1 transmission: Interaction between zidovudine prophylaxis and mode of delivery in the French Perinatal Cohort. *JAMA*. 1998 280:55-60.
23. Miotti PG, Taha TE, Kumwenda NI, et al. HIV transmission through breastfeeding: a study in Malawi. *JAMA* 1999;282:744-749

24. MOH/CBOH Background projections impacts and interventions HIV/AIDS in Zambia 1999.
25. MOH/CBOH Zambia Sexual Behaviour Survey 2000
26. MTCT Working Group Zambia Formative Research 2000 unpublished
27. Mwiinga K. HIV/AIDS and Adolescents: Knowledge Attitude and Practice in secondary school adolescents in Lusaka 1997. Unpublished MMed Dissertation
28. Nduati R, John G, Mbori-Ngacha D, et al. Effect of breastfeeding and formula feeding on transmission of HIV-1: a randomised clinical trial. *JAMA* 2000;283:1167-1174.
29. Palasanthiran P, Ziegler JB, Stewart GJ, et al. Breastfeeding during primary maternal human immunodeficiency virus infection and risk of infection from mother to infant. *J Infect Dis* 1993;167: 441-4
30. Piot et al An international perspective on HIV/AIDS. *AIDS Science* 239:573, 1988.
31. Quinn TC: Global burden of the HIV pandemic *Lancet* 1996, 348:99 – 106
32. Ram Yoger et al Nelsons textbook of paediatrics 16th edition 268 p1025-1025.
33. Selik et al HIV infection as a leading cause of death among young adults in united States cities and States. *JAMA* 1991,271:903

34. Shilalukey et al .Clinical presentation of HIV/AIDS in high risk neonates in Zambia: Early Human DevelopmentPg 221-224,1992
35. Sinyinza F. Impact of HIV on Childhood morbidity and mortality among under five children hospitalised at the UTH Lusaka 2002 unpublished.
36. UNAIDS. Report on the Global HIV/AIDS Epidemic. June 2000
37. The Working Group on Mother to Child Transmission of HIV – 1 in Africa, America and Europe: Results from 13 perinatal studies. *Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology*, 1995: 8:506 – 510.
38. Ziegler JB, Cooper DA, Johnson RO, Gold J. postnatal transmission of AIDS-associated retrovirus from mother to infant. *Lancet*.1885;1:896-898

PAEDIATRIC HIV/AIDS KNOWLEDGE QUESTIONNAIRE.

Study number / ___/___/___

Date ___/___/___

Site UTH[___] CLINIC [___] File NO/Clinic no [___]

Referral clinic or nearest local clinic _____

Social demographic data

1. Age of child in months ___/___ . Sex (child) M [___] 1 F [___] 2 3. Age of parent

/guardian ___/___

4. Relationship of caregiver to patient

Mother [___] 1 Father [___] 2 grand parent [___] 3 Uncle/aunt[___] 4 Sibling[___] 5
Other[___] 6

5. Are parents both alive [___] 1 one parent deceased M or F [___] 2 Ill [___] 3

6. Sex of caregiver /parent interviewed M [___] 1 F [___] 2

7. Educational background

none [___] 1 less than 3 [___] 2 3-7 [___] 3 7-10 [___] 4 10-12 [___] 5 more than
12[___] 5

Past medical history

8. Reason for hospitalization/referral

Malaria [___] 1 Pneumonia [___] 2 Diarrhea[___] 3 failure to thrive [___] 4 Tb [___] 5 other specify

9. How many previous hospitalisations to UTH has child had? none[___] 1 1[___] 2 , 2[___] 3 More than 2
[___] 4

Knowledge on HIV

10. Can children get HIV? Y [___] 1 N [___] 2

11. If yes how?

Don't know [___] 1

Through HIV Infected pregnant mother [___] 2

During labour and delivery [___] 3

Breast-feeding if mother is infected with HIV ☐ 4

Blood transfusions ☐ 5

Sexual contact with infected partner ☐ 6

Others specify _____

12. Does apparently healthy child mean parents don't have HIV? ☐ 1 N ☐ 2

13. Do you know any problems associated with HIV/AIDS in children? Y ☐ 1 N ☐ 2 If yes which ones

Recurrent fever at least one month's duration ☐ 1 respondent to mention duration

Recurrent oropharyngeal candidiasis (White sores in mouth) ☐ 2

Recurrent lower respiratory tract infections (Pneumonia) ☐ 3

Chronic diarrhoea of at least one month's duration ☐ 4

Weight loss or abnormally slow growth ☐ 5

Generalised lymphadenopathy ☐ 6

Persistent cough of at least one month's duration ☐ 7

tuberculosis ☐ 8

Confirmed maternal HIV-1 infection ☐ 9

Others _____

Infant feeding practices knowledge on MTCT/ARV's

14. Do you know if drugs are available to specifically manage HIV/AIDS? Y ☐ 1 N ☐ 2

15. Did you ever receive any talks on MTCT during antenatal period (If caregiver is a female & has children.) Y ☐ 1 N ☐ 2 N/A ☐ 3

16. Have you heard of drugs used to reduce MTCT of HIV during pregnancy/delivery? Y ☐ 1 N ☐ 2

17. Is child breast-feeding? Y ☐ 1 N ☐ 2

18. Do you think an HIV + mother should breastfeed her child? Y ☐ 1 N ☐ 2

19. Do you think exclusive breast feeding is possible for up to six months Y ☐ 1 N ☐ 2 don't know ☐ 3

20. Are VTC facilities available at your local health center Y ☐ 1 N ☐ 2 don't know ☐ 3

21. Would you and your child be willing to go for HIV test after receiving further information if you suspected your child of having the disease Y ☐ 1 N ☐ 2

22. Where would you go for a test should you want one

Don't know ☐ 1

Local clinic ☐ 2

Referral Hospital ☐ 3 Private clinic ☐ 4 Others _____

Sign for consent _____

INFORMED CONSENT FOR PARTICIPATION IN A STUDY TITLED;
KNOWLEDGE OF PARENTS/GUARDIANS ATTENDING OUTPATIENTS REGARDING
PRESENTATION OF SYMPTOMATIC PAEDIATRIC HIV AND RELATED FACTORS

English

The aim of this study is to find out how much parents/guardians know about how HIV presents itself in children. The study will in no way affect the treatment your child is to receive in hospital or at the clinic.

Also, participating in the study has no implication on the HIV status of you and your child.

I have been fully informed about this study and I am aware that should I choose not to participate in the study my child's treatment will not be affected. Equally should I consent to participate, I will be given no special service or any payments or gifts. I also understand that I may wish to withdraw at any stage of the study.

I hereby consent to participate

Nyanja

Mafunso aya ya tandisa kuti ti sibe amai, asibambo na bamene basunga bana chamene ba siwa pa matenda yamene yana bwela ya kadoyo ya AIDS. Mafunso aya si ya za chilgilila mankwala yamene mana a yenela ku tenga.

Nisiwa za mafunso aya. Ni ka vomela kuyanka mafunso aya kulibe chilli chonse chamene ni za pasiwa. Ni ka funa ku choka mu mafunso aya kulibe chilchone choipa chamene chi za chitiwa ku mwana wanga.

Na pasa lamulo kuti banifunse mafunso yamene yafunika.

----- Signature of Parent

-----Signature of research assistant Name