

CHAPTER 1 INTRODUCTION

1.0 BACKGROUND.

The Acquired Immune Deficiency Syndrome (AIDS) pandemic is challenging societies, and health systems in particular in myriad ways; many of these challenges involve significant ethical dilemmas (WHO 2002). Various ethical issues relating to Human Immune Deficiency Virus (HIV) prevention, testing and treatment have been discussed in published literature, including placebo trials for the prevention of mother-to-child transmission (PMTCT) and, most recently, routine testing (MOH essential competence ART, PMTCT 2006) .

Currently there are 1,028 Voluntary Counseling and Testing (VCT) centers and 678 PMTCT centers in Zambia to ensure accessibility to services and encourage individuals to know their HIV status (Sinkala et al 2005). This is very important because VCT/PMTCT is the entry point to prevention, treatment, care and support (National HIV/AIDS strategy framework 2006-2010).

Almost half of the 33.2 million people living with HIV in the world are women (15.4 million). In sub-Saharan Africa, where two-thirds (22.5 million) of all those living with the virus reside, the majority are the women still (UNAIDS/WHO 2008). The prevalence of HIV in Zambia is 14.3% generally but in urban areas alone it's 19.7% with 17% in Copperbelt and 23% for Kitwe in particular (Zambia Demographic and Health Survey- ZDHS 2007). This scenario may worsen with the proximity of Kitwe to Solwezi of North- Western province, where there is a hive of activity (increased population and socialization for both districts - business opportunities and job seekers) due to the newly opened Kantanshi and Lumwana mines. The majority of the infected are women (61% in Sub-Sahara Africa, 16% in Zambia), and since the disproportionate impact of AIDS on women has been widely documented it will not be reviewed again here. What has been less documented and examined, however, despite the emphasis on PMTCT, is the intersection between maternal/child health and AIDS.

Mother-to-child transmission (MTCT) is the overwhelming source of HIV-1 infection in young children (Joint UNAIDS/WHO 2006). According to the World Health

Organization (WHO), during the year 2002, despite effective antiretroviral (ART) therapy, there were approximately 800 000 new infections in children world-wide, the majority of whom were from resource-limited countries like Zambia (De Cock k. 2000).

In June 2001 the United Nations (UN) General Assembly Special Session on HIV/AIDS targeted PMTCT as one of the priority areas. More than 100 heads of state committed their governments to decreasing the proportion of infants infected with HIV by 20% (160000 infants) by 2005 and 50% by 2010. This is laudable but these goals demand enormous expansion of the projects, including widespread mobilization of the community, use of the existing Maternal and Child Health (MCH) services including testing children of positive mothers. The heads of states submitted “We need to reach 7,000,000 women, with 100% efficiency, a sero-prevalence of 16%, and a reduction in transmission of 50%, if there are to be 160,000 fewer infants infected”. If the efficiency remains between 18 and 37%, the number of women accessed in antenatal care geometrically increases from 17,000,000 to 38,000,000 to decrease the number of infected infants by 160,000. Seven million women with HIV exceed the estimates of annual deliveries to HIV+ mothers (Wilfert 2002).

The PMTCT strategy, defined by the World Health Organization (WHO) in the late 1990s and endorsed by the UN system, is the framework under which maternal health care is meant to be addressed within AIDS responses. PMTCT consists of four components:

1. Prevention of HIV infection among young people and pregnant women.
2. Prevention of unintended pregnancies among HIV-positive women.
3. Prevention of HIV transmission from HIV positive women to their infants.
4. Provision of treatment, care and support to HIV-infected women and their families.

While comprehensive in theory, in practice PMTCT programs have tended to focus on the third component of the strategy. The intersection between HIV and pregnancy exposes the ethical and legal inequalities inherent in a societal structure that places more value on a woman’s reproductive health (WHO Gender outcomes 2004). With

this consideration the child's welfare is taken care of and the issues of HIV testing in children will be addressed.

To understand why some women choose to have their children tested or not tested, as it is the case for those who drop out, the Health Belief Model (HBM) is used. This theory is appropriate because it deals with health promotion or illness prevention of acute or chronic nature. It focuses on an individual's perception of barrier, like stigmatization in case of HIV test, threat of serious illness or even death if diagnosis is delayed, and the benefit of avoiding the threat by probably knowing one's status, and early interventions and treatment. Motivation to take action comes by weighing all the three components of the HBM (Conner & Norman 1996).

Studies done to show adult compliance to testing even among the Antenatal mothers in PMTCT have shown apathy as well as high dropout rates for various reasons (Manzi et al 2005). However, very little has been done on child testing participation elsewhere or in this country.

There is need to investigate the cause of the disparity in mothers who test positive and the children tested/and or exposed babies and those who are tested e.g. 2589:392 positive mothers/tested babies in 2008; 1345:672 exposed/tested babies in 2009 & 1242:871 exposed/tested babies in 2010 (HIMS Kitwe DHMT on PMTCT).

Tables 1.1 HIV+ mothers & tested babies on PMTCT in 2008 from 6 selected clinics

| CLINIC | MOTHERS | BABIES | % |
|------------------|----------------|---------------|-------------|
| Intimpi | 179 | 13 | 7.3 |
| Chimwemwe | 1447 | 158 | 10.9 |
| Buchi | 282 | 66 | 23 |
| Ndeke | 329 | 86 | 26 |
| Luangwa | 316 | 53 | 16.8 |
| Zamtan | 36 | 16 | 44 |
| Total | 2589 | 392 | 14.4 |

Sources: HIMS Kitwe DHMT 2008

Tables 1.2 Exposed & tested babies on PMTCT in 2009 from 6 selected clinics

| CLINIC | Exposed babies | Tested babies | % |
|------------------|-----------------------|----------------------|------------|
| Intimpi | 30 | 9 | 30% |
| Chimwemwe | 336 | 120 | 35.7% |
| Buchi | 450 | 171 | 38% |
| Ndeke | 243 | 216 | 88.8% |
| Luangwa | 260 | 137 | 52.7% |
| Zamtan | 26 | 19 | 73% |
| Total | 1345 | 672 | 50% |

Sources: HIMS Kitwe DHMT 2009

These disparities have been attributed to insufficient and poor data collection as well as inability to track down mothers/exposed babies who are not brought for the test. Early diagnosis of HIV is crucial for timely initiation of ART in infants and children reducing morbidity and mortality in this vulnerable group.

The inability to diagnose HIV infection early in children especially through PMTCT programs, severely limits access to treatment.

The concept of “prevention is better than cure” is not just logical, but it’s also cost effective if the Government gave prophylactic treatment to the children who really need it (HIV+), and not to every child born of HIV+ mother (MOH children’s card 2007) .

This study will reveal acceptance level and factors that influence HIV testing in children born of HIV positive mothers in PMTCT, an area with very scanty information. It will help to generate data as a basis for subsequent studies and interventions in PMTCT. The results will also be used to give guidance in making changes in the approach and probably the policy on child testing in PMTCT and improve their management.

1.1 DEFINITION OF KEY CONCEPTS

- 1.1.1 **Acceptance:** Participation/agreement to have the child tested for HIV.
- 1.1.2 **Barriers:** Obstacle or difficulty experienced to have the child tested.
- 1.1.3 **Benefits:** The expected reward of having a child tested.
- 1.1.4 **Determinants:** Factor influencing decision to accept or not accept the HIV test.
- 1.1.5 **Exposed child:** Child born by an HIV+ mother.
- 1.1.6 **HIV status:** Infection status (+ or -) of an individual based on laboratory evidence of the presence or absence of the HIV in the blood, using standard tests.
- 1.1.7 **PMTCT:** A strategy under-taken to protect children born of HIV+ mothers from getting infected.
- 1.1.8 **HIV-test:** An investigation done to determine the HIV status.
- 1.1.9 **Child:** An infant or minor between the ages of 6 weeks-18 months who is legible to child HIV status test in PMTCT.
- 1.1.10 **Postnatal Mother:** A woman who gave birth to a child and is on PMTCT register.
- 1.1.11 **Delivery:** Giving birth.

CHAPTER TWO LITERATURE REVIEW

2.0 HIV/AIDS GLOBAL PICTURE

Literature shows that HIV is a big socio- economic and a major public health problem worldwide with over thirty three million people infected (Global AIDS epidemic/un aids.org 2010). Two third of these are in Sub-Sahara Africa where Zambia is. It was first reported and diagnosed in 1984 with a rapid prevalence among the reproductive age group of 15-49 years (WHO 1984).

The disproportionate distribution of the disease is also observed throughout the world not just geographically but also by gender, with women being the most affected than men.

In response to the pandemic the UN through the WHO, encouraged governments to scale up the fight against HIV/AIDS by including it in the Millennium Development Goals (MDGs) and achieve 50% reduction by 2010-MDG No 6 (en.wikipedia.org/wiki/UN Millennium Development Goals).

The developed countries were also prompted to support the developing countries in fighting the scourge by providing the much needed resources. For example the United States of America through the President's Emergency Plan for AIDS Relief (PEPFAR), provides funds for HIV prevention activities especially those to do with promotion of abstinence among the youth (PEPFAR 2008). This has been criticized because it discriminates the most vulnerable groups like prostitutes who earn a living sexually. None the less, to date there is no cure for HIV infection apart from the Anti retroviral drugs and an immune booster which delays the progress of the infection to full blown AIDS (WHO, 2008).

This makes prevention the only alternative to fight and conquer the scourge of HIV/AIDS world over, a struggle marred by social stigmatization, poverty, scarcity of resources and uncertainty especially in the case of children whose welfare service can only trickle down through their mothers or guardians (Deacon H. & Stephany 2007).

2.0.1 Sub-Saharan Africa

Sub-Saharan Africa, the hardest hit region, is home to two-thirds (67%) of people living with HIV/AIDS, or 22.0 million people, but only about 11–12% of the world's population. Most of the world's children with HIV/AIDS (90%) live in the region. Almost all nations in this region have generalized HIV/AIDS epidemics—that is, their national HIV prevalence rate is greater than 1%. In 9 countries, more than 10% of adults are already estimated to be HIV positive. South Africa is estimated to have 5.7 million people living with HIV/AIDS, the highest in the world, and almost one in five South African adults is HIV positive. Swaziland has the highest prevalence rate in the world (26.1%). However, the latest data are promising—in many countries, national HIV prevalence has either stabilized or is showing signs of decline (UNAIDS/WHO, 2008a).

2.0.2 Zambia's Profile of HIV/AIDS

Zambia's population is estimated at 12.3 million of which it is estimated that 14% are HIV positive (CSO, 2007) and at the moment, she is currently experiencing a myriad of crises because of the HIV/AIDS epidemic. Zambia, in southern Africa, has one of the world's most devastating HIV and AIDS epidemics with a prevalence of 14.3%. The ratio for women and men stands at 16% to 12% respectively (ZDHS 2007).

One in every six adults in Zambia is living with HIV and life expectancy at birth has fallen below 40 years. This has compounded Zambia's existing economic problems. In four decades of independence, Zambia has found peace but not prosperity and today it is one of the poorest and least developed nations on earth. Although Zambia has received hundreds of millions of dollars from rich country governments toward HIV programmes, prevalence rates are not dropping and have remained more or less stable since the nineties, at as high as 25% in urban areas (UNAIDS/WHO, 2006).

Although declining HIV trends have been observed in young people since 1998, HIV/AIDS in Zambia is still a major threat to the lives of women in the reproductive age group and their children. Approximately one in five expectant women in Zambia is infected with HIV. In Zambia, PMTCT services were implemented in October 2001 as part of Ministry of Health routine prenatal care in two Lusaka district clinics.

Services were scaled up to all 24 Lusaka District clinics and the University Teaching Hospital by December 2003. The current number of PMTCT sites nation wide is over 1,000 out of which 25 are in Lusaka Province (Sinkala et al. 2005). One of the thrusts of PMTCT has been motivating HIV status test and disclosure to partners among expectant mothers; drawing heavily from enunciations contained in The Power of Partnerships: The U.S. President's Emergency Plan for AIDS Relief (PEPFAR, 2008). This encourages the much needed male involvement in PMTCT.

2.1 VOLUNTARY COUNSELING AND TESTING (VCT)

HIV- Voluntary counseling and testing is the process whereby individuals or couples undergo pre-test counseling, risk assessment, and same-day or later rapid HIV test, post-test HIV prevention counseling, and referral for medical and support services by trained counselors (Irungu et al 2008).

VCT is an important HIV prevention strategy used in most of the countries. It's not only the entry point to all HIV and AIDS services – including the starting of life saving ARV treatment and other prophylaxis interventions, but it's also the only way that we can know for sure where the majority of the infections are taking place. Only then can we properly address and direct our resources and prevention strategies effectively and appropriately. It was considered to be a cornerstone of the UN's 2001 to 2005 strategic plan for HIV and AIDS prevention, particularly because it:

1. Helps people to learn more about HIV, their status, and how to prevent being infected or infect others, more so in cases of mixed cross where an HIV+ mother gives birth to an HIV- child or one spouse tests positive while the other is negative.
2. Serves as an entry point to other HIV prevention and care services, such as family planning, support groups, antiretroviral drugs, planning for the future, and prevention of mother-to-child transmission of HIV, sexually transmitted infections (STIs), prevention and management of opportunistic infections, normalization and destigmatization of HIV.
3. Assists clients to accept and cope with their HIV status.
4. It's considered to be an effective and cost-effective means of facilitating behavior change (Azwiangwi et al 2007).

Voluntary counseling and testing in its simplest concept is client initiated with minimal interference from the health provider. Traditionally it consists of the three 'Cs' – consent, counseling and confidentiality (Sofia et al).

Different types of counseling is done at every opportunity available e.g. preventive counseling in primary prevention, pre-test counseling before undertaking an HIV test, post-test counseling before receiving the test results usually done simultaneously with disclosure and supportive counseling. Other types include acceptance counseling as in positive living, crisis and bereavement counseling, couple counseling or stand alone site counseling (Irungu T. K et al 2008). In Zambia

Currently attention is also focused on other ways of providing counseling like 'provider - initiated HIV testing and counseling' (PITC) which was introduced by the UNAIDS in conjunction with the WHO in 2006 (WHO 2007). Mandatory testing is another widely discussed alternative especially among the antenatal mothers with critics emanating from Human rights groups and ethics committees (Russell Armstrong 2008). Some authorities also promote routine VCT for every person visiting any public health institution (Gruskin S. et al 2007). Such a step would require some form of evidence or proof that one underwent VCT at some point and time and for how long it should be valid. Also this may work very well for children, antenatal mothers, the sickly and the poor because of their frequent visits to public health facilities and not those without symptoms or able to afford private medical services.

2.1.1 Uptake of Voluntary Counseling and Testing.

Studies on acceptability done on adults in this country or elsewhere and particularly Malawi in 2005 have shown a very low participation in VCT, and unacceptable loss to follow up in PMTCT (Manzi M et al 2005).

In Zambia only about 1.5million people have taken an HIV test irrespective of the reason. This translates to only about 15% of the total population which is unacceptably low (ZDHS 2007). This has been attributed to numerous factors like stigma, distance to service centre, transport costs, and accessibility.

To promote accessibility and to overcome transport problems, mobile VCT, home-based VCT, and stand alone services apart from the types of VCT mentioned above, have also been suggested and proved to increase VCT uptake even in this country (Matovu & Makumbi 2007). These are positive efforts to ensure participation by individuals, couples or families, and not just for antenatal women who have no choice at this time when they are most vulnerable with anxieties for their unborn child. As such, it's only prudent that it's addressed with utter most importance that it deserved.

2.1.2 Ethical issues

Ethics is the systematic study of moral reasoning in theory and practice (Reich W 1995). It clarifies questions about right and wrong but also demonstrates their

complexity: most ethical theories and many moral judgments are contestable. Some norms, values or principles are sufficiently widely agreed for codes of professional practice or laws to be based on them. But no ethical theory or decision-making yields the same conclusions to convince everybody because of different beliefs, cultural backgrounds and life experiences that influence our views of right or wrong. However conceptual frameworks like deontology (doctrine of duty), philosophy of distributive justice, liberal or theology have been developed over the years to govern ethical issues (Journal of the Association of Physicians in AIDS care 9197).

In Health care ethics, the concept framework mostly used in analyzing medico-moral questions is that of the Principles of Bio-ethics. These are mainly respect for the autonomy of persons, beneficence and justice. Respect entails serious consideration and protection of personal decisions even for those who lack decision-making capacity like children or individuals vulnerable to abuse. It also includes issues of confidentiality especially over sensitive subjects like HIV testing (Boyle J 1987).

Beneficence imposes a positive obligation to act in the best interest or gain to an individual. Any kind of research concerning a human being or just in general, should have benefit or at least contribute to the body of knowledge to influence decisions on policy. Justice on the other hand requires people to be treated fairly with an equal distribution of burdens and benefits regardless of their HIV status. Both parties (HIV positive or negative) however, have an obligation to safe guard the public at large, hence the importance of effective laws and policies (Beauchamp, Childress J. 1989). All these principles and even those which may not have been mentioned here must be put into consideration when dealing with issues of HIV testing.

2.2. HIV/AIDS PANDEMIC AND CHILDREN

The UN convention on the rights of the child (CRC) states that children are entitled to special care and assistance and that this care and assistance should enable 'full and harmonious development' (CRC in Amon 2002: 143). There is a general consensus that there is an onus on society in general to care for children (especially when family care is inadequate), and that negative experiences in childhood can have very long term effects on adults, and thus on the future of society.

The HIV/AIDS pandemic poses major threats to the socio-economic and

psychological welfare of HIV-affected and infected children. The pandemic can adversely affect household stability and sustainability, children's access to healthcare and schooling, state of health and nutrition, and increase affected children's vulnerability to infection (Richter et al 2004). It can also increase the extent to which children are placed prematurely in the position of caregivers and household heads especially child headed households (Barrett et al 1999; & Stein et al 1999).

The massive impact of the HIV/AIDS pandemic on children and their support systems in families and communities has prompted fears that millions of children will not receive proper care and assistance for their proper development while these fears have prompted increased research interest in children affected by HIV/AIDS, a number of researchers now suggest that concerns' about threats to state security posed by growing numbers of orphans have been overstated- the main challenge is addressing increased poverty in high-prevalence countries (Nattras 2002). Extended family support systems especially in Africa have mitigated or delayed the effects of widespread orphan-hood on society but because of high poverty levels the burden is too much and Governments have to get involved. Children have also historically experienced similar disadvantages when faced with stressors but children affected by HIV/AIDS are more likely to become depressed than to act out their distress (Wild et al 2005).

A large number of organizations have attempted specifically to address the needs of children in the context of HIV/AIDS. Most concern about assessing and addressing the needs of HIV-affected children initially focused on identifying material needs that would no longer be met in conditions of increasing poverty, absence of parental protection and the erosion of parental protection and educational systems in the HIV/AIDS pandemic (Gilborn et al 2001). There has been some recent attention paid to the psychological needs of children affected by HIV/AIDS, a discussion in which stigma has featured prominently be it for those infected, at diagnosis, treatment or those affected by having sick parents etc (Deacon H & Stephaney 2007). This has repercussions on HIV prevention in children visa vie child testing and treatment.

2.3. PREVENTION OF MOTHER TO CHILD TRANSMISSION (PMTCT)

About 1.25 million of the 18 million women who deliver annually are HIV positive, and mother to child transmission (MTCT) accounting for the majority of the more than 700,000 latest estimation of new HIV infection in children worldwide annually, is the current global picture. Without interventions of PMTCT HIV infected mothers have around 40% (in the light of ART 35%) overall risk of transmitting HIV to their unborn child during pregnancy, delivery and breastfeeding. PMTCT gives 75% protection of the child and knowledge of the status would increase their safety and survival (USAID Global HIV news 2007).

The PMTCT strategy was first introduced by the WHO/UNAIDS in 1994. The Zambian Ministry of Health PMTCT program was implemented in 2001. This was to ensure that all expectant women are provided HIV testing and counselling as part of routine antenatal care. From October 2001 to March 2005, 188,027 expectant women were counseled for HIV out of which 137,007 (72%) were tested for HIV and 31,565 were diagnosed as HIV infected (23%) with 10,276 of them testing RPR positive. Of these women, 26,666 received Nevirapine prophylaxis (84%) but only 10,247 babies were documented to have received the Nevirapine at birth (38%) (Sinkala, et al. 2005). This signifies a very high drop out rate and has implications on the efficiency of counselling and inevitably PMTCT service provision component of child HIV status test. Improving efficiency means looking at PMTCT comprehensively including child HIV status test component.

The evidence based practices able to reduce Mother to Child Transmission are:-

- Prevention of HIV infection among young people, and unwanted pregnancies, testing pregnant women and their partners for HIV and providing them with services known to reduce MTCT such as use of ART, condoms and care during child birth and postnatal.
- Protecting adolescents and women in the reproductive age from infection through health education about HIV transmission and safer sex practices.

The WHO stated the PMTCT strategy components in the 1990s as;

Component 1: Prevention of HIV infection among young people and pregnant women.

This component of PMTCT strategy calls for preventing of HIV infection among women of reproductive age. Despite repeated calls for countries to scale up prevention services, as of 2006, globally only 9% of sex acts with a non-regular partner were undertaken with the use of a condom. Fewer than 20% of people with sexually transmitted infections, which are known to increase both risk of infection and transmission of HIV, were able to get treatment. In sub-Saharan Africa, only 12% of men and 10% of women knew their HIV status. These facts point to serious failures in prevention efforts despite proven evidence-based strategies that could dramatically reduce new HIV infections if scaled up (UNAIDS/WHO 2006 Update).

There are several reasons why prevention efforts are not at the scale and efficacy that they need to be. These include financing from governments and donors not being adequate, misallocation of resources, limited human capacity, stigma, disclosure challenges and discrimination (Sowell, R. et al 2003). All this limits the provision of quality services and results in services that are fragmented and or not integrated with related services, as well as preventing people, particularly those from marginalized groups from seeking services.

Component 2: Prevention of unintended pregnancies among HIV-positive women.

Women should have adequate access to contraceptive methods to enable them to decide freely if and when to have children. Currently, more than 120 million couples have an unmet need for contraception globally. 19 million unsafe abortions occur annually and 68,000 maternal deaths are the result of an unsafe abortion. Implementation of this component is still unsatisfactory and distorted by unclear policies and laws especially over abortion in most of the countries violating women's rights even among the HIV positive where abortion is so common.

Component 3: Prevention of HIV transmission from HIV- infected women to their infants.

This is the component that has received the most attention and resources except for child's status testing. The emphasis is placed on preventing transmission of HIV from

an infected mother to her infant through antiretroviral medication and other interventions. The steps followed in providing PMTCT in most of the countries are;

At 36 weeks the mother is given a single dose of nevirapine (200mg) to take at the onset of labor after being made aware of the limitations (i.e. that it does not treat the mother, does not completely prevent HIV transmission to the child, and that its advantage is reduced with prolonged breastfeeding). It's often taken at home when labor starts and the woman is requested to deliver at a health facility preferably a hospital where other interventions to reduce the risk further like caesarian section if chosen as mode of delivery can be done.

Within 72 hours of delivery, the baby is given a single dose of 2mg/kg of nevirapine syrup by the midwife. In case a mother is unable to make it to hospital for delivery she is expected to return within 72 hours of delivery to ensure administration of nevirapine to the baby.

Counseling on infant feeding options and support according to the mother's choice is given. In case she chooses bottle feeding, artificial milk is provided free of charge for a period of 12months. These mothers are given cabergoline in a single oral dose of 1mg to be taken immediately after delivery to suppress breast milk production. Appointments are given according to the MCH schedule where PMTCT is integrated. Septrin prophylaxis is offered to infants from 6 weeks to at least 6 months. HIV-testing of the child is supposed to be done at 6 and 18 months using rapid whole blood tests (Manzi et al 2005), but currently in Zambia the test can be done as early as 6 weeks using polymerase chain reaction (PCR).

The use of single dose nevirapine in both the mother and the infant has been criticized by other schools due to the increased risk of resistance if used repeatedly.

This can be unfortunate especially that, two of three of the first-line of ripple-combination HIV treatments contain nevirapine. To overcome this problem WHO recommended the use of combination antiretroviral treatment for PMTCT rather than a single dose of nevirapine during and after delivery although it might be too expensive for a developing countries with limited resources like Zambia (Wilfert C 2002).

Component 4: Provision of treatment, care and support to HIV-infected women and their families.

The final component of the PMTCT strategy has, until very recently, received the least attention despite calls for stronger links between prevention and treatment programs.

While HIV testing during prenatal care is supposed to provide access to HIV treatment beyond PMTCT, maternal and child services within which PMTCT program tend to be located, are generally not equipped to provide HIV treatment. Without strong referral links between antenatal and treatment facilities (stand-alone HIV treatment provision), the fourth component of the PMTCT strategy remains very weak and needs other models of provision.

In Columbia the model of MTCT-Plus initiative that began in 2002 is the first attempt to fully and effectively implement the whole PMTCT strategy. This initiative places a strong emphasis on the health and rights of women and actively promotes the treatment of the family unit. Once enrolled in MTCT-Plus program the women and their families receive a wide range of services, including medical care, HIV treatment and medicine to prevent opportunistic infections, patient education and counseling, reproductive health and counseling, reproductive health and family planning, nutritional education and support, and services to promote retention of patients in long-term care (Eyakuze et al 2008). While traditional PMTCT programs have been struggling to retain women from testing through treatment for PMTCT, the MTCT-Plus initiative has shown very high retention rates, with less lost to follow-up.

So far the initiative is scaled up in only eight African countries and Zambia is not among them (Sinkala, M. McFarlane Y. et al 2005).

PMTCT in Zambia is divided into Antenatal, Prenatal and Postnatal interventions. (M.O.H, essential competence, 2006). Antenatal, the pregnant woman is counseled and tested voluntarily (VCT).The expectant mother is tested only if she opts in and told her status or opt out and thus refrain from being told her status position. If she opts in, and is positive, she is enrolled on a PMTCT register and measures to protect the baby are instituted, for example strict use of condoms, Arts etc. intra-partum further interventions are instituted by the Midwife in attendance for example avoidance of manipulation and prolonged labor during delivery, and perhaps the most important intervention in this stage is following the mode of delivery chosen

where caesarean section is said to be the safest. Postnatal administration of ART to the baby and artificial or exclusive feeding of the baby for nine months followed by abrupt weaning is ensured. During postnatal period the baby is closely monitored and given septrin as prophylaxis against pneumocystis carinii pneumonia (PCP) (PMTCT Strategy 2008). The baby is also supposed to be tested using PCR at 6 weeks, and rapid test at 6, 12, and 18 months respectively (Children's clinic card 2007). This is important as it will assist in diagnosis, treatment and looking after the child, reducing costs due to frequent admissions or death, and increase the parents' productivity.

2.4 HIV CHILD TESTING

HIV child testing is the last requirement done in PMTCT to complete the whole strategy of ensuring protection of children born of HIV positive mothers. The test as already mentioned is supposed to be done at 6 weeks, 6 months, and 18 months although there could be some variations from country to country. In Zambia this is clearly stated on the under five clinic card. Testing for HIV in children is influenced by a number of factors like acceptance of VCT just like in adults except, decisions are made by the care takers with all their pre-conceived biases on behalf of the child.

2.4.1 VCT Acceptability in Child Testing

Acceptability of VCT among the adults is generally low (10-15%). For the children who are always at the mercy of adults, who are supposedly knowledgeable of what is good for the children, very little is known. This though generally acceptable, may be to the detrimental of the vulnerable children due to personal prejudices, stigma, fear, disclosure problems especially in women, etc. (Yep, G. A .2000).

In PMTCT mothers make decisions to protect their unborn children. A study conducted in Malawi indicated a high acceptability of VCT with unacceptable loss to follow up in PMTCT (Manzi et al 2005). This could be because of the vulnerability of the group under study – antenatal mothers but once they delivered the urgency and the need for follow up reduced especially if their health was not failing.

Usually expectant mothers in the waiting area of the antenatal clinic are given a motivation talk on VCT and the available package of PMTCT services. All mothers are systematically offered pre-test counseling on a one-to-one basis and undergo HIV-testing on an 'opt-in' / opt-out basis (Bulletin of the WHO 2011). Then pre-test counseling process essentially involves giving general information about HIV/AIDS and it's prevention with particular emphasis on mother-to-child HIV transmission; reasons for recommending the HIV-test including details on services that will be made available to the mother and child in the event of a positive test, and the right for the mother to delay or refuse an HIV- test. HIV-testing is conducted on site using rapid whole blood test kits according to the WHO strategy II for HIV antibody testing. Those who undergo HIV-testing are offered post-test counseling and HIV-positive mothers are integrated into the PMTCT program. These mothers receive specific counseling on pre-and neo-natal nevirapine, family planning as well as infant feeding

options. Counseling is done by full-time trained midwife-counselors. Each complete counseling session takes an average of 45-60 minutes. One counselor is expected to cover approximately 8-10 complete counseling sessions per day. This may work very well where staffing is good and there is no overworking and not where there is reduced human resource because it requires patience and time to allow the woman grieve and come to terms with the results especially if positive.

2.4.2 The Benefits of Child Testing

Child testing is very important for early diagnosis, treatment and management of opportunistic infections just like it is for adults.

Early diagnosis avails an opportunity for access to ART and a comprehensive prevention strategy to protect one from getting infected or infecting others.

The WHO Technical Reference Group (TRG) Briefing Meeting Report to review the existing treatment guidelines for ART in children made recommendations for revisions of the current WHO ART guidelines for children. In making its recommendations the TRG considered four overarching principles:-

1. Infants and children in need of ART treatment according to national and international guidelines should initiate treatment as soon as practicable.
2. The best evidence should inform the selection of ART treatment regimens.
3. Programs should be built around available resources, the availability of drugs, and a common regimen needed by the majority of children as this facilitates implementation and management.
4. Harmonization of the guidelines with the adult and PMTCT ART guidelines is desirable.

It was also guided by:

- The need to enable all children needing treatment to receive it as reserving initiation of treatment only for those children with the most severe stage of HIV disease (HIV clinical disease stage IV) would result in many lost lives as treatment at this stage would often come too late.
- The availability of HIV testing for young children as well as immunological assays such as CD4 cell count or percentage and viral load to assist in decision making on initiation of ART may limit early infant diagnosis and crucial timely initiation of ART in infants and children.

- The inability to diagnose HIV infection early in children, especially through PMTCT programs severely limits access to treatment (WHO TRG brief meeting report 2005).

To date ART is the only well known therapy for HIV/AIDS disease, be it for adults or children, and children being the future generation should be given priority for survival? The overwhelming evidence of the ability of ART to delay the progression of HIV infection to full blown AIDS makes it the more reason as to why children should be commenced on ART to improve their quality of living even if they were HIV positive.

Most of the opportunistic infections are curable and preventable if treatment and preventive measures are instituted early even though there is no known cure for HIV/AIDS infection as yet. Moreover opportunistic infections are the cause of death in HIV infection and not necessarily the HIV infection itself.

“Knowledge is power,” is not just a wise saying but in reality it enhances confidence, reduces anxiety and increases productivity as measures to deal with adverse effects can be taken timely.

It’s also cost effective for the government in terms of planning for the services, as well as spending money where the benefit is more, rather than blind expenditure based on assumptions and not facts.

2.5. THEORIES RELATED TO THIS RESEARCH

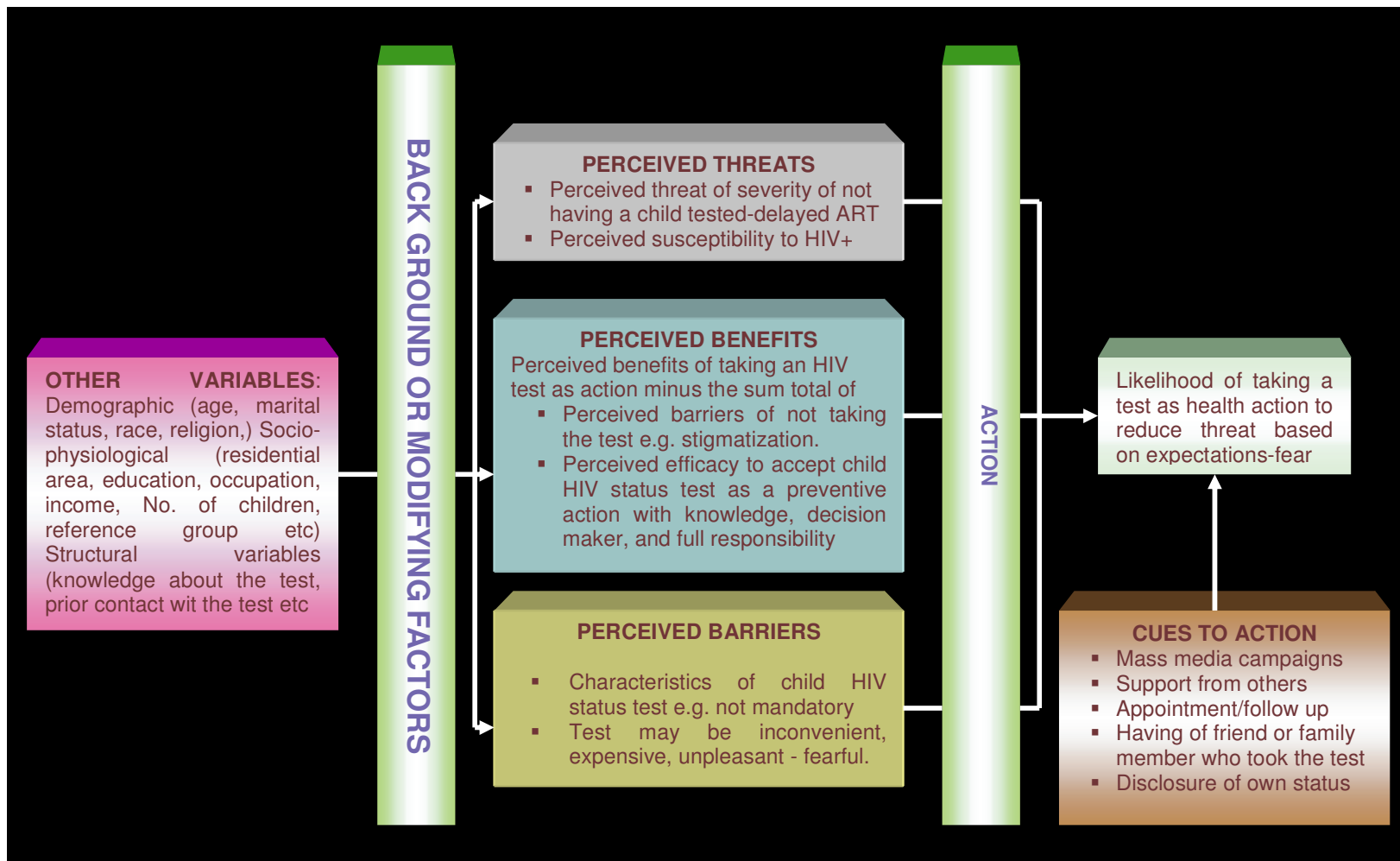
2.5.1. Health Belief Model

This is possibly the most known model in public health, and also the oldest one from social psychology, developed in the 1950s by Irwin Rosenstock, Godfrey Hochbaum and Stephen Kegels. At the moment, it is one of the most widely accepted theories for understanding health-seeking behaviour (Figure1). This theory is concerned with health promotion or illness prevention of both chronic and acute illness. It focuses on an individual's perceptions of the threat posed by a health problem, the benefits of avoiding the threat, and factors influencing the decision to act.

The Health Belief Model was originally developed as a systematic method to explain and predict who could engage in certain preventive behaviours. It is based on a 'value-expectancy' theory (Lewin et al., 1944), which means that cognitions and perceptions expectancy about the value of some health outcome drive the adoption of the behaviour that might influence that outcome argued Lewin et al. in 1944. In later years, the HBM was revised to include general health motivation for the purpose of distinguishing illness and sick-role behaviour from health behaviour. It is generally regarded as the beginning of systematic, theory-based research in health behaviour. It is also one of the most influential social-psychological approaches designed to account for the ways in which we could be able to explain and predict preventive health behaviour in which healthy people seek to avoid illness, as well as describing the sick-role and illness behaviour (Rosenstock et al., 1994) by focusing on the attitudes and beliefs of individuals when weighed against benefits and risks of taking or not taking an action.

This Model is based on the assumptions that people exist in a life space composed of regions with both positive and negative valences (values). An unhealthy condition would be a negative valence and would have the effect of pushing a person away from the region of normality and health, unless doing so (acting to remain healthy) would cause the person to enter a region of even greater negative valence. While people are pushed away from regions with negative valences, they are attracted or motivated toward regions of positive valences. Thus, a person's behaviour might be viewed as seeking regions that offer the most attractive values (Kleinman, 1988). There are three descriptors that determine the likelihood of action or probability of

appropriate health behaviour as shown in figure 1. (Champion, 1984; Conner & Norman, 1996).



1. **Perceived Susceptibility** – ‘My chances of being HIV positive are high.’ Each individual has his/her own perception of the likelihood of experiencing a condition that would adversely affect one's health. Individuals vary widely in their perception of susceptibility to a disease or condition. There are those at low end of the extreme and these deny the possibility of contracting an adverse condition like HIV. There are individuals in a moderate category like HIV positive mothers who submit to a statistical possibility of susceptibility to transmit HIV to their children, and there are those individuals at the high extreme of susceptibility like HIV positive mothers already on ART who feel there is real danger that their child will experience an adverse condition.

2. **Perceived Seriousness or threats** - refers to the beliefs a person holds concerning the effects of a given condition like being HIV positive or negative and what effects it would have on one's state of affairs. Perception of threat is conceived as two components: perceived severity of and susceptibility to an adverse outcome. These effects can be considered from the point of view of the difficulties that a condition would create. For instance, death, pain and discomfort, loss of work time, financial burdens, difficulties with family, relationships, and susceptibility to future conditions (AIDS), if HIV positive. It is important to include these emotional and financial burdens when considering the seriousness of a condition.

3. **Perceived Benefits of Taking Action** - Taking an HIV test will make me feel better and help me look after the child well and have access to ART. Taking action toward the prevention of a condition or toward dealing with an illness is the next step to expect after an individual has accepted the susceptibility of a condition and recognized it is serious. The direction of action that a person chooses will be influenced by the beliefs regarding the action. The beliefs are moderated by a number of factors and these include:
 - a. **Perceived Barriers to taking an action:** action may not take place, even though an individual may believe that the benefits to taking action are effective. This may be due to barriers. Barriers relate to the

characteristics of a treatment or preventive measure in this case child HIV status test that may be inconvenient, expensive, unpleasant, painful or upsetting e.g. stigma in HIV. These characteristics may lead a person away from taking the desired action.

- b. **Cues to Action:** an individual's perception of the levels of susceptibility and seriousness provide the force to act. Benefits (minus barriers) provide the path of action. However, it may require a 'cue to action' for the desired behavior to occur. These cues may be internal or external. Some of them include: physical symptoms (having AIDS and on ART) of a health condition or environmental (e.g., media publicity) that motivate people to take action. Cues to actions are an aspect of the HBM that have not been systematically studied.
- c. **Self-Efficacy:** is the belief in being able to successfully execute the behavior required to produce the desired outcomes. The ability to decide to have the test done.
- d. **Other Variables:** includes diverse demographic, socio-psychological, and structural variables that affect an individual's perceptions and thus indirectly influence health-related behavior. According to Rosen stock (1974) these are 'modifying factors', serving to condition an individual's perceptions about perceived benefits of preventive health actions.

This model has several notable limitations and the following stand (Rosen stock, 1974; Rosenstock, 1990; Glanz, et al., 2002):

- a) Most HBM-based research to date has incorporated only selected components of the HBM, thereby not testing the usefulness of the model as a whole;
- b) As a psychological model it does not take into consideration other factors, such as environmental or economic factors, that may influence health behaviors. Other than this, the theory has been attacked by holding the assumption that individuals undertaking health behaviors do so in a rational or conscious way when at times, there is irrationality.

- c) The model does not incorporate the influence of social norms and peer influences on people's decisions regarding their health behaviors.
- d) Some of the problems that have plagued the HBM are that different questions are used in different studies to determine the same beliefs; consequently, it is difficult both to design appropriate tests of the HBM and to compare results across studies.
- e) The HBM approach fails to adequately consider the bases of variation in individuals' ability to both evaluate the potential consequences of behaviors, and to utilize these evaluations.
- f) Research does not always support the HBM in that factors other than health beliefs also heavily influence health behavior practices and particularly personal and social factors. These factors may include: special influences, cultural factors, socioeconomic status, and previous experiences.
- g) There has been lack of evidence to support the belief behavior relationship;
- h) There has been the difficulty associated with modifying beliefs and no suggestion of strategies for change;
- i) There has been focus on individual factors in terms of health intervention, rather than considering socio environmental factors as well; limitations with logical explanation, clarity and accuracy of the HBM due to unclear construct and relationship development.

Although these criticisms are acknowledged, some of them can be challenged. For example, if the criticism of the lack of evidence to support the belief-behavior relationship is examined it can be argued that there is already extensive evidence to support the attitude, belief, behavior and intent relationship.

Within this theory the factors mentioned below have been noted to be key in deciding to take particular health behavior.

According to Irungu et al 2008 the following are factors that have been attributed to accepting or rejecting HIV testing and these include:

Socio-economic status

Level of education

Religion

Income

Marital status

Service related

Inaccessible service

Long distance from service centre

Poor infrastructure

Shortage of resources e.g. staff, equipment etc.

Unawareness of service

Unacceptable service

Disregard of ethics by professionals

Lack of privacy and confidentiality

Disrespect of customs

Inability to follow up mothers; and

long waiting time (Pignatelli et al. 2006).

All these factors can be blended in the health belief model which is used in this research for example:-

Benefits of testing

- Early diagnosis ensures early preventive interventions.
- It enhances acceptance of the situation as knowledge is power.
- It opens accessibility to ART.
- It allows for modification and planning one's life in a positive way.
- It reduces anxieties of an unhealthy life.
- It increases the welfare and survival of the infected.
- It also increases productivity for the parents and a nation as a whole.
- It's cost effective for the nation as a whole.

Barriers of testing

- Fear of social isolation by the community – avoidance of affected family.
- Discrimination – some people don't even want to interact with the infected or affected.
- Stigmatization – being on PMTCT register is already indicative of status.
- High drop out of mothers on PMTCT – no continuity of other interventions like HIV child testing.
- Victimization of women (gender violence) – the woman is blamed for being

HIV positive.

- Family disruption – abuse, violence and divorce.
- Ignorance of the service – emphasis is normally so much on testing the mother not the child.
- Inaccessibility of service – many clinics are not doing the test.
- Lack of follow up when one drop out.
- Shortage of staffing – haste and hurried interaction with clients.
- Lack of community support – no encouragement.
- Disclosure problems – no disclosure of the woman/child's status to the spouse.
- Unclear and difficulties related with referral of the positive i.e. home based care or ART clinic which is not under the MCH/PMTCT clinic usually.
- Mother or care taker's ill health coupled by lack of support and follow up.
- Gender violence, discrimination and stigmatization fears.

2.5.2. Other Models of Health Promotion

Other models of health behavior and health behavior change include;

a. Reasoned action and planned behavior: The theory of reasoned action was developed by Ajzen and Fishbein to explain human behavior that is under 'voluntary' control. The major assumption underlying the theory is that people are usually rational and will make predictable decisions in well-defined circumstances. It's composed of six major components- behavioral beliefs, evaluation of behavioral outcomes, normative beliefs, motivation to comply, control beliefs and perceived power.

Reasoned action and planned behavior

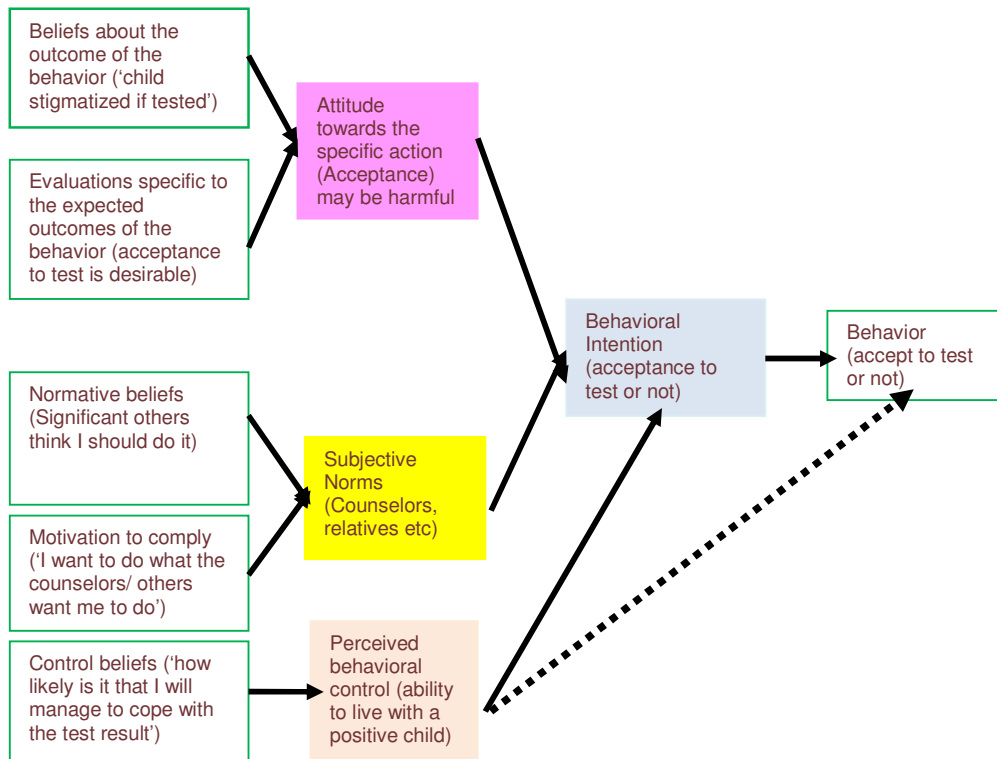


Figure 1.2 Theory of Planned Behaviour (Ajzen and Madden, 1986)

This model also does not consider other environmental factors and is best applied when planning programs to reduce on certain behavior.

b. The trans-theoretical (stages of change) model: This model was developed by Prochaska and Diclimente to describe and explain different stages of change which appear to be common to most behavior change processes. This model is based on the premise that behavior change is a process, not an event, and that individuals have varying levels of motivation or readiness to change.

Five basic stages of change have been identified:

1. Pre-contemplation: this describes individuals who are not even considering changing behavior, or are consciously intending not to change.
2. Contemplation: the stage at which a person considers making a change to a specific behavior.
3. Determination or preparation: the stage at which a person makes a serious commitment to change.
4. Action: the stage at which behavior change is initiated.

5. Maintenance/relapse: sustaining the change and achievement of predictable health gains or go back to the old ways.

This model is best suited where determinants are established and change of attitude is desired.

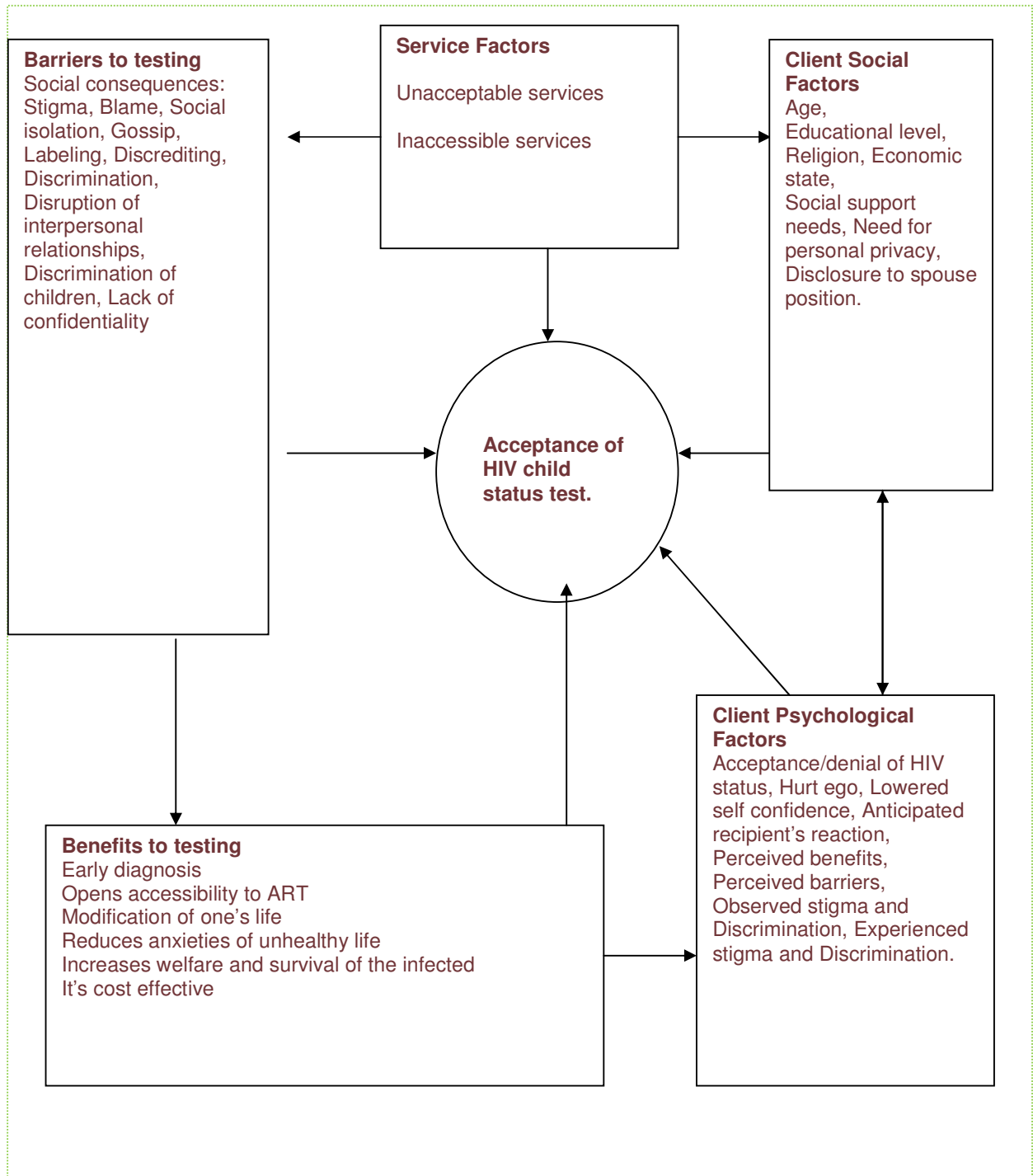
c. Social cognitive theory: this was built on an understanding of the interaction that occurs between an individual and his/her environment. Bandura refers to this interaction as reciprocal determinism describing the way an individual, their environment and behavior continuously interact and influence each other (Nutbeam and Harris 2001). This theory is more comprehensive than other models and more appropriate for health promotion programs.

All these and other health promotion theories like communal action for health theory-diffusion of innovation theory, community organization and community building as well as communication-behavior change models can be considered for health promotion/behavior change though not used in this research.

2.6 SUMMARY

The literature has shown that acceptance to test child's HIV status is a serious decision that involves calculating what is at stake for accepting to test or not to test the child's status. The decision to test or not to test has benefits and risks. For an HIV-positive woman, the challenge of having a child tested includes determining the risks or losses vis-a-vis gains. When one decides to have a child tested, there are quite a number of reasons to consider and these include: it is the right thing to do to protect the child, reaffirmation of self, increased social support, reduced anxiety of unhealthy life, early diagnosis early treatment, being accepted, and modification of one's life to deal with the condition. However, the reasons for not accepting include: stigma, need for privacy, fear of rejection by significant others, threats to personal well-being, blame, denial, and social obligation not personal (Government policy).

Figure 1.3 Conceptual model of Accepting or rejecting child HIV status Test.



CHAPTER THREE RESEARCH PROBLEM

3.0 STATEMENT OF THE PROBLEM

Very little has been reported about child testing and acceptance in Zambia since the implementation of the PMTCT program in 1999, though by the end of 2007 it was offered by 678 clinics in all the 72 districts (Phiri, 2008). In 2006 the emphasis was placed on child testing to complete all the PMTCT activities with Kalingalinga clinic spear heading the exercise followed by Arthur Davison Hospital in Ndola. However statistics at local facility level (no national child testing proportion as yet) show that child testing is very low as compared to the number of women tested and put on the PMTCT program, probably due to a number of reasons like high drop out rate among the mothers.

Out of the **1242** exposed babies, in the named six Kitwe urban clinics, only **871** (70%) were tested (Health Information Management System (HIMS) according to the PMTCT program in 2010. Kitwe District Health Management Team (KDHMT HIMS 2010). This is contrary to having all the children born of HIV+ mothers tested for HIV status at six weeks and eighteen months unless they die before the age of six weeks.

Tables 1.3 Exposed babies & tested babies on PMTCT in 2010 from 6 selected clinics

| CLINIC | Exposed babies | Tested babies | % |
|------------------|-----------------------|----------------------|------------|
| Intimpi | 31 | 10 | 32% |
| Chimwemwe | 239 | 185 | 77% |
| Buchi | 486 | 211 | 43% |
| Ndeke | 205 | 190 | 92% |
| Luangwa | 255 | 249 | 97% |
| Zamtan | 26 | 26 | 100% |
| Total | 1242 | 871 | 70% |

Sources: HIMS Kitwe DHMT 2010

Recently the Government introduced ART for children (2000 of the 150,000 children reported to be accessing) in an effort to combat the scourge of HIV/AIDS in children. Access to these drugs and justification of compulsory prophylaxis cotrimoxazole administration and the ear marked ART to these children can only be possible after testing their HIV status.

Knowledge of health benefits for the test, availability of resources and stigmatization are some of the attributes to acceptance to testing the child's status. However generally there is a dearth of literature on acceptance levels, perceived barriers, and benefits among HIV positive mothers in relation with desiring to have their children tested for HIV. Given this insufficient knowledge, the study wishes to advance determinants of HIV counseling and acceptance of child testing among mothers participating in a Prevention of Mother-to-Child Transmission program in an urban setting.

3.1 RESEARCH QUESTIONS

1. What is the proportion of HIV testing in children born of HIV+ mothers on PMTCT?
2. What influences HIV+ mothers to have their children tested for HIV status?
3. Based on the HBM why do HIV+ mothers consider acceptance or not accept having their children tested for HIV status?

3.2 RESEARCH OBJECTIVES

3.2.1 General objective

To explore the barriers and determinants of accepting or not accept to test the HIV status of children born by HIV+ mothers on PMTCT.

3.2.2 Specific Objective

1. To estimate the proportion of children tested within 18 months of delivery among HIV+ mothers on PMTCT in selected Kitwe urban clinics.
2. To establish the barriers and determinants of child HIV status test within 18 months of delivery among HIV+ mothers on PMTCT in six selected Kitwe urban

clinics.

3. To explain observable choices that HIV+ mothers on PMTCT make over child HIV status test within 18 months of delivery in selected Kitwe urban clinics.

3.3 HYPOTHESIS

H0: “There is no relationship between mother’s knowledge of benefits, barriers or any other determinant and acceptance to have a child HIV status test within 18 months of delivery among HIV+ mothers on PMTC in Kitwe urban clinics.”

CHAPTER FOUR METHODOLOGY

4.0 STUDY DESIGN

This was a cross sectional study that looked at acceptance of testing the HIV status of children born of HIV+ mothers on PMTC. Noting that a cross sectional study involves the measurement of all variables for all cases within a narrow time span, the researcher intends to measure acceptance of testing the HIV status of children born of HIV positive mothers and the factors linked to it contemporaneously. The researcher has chosen a cross section design because she does not wish to follow a development process. In this case data was collected at only one point in time, comparing different participants on a number of variables (Baltes et al., 1988; Creswell 1994). It was the only appropriate design for measuring levels or rates of factors. It was also used to determine factors associated with an outcome (Blaikie 2003; Neumann 2000). However the design severely limited the researcher's ability to address developmental process of causal and effects relationships of the problem, which might have occurred over a long period of time and could have been more elaborate as in a cohort study (Johnson & Reynaud 1997).

4.1 STUDY SETTING

The study was conducted on the Copperbelt Province of Zambia in Kitwe District where six clinics with the most comprehensive PMTCT service were selected for the study. The district was selected because it had been chosen by the sponsors Kitwe has the second highest HIV prevalence (23%) in the country.

The six clinics were selected because they offer the most comprehensive PMTCT services.

4.2 STUDY POPULATION

The study population was the population surveyed and will be all the postnatal

mothers. The target population was the HIV+ mothers who delivered within the last 18 months at the time of the study, and are on the PMTCT registers at selected clinics in Kitwe Urban District. This is because most of these mothers are referred and seen at the clinics before and after delivery.

A **sample size** representative enough calculated using the *Yamane's* random sampling formula to determine the ideal sample size (Yamane 1967).

$$n = \frac{N}{[1 + N (e^2)]} \times 50\%$$

Where:

N = known population

n = the desired sample size and factor from the normal distribution

e = the error of precision set at 0.05

$$n = \frac{2589}{1 + 2589 (0.025)}$$

$$n = \frac{2589}{1 + 64.7}$$

$$n = \frac{2589}{1 + 64.7(50\%)}$$

$$n = \frac{2589}{1 + 32.35}$$

$$n = \frac{2589}{33.35}$$

$$n = 77.6$$

$$n = \mathbf{78}$$

Thirteen participants were sampled from each of the six clinics.

4.3 Figure 1.4 Variables of interest

| Dependent variable | Independent variables |
|--------------------|-----------------------|
|--------------------|-----------------------|

| | |
|--|---------------------------------|
| Acceptance or non acceptance to child HIV status test. | Determinants <i>Barriers</i> |
| | <i>Benefits</i> |

- Lack of understanding importance of HIV test
- Delayed HIV results
- Increased anxiety of an unhealthy life
- Isolation by friends and family
- Name calling
- Fights with partner
- Shortage of staff affecting time management

- Knowledge of benefits like:
 - Understanding importance of testing
 - Increased support & encouragement from spouse & friends
 - Peace of mind
 - Early diagnosis guarantees early treatment
 - Test result allows for modification & planning for life
 - Avoid blame

Perceptions of HIV testing assessed the benefits, and barriers of HIV testing acceptance. The scale measure uses numeric, nominal and a point Likert-type response scale. Likert-type scales were used with responses ranging from *never* to *always* or *almost every day* (depending on the construct being measured). The scales measured subjective response to accepting the counseling in an effort to obtain a more complete understanding of factors influencing acceptance.

-Acceptance was assessed by agreement to child HIV status test or refusal.

-Barriers being a difficulty faced by a mother in accepting to have the child tested as difficulties arising on account of psycho social and health service factors.

-Threats were assessed by the immediate or long term danger of child HIV status testing acceptance and the scale measure used numeric, nominal and a point Likert-type response scale too.

-Benefits assessed the immediate or long term gains of HIV testing acceptance and the scale measure used numeric, nominal and a point Likert-type response scale also. This scale measured subjective response to accepting the counseling and test in an effort to obtain a more complete understanding of factors that yield gains.

4.4 OPERATIONALIZATION OF VARIABLES

This study was set to examine an association between acceptance being dependent

variable with potential barriers as psycho social factors and health service factors, as well as threats and benefits being independent variables.

1. Age was operationalised as a measure of maturity (mother) and time of test for the child that was measured on a numeric and interval scale.
2. Education was operationalised as a measure of literacy and this was measured on nominal scale using the values: never been to school, lower primary upper primary, junior secondary, senior secondary, college, university
3. Acceptance was operationalised as agreeing or refusal to have a child's status for HIV tested and it will be measured using the values: yes or no on a nominal scale.
4. Barriers/threats being a difficulty faced by a mother in accepting to have the child tested as difficulties arising on account of psycho social and health service factors.
 - Mothers' psycho-social factors being bothers inherent influencing them to comply with the set standard for testing was measured using numeric scale to indicate whether one follows the instructions about getting to test the child as follows.
 - a. Education
 - b. Psychosocial factors
 - c. I receive social support
 - d. I live alone
 - e. I have no one to support me to look after the child if I knew the status.
 - f. My responsibility for following your counseling message is entirely mine and this makes me not to accept.
 - g. The responsibility for doing the test is entirely my husband's and this makes me not to accept.
 - h. I get support from friends during discussions and this made me do the test.
 - i. The distance to clinic is not a factor to do the test.
 - j. I have no reason for failing to bring the child to children's clinic.
 - k. When there are changes to my regimen, I sometimes get confused.
 - l. It's hard for me to stay organized enough to keep track of the appointments or other things related to the child's care.
 - m. Nothing bad would happen to me if I didn't have the test done.

- n. I sometimes forget to bring the child for follow up.
- o. I feel responsible for having the child tested.
- p. I am not obliged to having the test done.
- Health service factors being inherent bothers influencing them to comply with the regimen was measured using numeric scale to indicate whether one follows the instructions about testing the child's status as follows:
 - a. Lay people do the counseling
 - b. Health care staff fail to make follow-ups.
 - c. The waiting times are long
 - d. Staff has made me understand about testing and I do not mind.
- 5. Benefits being the immediate or long term gains of HIV testing acceptance.
 - Early diagnosis ensures early treatment.
 - Reduced anxiety of unhealthy life.
 - Increased social support etc.

4.5 SAMPLING PROCEDURE

HIV positive mothers were conveniently selected using an existing sampling frame (PMTCT register). Study unit was drawn using (Pre-determine) simple random probability sampling with numbers assigned to each name. The numbers were then compared to the list and a number of HIV positive mothers eligible for inclusion in the sample. The advantage of this sampling method is that all the elements in the population stand an equal chance of being selected. This is a fair way of selecting a sample and generalizations of the findings can be made based on the sample and not necessarily the population.

4.5.1 Inclusion Criteria

All postnatal HIV+ mothers on PMTCT register and would have delivered within the last 18 months, at the time of the study were eligible for inclusion in the sample.

4.5.2 Exclusion criteria:

- Antenatal mothers.
- HIV negative postnatal mothers.
- All postnatal HIV positive mothers on PMTCT register who would have

delivered before or after the last 18 months at the time of the study.

4.6 DATA COLLECTION

Data was collected over a period of two months beginning last week of July to the last week of August 2010 using structured questionnaire.

Table 1.4 Data collection methods profile

| Research Questions | Data collection tools |
|---|-----------------------|
| 1. What is the proportion of HIV testing in children born of HIV+ mothers on PMTCT? | Questionnaire |
| 2. What barriers, benefit & threats influence HIV+ mothers to have their children? | Questionnaire |
| 3. Based on the HBM why do HIV+ mothers consider the two choices? | Questionnaire |

4.6.1 Survey Structured Questionnaire

A standard structured questionnaire was used to capture the views of mothers. Mothers were questioned on their beliefs, barriers and, benefits related to testing their children for HIV.

Development of the Questionnaire

The questionnaire (Appendix I) was developed and validated using the guidelines of developing a new research instrument by relying on Guillemín *et al.*, (1993) and Burns and Grove (1997) approaches. The development was based on theoretical knowledge in the domain of disclosure. After reviewing relevant literature, key concepts that were thought to be reflective of acceptance and determinants of HIV status testing were identified. This was followed by identification of variables and their operationalisation. In this way, it was then possible to cast the variable items into questions relying as much as possible on what authors of various literature applied meaning to the terms.

Some of the questions were constructed on an ordinal scale, in order to eliminate social desirability biases. Social desirability according to Smith (1981:300-302) are tendencies by most participants to give answers that present a favourable self concept to make them appear “well adjusted, or unprejudiced or democratic or open minded or rational.” In this study, social desirability was controlled for by providing in some questions examples as

enhancement in order to provide extra contextual information to participants so as to make it easy for them to give honest answers (Neuman, 2000:258).

When the instrument was developed, what was needed was to accord them measures of validity and reliability. The approach, used in this study, was based on the Delphi technique (Bernard, 2000:247) and the recommendations by Oberle *et al.*, (2000). The process involved content validity check and reliability check.

The structured questionnaire was administered to all the postnatal mothers who came to the clinic and met the criteria under the guidance of the researcher and research assistant. Questionnaires were administered at participants' convenience and five-eight questionnaires were administered every day within 10-20 minutes. This was done in a PMTCT counseling room for privacy. Participants who could not read were assisted by the researcher and the research assistant to fill in the questionnaire in privacy. All the completed questionnaires were then placed in envelop and deposited in a box within the clinic.

4.6.2 Validity

It was important to establish the validity of the data collection tool before use. This was measured by using the expertise of HIV/PMTCT specialists to check the questions in the questionnaire before pre-testing as content and item validation (Bernard, 2000:48).

Content validity was examined at the level of the entire instrument and at that of the individual items. The questionnaire was examined to see if the variables fitted with the theoretical concepts. Content validity was also examined at the item level to determine the extent to which each item was to be measured. To achieve all these, the questionnaire was reviewed by specialists at UTH Department of Paediatrics, PMTCT Coordinator Kitwe District and Staff in the School of Humanities and Social Sciences as well as those at School of Medicine who are all researchers. This was done in order to obtain expert opinions on the relevance of items to the purpose of the study and whether the test items would provide answers to the raised research questions. Other areas included checking, possible wording problems, and clarity of instructions. Wording and conceptual problems were discussed, and additional ideas were invited in order to ensure that sufficient issues relevant to the inquiry were covered. Following comments raised, the draft instrument was revised eliminating

irrelevant items, collapsing related statements, and addressing a number of wording problems. This helped to eliminate totally irrelevant items from the instrument (Chaiyawat, 2000), and to re-phrase or supply new wordings for items related to the measured constructs where it was pointed out (Hughes, 1998; Aminzadeh *et al.*, 1999). Pre-testing of the instruments was also done to determine whether they would bring out desired information, and adjustments were made on the content and even question sequencing.

Although validation of data collection instruments is a necessary step in research (and this is emphasised in research manuals e.g. Seliger and Shohamy, (1989), Hatch and Lazaraton, 1991), there is little detail and practical guidance on how validation should be conducted. As Converse and Presser (1986:52) point out when discussing the issue of pre-testing questionnaires, there are no general principles of good pre-testing, not even systematisation of practice, not even consensus about what is expected ;regrettably, researchers do not leave any records for each other. Alderson and Banerjee (2002) make similar arguments and the researcher's own readings confirm that few studies actually report validation data processes. This makes it practically difficult to obtain information about commonly accepted practices and standards in the field. The decisions made in the validation process in this study were therefore based partly on the literature, and largely on the researcher's sense of plausibility regarding situational analysis and making decisions in dealing with practical constraints.

4.6.3 Reliability

Seliger and Shohamy (1989), Hatch and Lazaraton (1991) and Alderson and Banerjee (1996) guided the process of reliability that was used in this study. From the methods that these authors recommend, for establishing the reliability of data collection instruments, which are applicable to new questionnaires, the researcher did not use the *Cronbach alpha* coefficient. This was not done because it was going to be of limited value for nominal and ordinal scales upon which the SASSQ was framed. In addition, *Cronbach alpha* coefficient does not reveal whether the obtained quantitative value is an indicator of item heterogeneity¹ or unreliability. Furthermore, Alderson and Banerjee (2002) point out that

internal consistency may not be a good check of questionnaire reliability since questionnaire items in research, unlike items in a test or examination, are usually not intended to measure one thing but many things. In order to be sure, it was necessary to look into individual items. To do this, the researcher chose the test–retest method measure of external reliability as an appropriate way of guaranteeing reliability for this study. The test–retest method was chosen as the main reliability check method because it enabled the researcher to establish the reliability of the questionnaire for stability over time and, because it is a relatively feasible method to apply. Two considerations were taken to be important to bear in mind when using this method: first, the variables measured could be subject to significant change over time, and second, a repeated administering of the same questionnaire may result in the sensitisation of the participants to the issue being researched. Both concerns are related to the time between the test and retest, which implies that the decision about the appropriate length of time is crucial; however, little information is available on this issue in the literature. So to overcome this limitation, we chose to pilot test the instrument at Kamfinsa clinic that was not part of the study.

Pre-testing or pilot test also measures reliability of an instrument. During pre-testing participants were asked to identify ambiguous questions and comprehension problems. The open ended questions availed the participants an opportunity to add their own ideas which may not have been thought of when designing the tool.

4.7 PRE-TEST

Pre-testing of data collection tool was done using HIV positive mothers at Kamfinsa clinic which will not be included in the main study. Kamfinsa clinic is one of the clinics in Kitwe urban district. This clinic was chosen because it had a similar setting, though not as busy as the clinics in the main study. The participants in the pre-test therefore were under similar circumstances as those in the main study.

The participants for the pre-test were conveniently selected as 10% of the main study. The purpose of pre-testing was also to make revision and strengthen the methodology as well as assess whether the variables were observable and measurable apart from detecting flaws such as ambiguity and incomprehensive questions.

Participants were asked by the researcher to seek clarification in case of difficulties in understanding or interpreting items. The first questionnaire had 36 items. Two pilot tests were done on the same participants over a period of two weeks. On the first occasion, the

general feedback was positive. Participants were interested in the topic and the study itself. However, on the second occasion, some of them were irritated about having to fill the questionnaire for the second time. The researcher, however, explained the purpose of the second test and asked for their co-operation. Their cooperation was in turn obtained. After the retest, a qualitative analysis was done (not to aggregate the data) to compare individual responses on each item by looking for consistency between the initial responses and the second responses. This was done to see how the participants kept on picking the same answers. Some questions that gave inconsistent and ambivalent responses were revised. In the end, the items in the questionnaire still remained 36 (Appendix III).

4.8 DATA PROCESSING AND ANALYSIS

This was done using Statistical Package for Social Science (SPSS).

4.8.1 Quantitative data

A computer was used for data entry. The questionnaire data was edited for consistency, completeness, legibility and accuracy.

The researcher also checked for errors and sort clarification on incomplete questionnaires while in the field.

Numeric codes were assigned and data categorized accordingly. For open-ended questions, responses were categorized and numeric codes assigned. Then it was entered into the computer and analyzed using soft ware computer package SPSS. Data was analyzed by univariate analysis to make frequencies then bivariate analysis.

Chi-square was used to test association of variables. Regression analysis was used to determine factors associated with acceptance and non acceptance.

Confidence interval was set at 95% and level of significance at 5%, statistical significance level was achieved if P value was <0.05.

4.8.2 Qualitative content analysis

There was no need for categorizing responses to the open-ended questions. When dealing with qualitative content analysis, it's important to decide whether, the analysis should focus on manifest (visible) or latent (hidden) content only or both (Downey, 1992). This study dealt with both forms of content analysis. An analysis of

what the text says deals with the content aspect and describes the visible, obvious components, which are referred to as the manifest content. In contrast analysis of what the text talks about deals with the relationship aspect and involves an interpretation of the underlying meaning of the text, and this is referred as the latent content (Kondracki et al 2002). Both manifest and latent content deal with interpretations of what has been constructed by the producers of data but interpretations are done by both the producers and the researcher invariably in terms of depth, level of abstraction and purpose. Since data was in textual form, it was categorized in themes and assigned numeric codes. The codes were entered and analyzed on the computer using the Non numerical Unstructured Data Indexing (NUD*IST) Computer package.

4.9 ETHICAL CONSIDERATION

Approval from University of Zambia Research Ethics Committee and permission from MOH was sort to carry out the research. Written and verbal consent was obtained individually from the mothers and permission requested from the Provincial Health Office, District Health Management Team (DHMT) and the clinic in-charges where participants were drawn after explaining the purpose of the study and the benefit.

Those who agreed to take part in the study were requested to sign consent and those who refused assured that no privilege would be taken from them.

Anonymity and confidentiality was ensured by administering the questionnaire individually and in privacy.

Names of participants were not indicated on any tool as participants were only picked using the national identifiers on the postnatal and or children's card. Thereafter no other person had access to the research data apart from the researcher and the supervisor.

No invasive procedure or interrogative method was used to obtain data in this particular research, considering the issues of stigmatization, and that HIV counseling and testing is still voluntary in Zambia.

A token of fifteen thousand kwacha was given to each participant as transport contribution and gratitude expression for their time and information.

4.10 DISSEMINATION OF FINDINGS

Findings will first be presented to the Department of Community Medicine.

Five copies will be printed and given to the following:-

- 1) Department of Community Medicine for lecturers and students' reference.
- 2) Medical library for all the lecturers and students reference.
- 3) Sponsor Ministry of Health for policy makers as guidance when making decisions.
- 4) The researcher.

An executive summary will be sent to Kitwe District Health Management Team, the research location, for the management and staff to carry out the recommendations on improving child testing participation.

CHAPTER FIVE FINDINGS AND ANALYSIS

5.0 RESEARCH FINDINGS

Table 1.5 Demographic Presentation of Findings for respondents

| Parameters | Frequency | Percent |
|---------------------------|-----------|---------|
| Respondent's Age | | |
| 11-20 | 13 | 16.7 |
| 21-30 | 47 | 60.3 |
| 31-40 | 17 | 21.8 |
| Missing Value | 1 | 1.3 |
| Total | 78 | 100 |
| Level of Education | | |
| None | 3 | 3.8 |
| Primary | 26 | 33.3 |
| Secondary | 44 | 56.4 |
| College | 5 | 6.4 |
| Total | 78 | 100 |
| Occupation | | |
| School Girls | 3 | 3.8 |
| Business person | 16 | 20.5 |
| Civil Servants | 3 | 3.8 |
| Private Sector Employee | 2 | 2.6 |
| None | 53 | 67.9 |
| Others | 1 | 1.3 |
| Total | 78 | 100 |
| Marital Status | | |
| Single | 11 | 14.1 |
| Married | 57 | 73.1 |
| Divorcee | 1 | 1.3 |
| Widow | 5 | 6.4 |
| Separated | 2 | 2.6 |
| Cohabiting | 2 | 2.6 |
| Total | 78 | 100 |

Out of 78 respondents, 60.3% were aged between 21 and 30 years. 56.4% of the respondents reached secondary school. Close to 70% of the interviewees do not work. Most (73.1%) of the respondents were married.

Table 1.6 Age at which child test was done.

| Responses | Frequencies | Percent |
|------------------|-------------|---------|
| At 6 weeks | 62 | 79.5 |
| At 12 months | 7 | 9.0 |
| At 18 months | 3 | 3.8 |
| At any other age | 6 | 7.7 |

| | | |
|--------------|----|-----|
| Total | 78 | 100 |
|--------------|----|-----|

79.5% of the respondents preferred the child to be tested at 6 weeks, 9% at 12 months, 3.8% at 18 months and 7.7% at any other age.

Figure 1.5 Pie chart of age at which child test is done

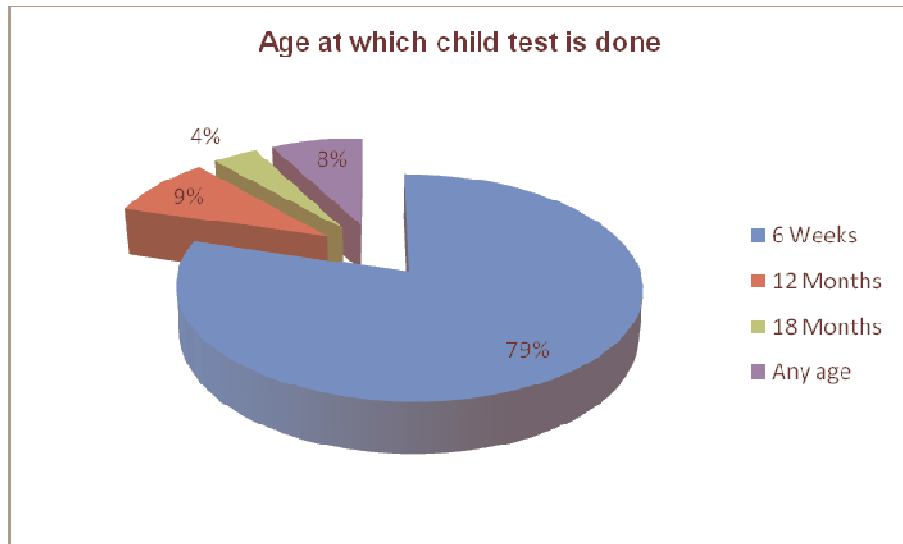


Table 1.7 Mothers who felt bad about knowing their child’s HIV status.

| Responses | Frequencies | Percent |
|--------------|-------------|---------|
| Yes | 13 | 17 |
| No | 65 | 83 |
| Total | 78 | 100 |

83% of the respondents did not feel bad about knowing their child's HIV status, and 17% felt bad knowing their child's status.

Figure 1.6 Mothers who felt bad knowing their child's HIV status.

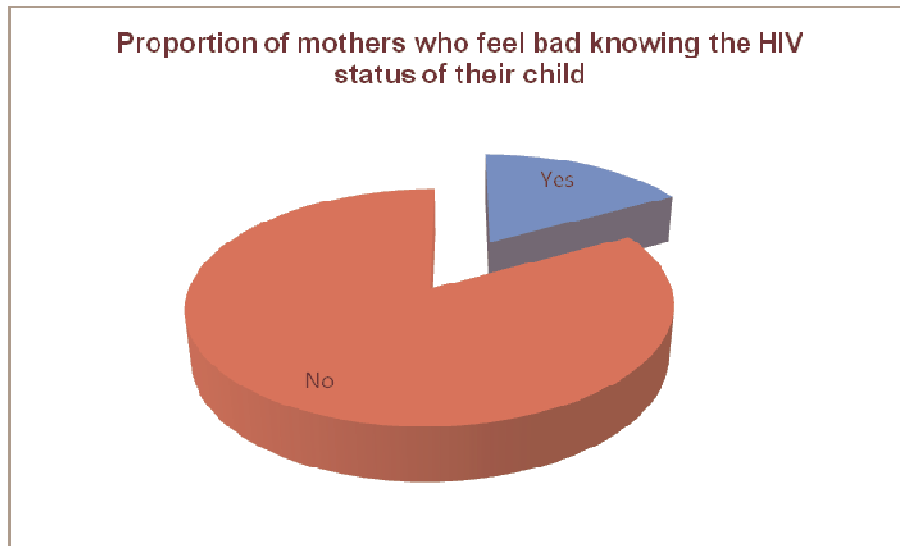


Table 1.8 Mothers willing to take their child for an HIV status test.

| Responses | Frequencies | Percent |
|--------------|-------------|------------|
| Yes | 76 | 97 |
| No | 2 | 3 |
| Total | 78 | 100 |

97% of the mothers were willing to take their child for an HIV test and 3% not willing to take their child for an HIV test.

Figure 1.7 Percentage of mothers willing to take their child for an HIV status test.

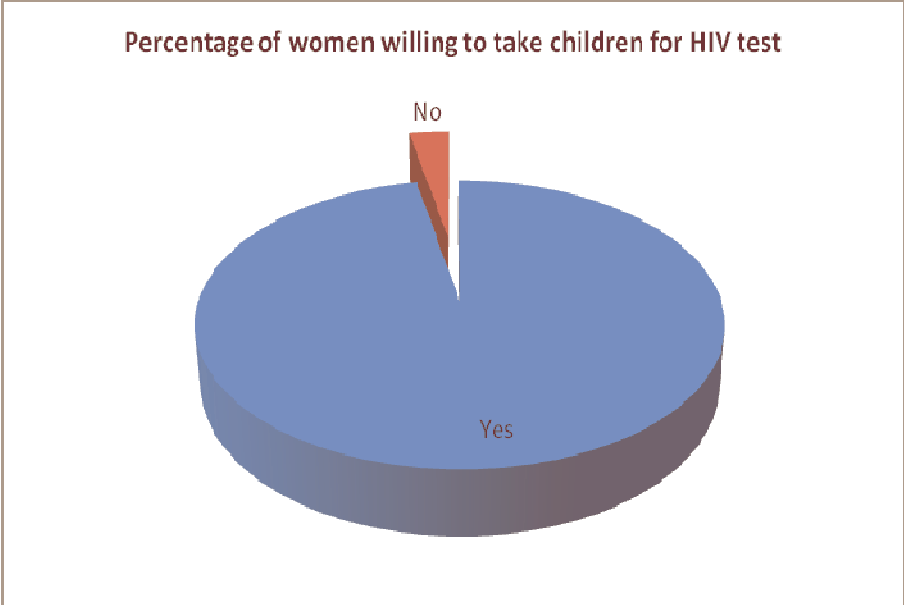


Table 1.9 Degree to which barriers affect respondent’s decision to take their child for an HIV status test.

| Kind of Barrier | Lack of understanding importance of HIV test (1) | | Delayed HIV results (2) | | Increased anxiety of an unhealthy life (3) | | Isolation by friends and family (4) | | Name calling (5) | | Fights with partner (6) | | Shortage of staff affecting time management (7) | |
|-----------------|--|--|-------------------------|--|--|--|-------------------------------------|--|------------------|--|-------------------------|--|---|--|
| | Yes | | Yes | | Yes | | Yes | | Yes | | Yes | | Yes | |
| Responses | 8 | | 7 | | 7 | | 2 | | 3 | | 3 | | 3 | |
| Count | 8 | | 7 | | 7 | | 2 | | 3 | | 3 | | 3 | |
| Percent | 10 | | 9 | | 9 | | 3 | | 4 | | 4 | | 4 | |

90% to 97% of the respondents not affected by the barriers on deciding to take their child for an HIV test, only 3% to 10% were affected.

Figure 1.8 Extent to which barriers affect the respondent’s decision to take the child for an HIV test.

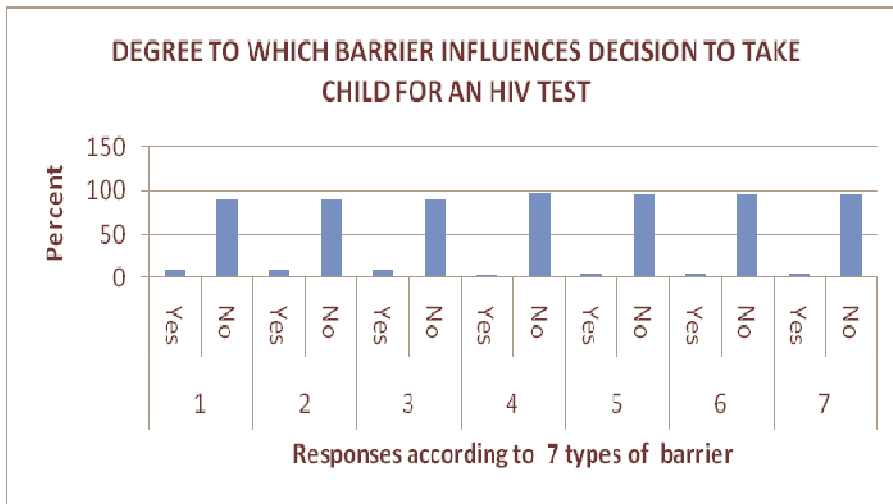
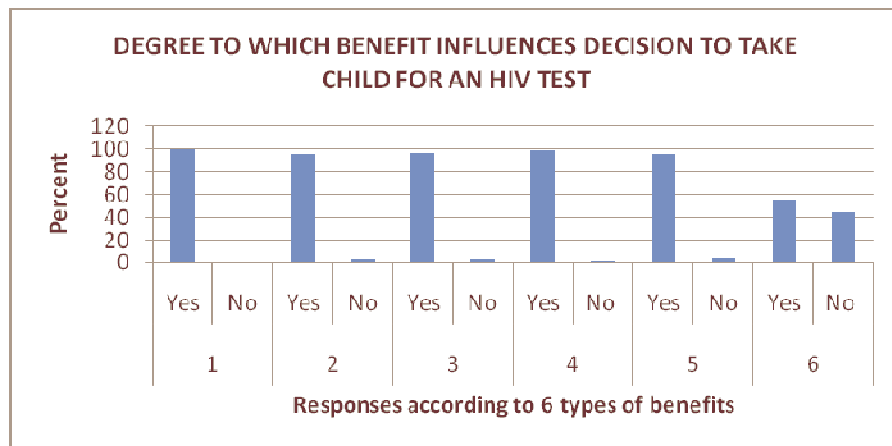


Table 1.10 Degree to which perceived benefits affect the respondent's decision to take their child for an HIV test.

| Kind of Benefit | Understanding importance of testing (1) | | Increased support & encouragement from spouse & friends (2) | | Peace of mind (3) | | Early diagnosis guarantees early treatment (4) | | Test result allows for modification & planning for life (5) | | Avoid blame (6) | |
|-----------------|---|----|---|----|-------------------|----|--|----|---|----|-----------------|----|
| | Yes | No | Yes | No | Yes | No | Yes | No | Yes | No | Yes | No |
| Responses | 78 | 2 | 75 | 25 | 76 | 24 | 77 | 23 | 74 | 26 | 43 | 57 |
| Counts | 78 | 2 | 75 | 25 | 76 | 24 | 77 | 23 | 74 | 26 | 43 | 57 |
| Percent | 100 | 2 | 96 | 24 | 97 | 23 | 99 | 26 | 95 | 24 | 55 | 45 |

95% to 100% of the respondents affected by perceived benefits except 'avoid blame' (55%-45%) on deciding to take their child for an HIV status test.

Figure 1.9 Extent to which perceived benefits affects the respondent's decision to take the child for an HIV test.



5.1 ANALYSIS

5.1.1 General analysis

- About 70% of the respondents are married, aged between 21 and 30 years, have reached secondary school and do not work.
- Almost 80% of child test is done at 6 weeks. Most (83%) of the mothers exposed to PMTCT do not feel bad knowing their Children's HIV status.
- Out of the 78 PMTCT mothers interviewed, 97% of them said they were willing to take their child for an HIV test.

5.1.2 Analysis of the chi-square statistics by Barriers (Appendix IV)

- The Pearson Chi-square value for the relationship between distance to the nearest clinic and willingness to take the child to the clinic is 0.85, which is higher than 0.05, implying that a relationship does exist. Hence, the Null hypothesis can be rejected that there is no relationship between the two variables. If the relationship between distance to the nearest clinic and willingness to take the child for an HIV test is controlled for, by the effect of age of the respondents, the Pearson Chi-square values are still greater than 0.05 which is still not significant except for the age group 31 to 40 years. Therefore, the relationship between the two variables still holds for the first two age groups.
- The Chi-square value for the relationship between reception from health workers at the clinic and willingness to take child for an HIV test is 0.281, which is not significant. When we further control for the effect of education on the relationship, the Chi-square value is only greater than 0.05 for the primary education, implying that the relationship does not hold in all situations.
- The Pearson Chi-square value for the relationship between time spent waiting at the under 5 clinic and willingness to take the child for an HIV test is 0.028 (significant), which is lower than 0.05, implying that the two variables are independent (unrelated). However, if we control for the effect of the control education, the Chi-square values become insignificant, meaning the independence does not hold in all situations.

5.1.3 Analysis of the chi-square statistics by Benefits (Appendix V)

- The Chi-square value for the relationship between understanding the importance of the test and acceptance to take the child for the test was not computed because taking the child for a test due to understanding the importance was a constant.

- The Chi-square value for the relationship between increased support and encouragement from spouse, relatives, friends and acceptance to take child for test is 0.77, which implies that a relationship does exist. If we control for the effect of education on the relationship, the chi-square values are still greater than 0.05 for secondary and college education.
- The Chi-square value for the relationship between having peace of mind and acceptance to take the child for the test is 0.82, implying that a relationship exists between the benefit and willingness to take the child for a test. When we control for the effect of a layer variable, the relationship still holds only for primary education.
- The Chi-square value for the relationship between early diagnosis ensuring early treatment and acceptance to take the child for the test is 0.87, which means that the relationship exists. However, when we control for the effect of education on the relationship, no chi-square values are computed because the relationship is a constant.
- The Chi-square value for the relationship between modify or plan one's life and acceptance to take the child for the test is 0.74, implying that the relationship exists. If we take into account the layer variable (education), the relationship still holds because the chi-square values are still not significant.
- The Chi-square value for the relationship between not likely to be blamed and acceptance to take the child for the test is 0.20, implying that a relationship exists. If we control for the effect of the layer variable, the computed chi-square values are still greater than 0.05, which means that the relationship still holds.

Therefore the null hypothesis in this study was rejected.

CHAPTER SIX DISCUSSION OF FINDINGS

6.0 WHAT FINDINGS OF THIS STUDY SHOWS

This cross section study shows the following answers to the three research questions.

To the first research question: What is the proportion of HIV status test in children born of HIV+ mothers on PMTCT?

All the children were tested and the majority of these were tested at six weeks (79.5%). Almost all the mothers (97%) were willing to take their children for an HIV status test probably due to conviction after all the counselling or it could be due to awareness of the many benefits of knowing the child's status. This could be due to the fact that most of the mothers interviewed in this study were postnatal mothers usually seen at 6 weeks for examination of both the mother and the child to detect any complications after delivery. This is also the time a children's clinic card is issued for vaccines and close monitoring of the child's growth for five years. The fact that this card is required at grade one school enrolment have had a very big role in encouraging mothers to ensure they are given the card especially in urban areas. This implies that they looked at child status test as a must especially during this period. The test is almost mandatory for antenatal mothers and postnatal mothers at six weeks.

The second research question: What influences HIV+ mothers to have their children tested for HIV status?

Before we could establish the determinants and barriers of acceptance, the study shows that the decision to accept is a selective one and consists of several considerations, including counseling pre/post test, understanding the Importance of the test, distance from the service centre (clinic) preparedness to face the consequences of acceptance, as well as availability of social support. The majority of the women (almost 100%) were not affected by the perceived barriers. Most of the women responded positively to being affected by the perceived benefits except for 'avoidance of blame' where the number of women affected almost equals to those not affected by this variable. This probably is because avoid blame could be double edged with one side being avoid blame in case the results are positive especially where there are problems of disclosure. On the other side avoid blame for not testing may be

a catalyst to take the child for a test considering the benefits for knowing the HIV status for the child. This could be because the benefits outweigh the barriers or that they have no choice given the fact that it's mandatory at this stage unless they had opted out during antenatal care.

The few who are affected by the barriers could be those who delayed to book for Antenatal care and have challenges with stigma and disclosure to other members of the family especially the spouse.

However, it was evident that just after counseling, the participants were willing to accept the test irrespective of the barriers which were there at that particular time. The majority (83%) of the mothers did not feel bad as counseling of mothers starts from antenatal up to the time the child is tested. This shows that they looked at acceptance as a must because it was after all beneficial. It is not surprising to note that most mothers initially accepted the HIV child status test at six weeks the earliest possible time, notwithstanding the implication of their action or choice. However it was interesting to note that most of these mothers did not collect the results, probably because they took one or two months to come out as specimen had to be sent to a bigger children's hospital for analysis. The 17% who felt bad could be those mothers usually starting antenatal care late due to challenges of stigma or distance from the clinic.

To show that acceptance was not a hassle in this sample, one would not be surprised that the vast majority of these initial acceptance were done long before the actual day of the child's HIV status test. To the third research question: Based on the HBM why do HIV+ mothers consider acceptance or not accept having their children tested for HIV status?

This was in essence an answer based on the hypotheses that were derived from Rosenstock et al's theory of Health Belief Model and the theory of planned behaviour. Concerning Lewin et al's theory of value-expectancy, the participants' cognitive perception of accepting child HIV status test and their reaction to it (Lazarus and Folkman, 1984) showed that fear was a factor to accepting and they however made their decisions after calculating risks that were involved (including anxiety of unhealthy life, isolation from family and friends, name calling, fights with spouse likely to be blamed for accepting the child HIV status test. Even after weighing the risks (barriers), the majority (97%) of the participants in this study accepted the child HIV status test and only 3% could not accept.

With regards to the theory of reasoned action , nearly all participants scores and descriptions of their decision processes reflected weighing benefits and costs of acceptance similar to that described in theories of reasoned actions (Ajzen, 1985; 1988; Ajzen and Madden, 1986; Fishbein and Middlestadt, 1994) as well as ways to apply criteria regarding the appropriateness of acceptance or non-acceptance. However, the participants' decisions were based on their emotional and intuitive processes as their sole criteria for acceptance, clearly reflected by their personal perception of the positive consequences than negative consequences associated with acceptance, than reasoned actions. These participants were more likely to agree for their children's sake than for anything or anybody else.

6.1 SYNTHESIS OF FINDINGS

The current study represents the first to explore acceptance of child HIV status test in Zambia and in a sample of predominately-African nursing mothers of reproductive age residing in the urban city. The sample was recruited from clinics, and is representative of mothers receiving PMTCT care and of similar demographic background. It is not surprising to note that most mothers initially accepted their child HIV status test at six weeks, the first postnatal review of a mother after delivery and when a lot of changes to normality would have occurred. To show that acceptance was not a hassle especially at that particular time when a mother is very open to advice due to giving of birth experience, in this sample, one should not be surprised that the vast majority of these initial agreement were done on first appointment after six weeks. The decision to accept a child's HIV status to be tested is psychologically significant as it reveals even ones' status regardless of where it was done unless one is just a caretaker.

The mothers in this study demonstrated that acceptance to child HIV status test, for the vast majority, did not reflect any hesitancies to accept based on their perceptions of the negative consequences or barriers associated with acceptance. Many women's choices or decision reflected weighing benefits and costs of acceptance similar to that described in theories of reasoned actions (Fishbein and Middlestadt, 1994) as well as ways to apply criteria regarding the appropriateness of their acceptance or non- acceptance. However, there was no allowance for the possibility of mothers making decisions based on their emotional and intuitive processes as their sole criteria for acceptance, which would have more clearly reflected their personal perceptions of the negative consequences associated with acceptance than reasoned actions. Probably these women would have been less likely to

accept testing of the child HIV status test possibly reflected by the non collection of results –researcher’s observation. This study supports past research that have argued that women’s concern about stigma, rejection and violence related to accept their HIV-seropositive status are unwarranted. Defeu et al. documented that negative reactions to acceptance to test (usually coming after the actual testing) are common, including betrayed confidence (50%), negative reactions from partners (30%) and abandonment (21%) (Defeu et al., 1994) and yet we did not find it to be significant in this study. In a study by Zierler et al., 45% of the adults who had experienced relationship violence reported that it was the result of their HIV infection (Zierler et al., 2000). While the above-cited research, documents women’s concerns about negative responses such as rejection, abandonment and violence primarily within the context of women’s relationships with husbands and sex partners, they are unsupported in this study, mothers may also not fear similar negative consequences associated with acceptance of child HIV status test.

A small proportion of mothers felt uncomfortable with child HIV status test acceptance as compared to mothers who had no hesitations. These mothers seemed afraid of potential negative consequences of accepting child HIV status test, and only 3% could not accept at all. However, the reasons for not accepting may have been similar to some notable studies done elsewhere and these include: stigma, need for privacy, fear of rejection by sexual partners, threats to personal well-being, potential loss of income, substance use, difficulty in communicating (disclosure), denial, low viral load, lack of social amenities etc, (Carr and Gramling, 2004; Derlega et al.2002; Garbach et al., 2004; Parsons et al.2004; Serovich and Mosack, 2003).

Further, reasons for non-acceptance to HIV status test may be attributed to following studies’ findings; probability of disruptions in interpersonal and intimate relationships (Black, 1993; Yep, 2000), abandonment and rejection (Mooney *et al.*, 1992; Black, 1993), and discrimination (Yep, 2000). Simoni et al., 1995, one in five women who disclosed her HIV to her partner was abandoned (Simoni et al., 1995). A woman’s disclosure of her HIV infection to sexual partners may trigger violent episodes (Rothenberg and Paskey, 1995; Zierler, 1997; Zierler et al., 2000). Gielen et al. 1997 found that one-fourth of women in their study had experienced negative consequences of disclosure that included rejection, abandonment, and verbal and physical abuse (Gielen et al., 1997). Child HIV status test may be an indicator of the mother’s or even the father’s HIV status drawing suspicion and uncertainty especially when positive, even if their status was not disclosed.

This belief in the risks or losses arising from openness and/or confrontation of HIV-related stigma may have served as a resource for these women, maintaining the fear of negative consequences (Lazarus and Folkman, 1984), later on child HIV status test. Acceptance almost evenly spread across categories in this study, and the highest levels of acceptance were for 'Being made to understand by staff', and 'early diagnosis ensures early treatment'. Perhaps service providers are well positioned for the task—this is where complete accessibility of child HIV status counseling and testing would make the most differences because these mothers seem to be 'freer' and 'open' when dealing with health personnel. Clinically, avoidant behavior is associated with a host of negative outcomes including depression and anxiety (Folkman *et al.*, 1991). From a public health perspective, Kalichman and Nachimson found in their study of disclosure that women who did not disclose their HIV status to their sexual partners also did not practice safer sex, particularly condom use (Kalichman and Nachimson, 1999). The same may be true of not accepting to test child HIV status test risking the lives of their children by not considering other safer practices like feeding options to minimize risks of infection. Hence, even a small number of mothers in this study who did not accept to test the child's HIV status may be more likely to place the child, the partners and entire family at risk of undiagnosed HIV infection consequences. The risk of losing the child due to delayed diagnosis and treatment takes greater significance for mothers in this study.

There are also similarities in reasons that have been revealed in this study with those documented elsewhere, that advance reason of acceptance to child HIV status test such as peace of mind support from friends and family members as revealed in some disclosure studies. Some Mothers have perceived the acceptance to child HIV status test process to be too difficult or risky to undertake and engaged in avoidant behaviors to hide even their own status. There are also many reasons given for and against HIV infection at risk persons accepting to have a status test. Reasons for accepting include the following: it is the right thing to do to protect others, reaffirmation of self, increased social support, catharsis, desire to educate others, seeking help, desire to test someone's reaction, being in a close or supportive relationship, and a mechanism for dealing with the disease. (Holt *et al.*, 1998; Derlega, *et al.*, 2002; Parsons *et al.*, 2004; Serovich and Mosack, 2003; Wolitski *et al.*, 2003).

Because of the complexity and the on-going nature of HIV-infected mothers' struggle with acceptance issues, counselling support from health educators is critical to help women realistically perceive their concerns related to acceptance so that they can access needed support and services. Even though a majority of the mothers demonstrated the importance of accepting child HIV status test in order to maximize life and health care options, the few mothers who did not accept require support to successfully assess the benefits of acceptance and cope with the negative reactions to accepting child HIV status test. These mothers may have a critical need for stressing health education counselling in order to develop a plan for accepting and coping with reactions of people with negative attitudes about individuals with HIV infection.

The theories presented earlier suggest that a better understanding of HIV-infected women's perceptions, determinants of their decisions, and the potential reactions of partners, family, friends, and care givers, is a key to maximizing positive health outcomes and access to needed services. The nurse midwives working with HIV-infected nursing mothers need to be aware of the wide range of determinants that influence women when making decisions to accept child status test. Nurse midwives may be in a unique position to intervene to assist mothers, in understanding the importance of acceptance of child HIV status test in making long-term plans for their children. By being aware of these and sensitive to conceptual linkages proposed by the above mentioned theories, nurse counsellors could more effectively counsel mothers in the benefits of acceptance to select those sitting on the fence or the hardliners as well as assist the mothers to develop plans for any consequences of accepting child HIV status test. Our findings over score the need for counselling to be culturally and personally sensitive in order for acceptance to be as positive and successful experience as possible. Additionally, the nurse health educator who understands cognitive processes is better prepared to respond effectively to a range of mothers' decision in order to provide appropriate counselling to reduce unsafe and unhealthy behaviour.

6.2 CONCLUSION

The child HIV status test acceptance rate in this study was extremely high with very few (3%) mothers declining to accept their child HIV status test. Additionally, mothers that felt bad about knowing their own HIV status were 13.8%. The majority of these mothers accepted knowing their status. There were no differences in the acceptance rates in relation to age, education and marital status.

Two variables influenced (benefit and barriers) acceptance. The barriers or fears that led to non-acceptance were fear of isolation, fear of triggering violence, fear of rejection and abandonment and a desire for personal privacy. The risks that the women in this study had to consider before deciding whether or not to accept child HIV status test were, not knowing the out come, reactions of partners, friends and relatives towards counseling and child HIV status test. The rewards to consider were the factors that favored acceptance which ultimately led to the high rate of acceptance in this study, and these were mainly, a desire to obtain support from the partner for the mothers themselves and for their prospective baby in form of physical, emotional and financial support, a healthy life free of anxieties and early diagnosis and treatment if child turned out to be positive.

The analysis show that most mothers accepted child HIV status test. The vast majority of this acceptance was done at six weeks at postnatal visit. The mothers in this study, for the vast majority, did not reflect any hesitancy based on their perceptions of the negative consequences or risks associated with acceptance to counseling and testing and this varies from what has been established in other studies. Many mothers' determinants of their decision were made by weighing benefits and risks of acceptance to test, similar to that described in the above mentioned theories of Health Belief and reasoned actions. However, very few mothers reflected making decisions based on their emotional and intuitive processes as their sole criteria for accepting child status test. They more clearly reflected their personal perceptions of the negative determinants associated with acceptance to child HIV status test than reasoned actions. This study supports past research that have argued that women's concern about stigma, rejection and violence related to their HIV-sero-positive status are unwarranted.

6.3 RECOMMENDATIONS

Though acceptance seems not to be a problem as shown in this study, this study offers significant implications for healthcare providers including nurses, in clinical practice, education, and research particularly for those situations where acceptance is not possible.

Primary prevention of mother to child HIV transmission from an HIV+ mother to her unborn or newly born child is even more important today, now that PMTCT strategies and ART for children allows many HIV+ mothers to protect their children and children who may still be infected to live a healthier life and longer. It is recommended that nurses and other primary health care workers need to be open and supportive in caring for the HIV+ mothers and their children, discussing the advantages of accepting child status test, but at the same time, respecting the rights of these mothers to make their own decision about accepting especially at this time when they are most vulnerable not just for themselves but for their child as well.

If mothers choose not to accept their child HIV status test, Nurses should be non-judgmental of their decision. But at the same time, Nurses should continually reinforce the use of other PMTCT strategies like feeding options. If HIV+ mothers wish to accept the child status test, techniques to reinforce the decision could be utilized such as role-playing acceptance conversations, along with counseling and support ensuring as well as constant provision of the service –actual test and ensuring results collected. In addition follow up of children who are not brought for the test should be made and this should be supported with proper funding to facilitate movement of the health care givers.

Ideally, mothers and their partners should go through the whole pre-test counselling, testing procedure and post-test counselling together. However, since men very rarely accompany their wives or partners at reproductive health facilities, this is unlikely to happen unless efforts are made, where culturally appropriate, to make reproductive health-care settings male friendly. It is recommended that counsellors discuss the benefits of couple counseling with their wives especially at this time during pre-test/post counselling sessions. Those mothers who would like to be counseled and tested together with their partners should be catered for or referred to specialized counselling and testing services. In the latter situation, a mechanism must exist for communicating test results to the original service providers, with the consent of the couple and without breaching confidentiality.

As for HIV research, various types of determinants especially social relationships associated with HIV child status test acceptance are underexplored but yet have the potential for increasing HIV child status test acceptance, decreasing unhealthy lives, child morbidity/mortality, and reducing the number of new HIV infections to unsuspecting other care givers. A follow up study on exposed babies and tested babies at eighteen months would also give more information about child testing acceptance/coverage. In addition “Health care professionals and researchers need to continue to actively pursue clues as to what facilitates HIV child status test acceptance, because acceptance has the potential to improve well-being, provide informed choice, and protect life” (Sullivan, 2005: 45). The Government should consider making the test mandatory for all the mothers/children attending Maternal and Child Health service.

6.4 LIMITATIONS AND STRENGTHS OF THE STUDY

A Cross-sectional study does not look at the developmental process of causal and effects relationships of the problem which occurs over a long period of time.

It's a non comparative and non experimental study so caution is warranted in the interpretation of data based on only subjects who are confined to Kitwe mothers within 18 months of delivery and on PMTCT. The participants attending postnatal or children's clinic are not representative of all HIV infected mothers attending HIV service providing centers in Kitwe and as such the sample limits the generalisation of the findings. In addition, the mothers' population here excludes those in rural areas. Studies without mixed demographics tend to show similar rather than important differences according to the social, cultural and sexual characteristics of the subjects and the stage they have reached in their HIV disease. This study has failed to point towards the need for more information about such differences in relation to the impact of HIV on the family in a locality like Kitwe. Ideally, an in depth interview schedule should have been used for an inner assessment of the mothers' choices. However, there was no interview schedule included.

However, this study is of great significance. The study indicates that research into HIV child status test acceptance could be investigated further on a larger scale. The acceptance of HIV status test opens up the opportunity to receive social support and timely health care. Research has shown that people with HIV infection who have accepted their HIV status test easily access social networks including health care and have higher levels of psychological wellbeing than those who are not (Kelly et al., 1993). Clinicians and managers should avoid interpreting these findings as 'league table' results but instead use them to demonstrate that they are working collaboratively to respond to patients' health dilemmas and communication concerns. This survey is credible because it describes acceptance from a quantitative point of view and from a lived experience and points to determinants of acceptance. It is also credible because the sample size is adequate relative to the HIV+ mothers on PMTCT and in addition, subtleties of the complex process of child HIV status test have been captured, as the questions focused on the acceptance of child HIV status test and its determinants and this have been answered.

REFERENCES

AIDS Alert (2003) Too many still fail to tell sex partners of serostatus: national study shows major problems, AIDS Alert, 18, 8, 106.

- American Civil Liberties Union (2004) State criminal statutes on HIV transmission – 2004 (Lesbian and Gay Rights Project AIDS Project).
- Azwihangwisi H.et al (2007) Nurses' experiences of delivering voluntary counseling and testing service for people with HIV/AIDS in the Vhembe District, Limpopo Province, South Africa, *Nurses and Health Sciences* 2007, Blackwell Publishing Pty Ltd Asia.
- Bayer, R. (1996) AIDS prevention – sexual ethics and responsibility, *New England Journal of Medicine*, 334, 1540–42.
- Beauchamp, Childress J. *Principles of Biomedical Ethics*. 3rd ed. New York: Oxford University Press; 1989.
- Belsley, D., Kuh, E., and Welsch, R. (1980). *Regression statistics: Identifying influential data and sources of collinearity*. New York: Wiley.
- Black, B.P., and Miles M.S (2002) Calculating the Risks and Benefits of Disclosure in African American Women Who Have HIV. *JOGNN*. 31 (6) 88-97.
- Black, L. W. (1993) AIDS and secrets. In Imber-Black, E. (ed.), *Secrets in Families and Family Therapy*. Norton, New York, pp. 355–369.
- Blaikie N (1993) *Approaches to Social Enquiry* Blackwell Publishing Ltd. New York.
- Blaikie N (2000) *the logic of anticipation*, Polity Press Cambridge.
- Blieszner, R., and Mancini, J. A. (1987). Enduring ties: Older adults' parental roles and responsibilities. *Family Relations*, 36, 176– 180.
- Bor, R., and du Plessis, P. (1997). The impact of HIV/AIDS on families: An overview of recent research. *Families, Systems, and Health*, 15, 413– 427.
- Boyle J. *The Right to Health Care and Its Limits*. In: McCarthyD, ed. *Scarce Medical Resources and Justice*. Braintree, Mass: The Pope John Centre; 1987:643-649.
- Bray, S.J. (2003) Criminal prosecutions for HIV exposure: overview and analysis, *Yale University Center for Interdisciplinary Research on AIDS Working Paper*, 3, 1 (Fall).
- Bunting, S. M. (2001). Sustaining the relationship: Women's care-giving in the context of HIV disease. *Health Care for Women International*, 22, 131– 148.
- Canadian HIV/AIDS Legal Network (1999). *HIV/AIDS and discrimination*. Montreal : Author.
- Carr, R. L.,andGramling, L. F. (2004). Stigma:Ahealth barrier for women with HIV/AIDS. *Journal of the Association of Nurses in AIDS Care*, 15(5), 30–39.
- Casteneda, D. (2000). HIV/AIDS-related services for women and the rural community context. *AIDS Care*, 12, 549– 565.
- CDC (1982) Update on acquired immunodeficiency syndrome (AIDS)—United States. *Morbidity and Mortality Weekly Report*, 31, 507–514.
- CDC (1986) Current trends: additional recommendations to reduce sexual and drug abuse-related transmission of Human T-Lymphotropic Virus Type III/Lymphadenopathy-Associated Virus, *Morbidity and Mortality Weekly Report*, 35, 10, 152–55.

- CDC (1993) 1993 revised classification system for HIV infection and expanded surveillance case definition for AIDS among adolescents and adults. *Morbidity and Mortality Weekly Report*, 41, 1–19.
- CDC (1999) Births and deaths: preliminary data Fall 1998. *Morbidity and Mortality Weekly Report*, 47, 1–48.
- CDC (2000) HIV Surveillance Report 11. Centers for Disease Control and Prevention, Atlanta, GA, pp. 1–45.
- CDC (2006) Twenty-five years of HIV/AIDS – United States, 1981–2006, *Morbidity and Mortality Weekly Report*, 55, 21, 585–89.
- Center for Communicable Diseases. (1992). 1993 revised classification system for HIV infection and expanded surveillance case definition of AIDS among adolescents and adults. *Morbidity and Mortality Weekly Report*, 41, RR-17.
- Central Statistics Head Office (2002) HIV/AIDS Prevalence 2001-2002: Zambia Demographic and Health Survey (ZDHS), Lusaka.
- Central Statistics Head Office (2007) HIV/AIDS Prevalence 2004-2006: Zambia Demographic and Health Survey (ZDHS), Lusaka.
- Ciccarone, D.H., Kanouse, D.E., Collins, R.L., Miu, A., Chen, J.L., Morton, S.C. and Stall, R. (2003) Sex without disclosure of positive HIV serostatus in a US probability sample of persons receiving medical care for HIV infection, *American Journal of Public Health*, 93, 949–54.
- Clemen, R. T.(1990) *Making Hard Decisions*, Belmont, CA: Duxbury Press.
- Cline, R. J. W. and Boyd, M. F. (1993) Communication as threat and therapy: stigma, social support, and coping with HIV infection. In Ray, E. B. (ed.), *Case Studies in Health Communication*. Lawrence Erlbaum, Hillsdale, NJ, pp. 131–147.
- Collins, C., Morin, S.F., Shriver, M.D. and Coates, T.J. (2000) *Designing Primary Prevention for People Living with HIV*. AIDS Policy Research Center and Center for AIDS Prevention Studies. Policy Monograph Series – March.
- Connery, B.A. (1997) IMHO: Authority and egalitarian rhetoric in the virtual coffeehouse. In Porter, D. (ed.) *Internet Culture*. NY: Routledge.
- Connidis, I., and McMullin, J. A. (1993). To have or have not: Parent status and the subjective well-being of older men and women. *The Gerontologist*, 33(5), 630– 636.
- Crystal, S., and Sambamoorthi, U. (1998). Health care needs and service delivery for older persons with HIV/AIDS. *Research in Aging*, 20, 739– 759.
- Cusick, L. and Rhodes, T. (1999) The process of disclosing positive HIV status: findings from qualitative research, *Culture, Health and Sexuality*, 1, 3–18.
- Danziger, R. (1996) An epidemic like any other? Rights and responsibilities in HIV prevention, *British Medical Journal*, 312, 1083–84.
- David A. Rier (2007) Internet social support groups as moral agents: the ethical dynamics of HIV+ status disclosure. *Sociology of Health and Illness* 29 (7) , 1043–1058 .
- Deacon H. & Stephaney (2007), *HIV/AIDS, Stigma and Children*. HSRC/W. K. Kellogg, Foundation Cape Town South Africa.
- De Cock K. (2000) Prevention of mother-to-child HIV transmission in resource-poor countries: Translating research into policy and practice. *JAMA* 2000 Mar 1; 283(9); 1175-82

- Defeu, I., Van Renterghem, H., De Vuyst, H., Flerackers, Y., Peeters, R. and Colebunders, R. (1994) Consequences of telling one's seropositivity to others [Antwerp. Abstract PD 224]. Presented at International Conference on AIDS, Yokohama, Japan.
- Denzin, N.K. (1998) In search of the inner child: co-dependency and gender in a cyberspace community. In Bendelow, G. and Williams, S.J. (eds) *Emotions in Social Life*. London: Routledge.
- Derlega, V. J., Winstead, B. A., and Folk-Barron, L. (2000). Reasons for and against disclosing HIV-seropositive test results to an intimate partner: A functional perspective. In S. Petronio (Ed.), *Balancing the secrets of private disclosures* (pp. 53– 69). Mahwah, NJ: Lawrence Erlbaum Associates.
- Derlega, V., Winstead, B., Greene, K., Serovich, J., and Elwood, W. N. (2002). Perceived HIV-related stigma and HIV disclosure to relationship partners after finding out about the seropositive diagnosis. *Journal of Health Psychology*, 7(4), 415–432.
- DeRosa, C.J. and Marks, G. (1998) Preventive counseling of HIV-positive men and self-disclosure of serostatus to sex partners: new opportunities for prevention, *Health Psychology*, 17, 224–31.
- Diaz, R. M. (1993). Latino gay men and the psycho-cultural barriers to AIDS prevention. Unpublished manuscript, Stanford University and University of California at San Francisco, Center for AIDS Prevention Studies.
- Dodds, C. (2002) Messages of responsibility: HIV/AIDS prevention materials in England, *Health*, 6, 139–71.
- Duffin, R. (2004) Serostatus, risk and responsibility, *Social Research Briefs* [National Centre in HIV Social Research], 6, 1–2.
- Emler, C. A., and Poindexter, C. C. (2004). Unserved, unseen, and unheard: Integrating programs for HIV-infected and HIV-affected older adults. *Health and Social Work*, 29(2), 86– 96.
- Epstein, S. (1996) *Impure Science*. Berkeley: California.
- Ess, C. and the AoIR [Association of Internet Researchers] Ethics Working Committee (2002) Ethical decision-making and Internet research: Recommendations from the AoIR ethics working committee (approved by AoIR, 27 November). Available from URL: <http://www.aoir.org/reports/ethics.pdf> [retrieved 6 July 2006].
- Eyakuze et al (2008), from PMTCT to a comprehensive AIDS response for women: a Much need shift *Developing World Bioethics* 1471-8731 pp33-42.
- Eysenbach, G. and Till, J.E. (2001) Ethical issues in qualitative research on Internet communities, *British Medical Journal*, 323, 1103–5.
- Eysenbach, G., Powell, J., Englesakis, M., Rizo, C. and Stern, A. (2004) Health related virtual communities and electronic support groups: systematic review of the effects of online peer to peer interactions, *British Medical Journal*, 328, 1166–71.
- Fishbein, M. and Middlestadt, S. (1975) Using the Theory of Reasoned Action as a framework for understanding and changing AIDS-related behaviors. In Mays, V. M., Albee, G. W. and Schneider, S. F. (eds), *Primary Prevention of AIDS: Psychological Approaches*. Sage, Newbury Park, CA, pp. 93–110.
- Fishman, S. H. (1981). Losing a loved one to incarceration: The effect of imprisonment on family members. *The Personnel and Guidance Journal*, 32, 372– 375.
- Folkman, S., Chesney, M., Pollack, L. and Coates, T. (1993) Stress, control, coping, and depressive mood in human immunodeficiency virus-positive and -negative gay men in San Francisco. *Journal of Nervous and Mental Disorders*, 181, 409–416.

- Fox, N.J., Ward, K.J. and O'Rourke, A.J. (2005a) The 'expert patient': empowerment or medical dominance? The case of weight loss, pharmaceutical drugs and the Internet, *Social Science and Medicine*, 60, 1299–309.
- Fox, N.J., Ward, K.J. and O'Rourke, A.J. (2005b) Pro-anorexia, weight-loss drugs and the Internet: an 'anti-recovery' explanatory model of anorexia, *Sociology of Health and Illness*, 27, 7, 944–71.
- Forbes, K.M., Lomax, N., Cunningham, L., Hardie, J., Noble, H., Sarnier, L., Anderson, J. (2008) Partner notification in pregnant women with HIV: findings from three inner-city clinics. *HIV Medicine*.
- Frankel, M.S. and Siang, S. (1999) Ethical and Legal Aspects of Human Subjects Research on the Internet: a Report of a Workshop, June 10–11. American Association for the Advancement of Science. Available from URL: <http://www.aaas.org/spp/sfrl/projects/intres/report.pdf> [retrieved 6 July, 2008].
- Frascino, R.J. (2005) Must disclose it is law – Response from Dr. Frascino. Ask the experts about fatigue and anemia. Available from URL: <http://www.thebody.com/Forums/AIDS/Fatigue/Current/Q170626.html?h60o> [retrieved 6 July 2008].
- Garbach, P. M., Galea, J. T., Aman, B., Shin, A., Celum, C., Kerndt, P., et al. (2004). Don't ask, don't tell: Patterns of HIV disclosure among HIV positive men who have sex with men with recent STI practising high risk behaviour in Los Angeles and Seattle. *Sexually Transmitted Infections Journal*, 80, 512–517.
- Gard, L. (1990). Patient disclosure of human immunodeficiency (HIV) status to parents: Clinical considerations. *Professional Psychology: Research and Practice*, 21, 252– 256.
- Gerbert, B., Maguire, B. T., Bleecker, T., Coates, T. J. and McPhee, S. J. (1991) Primary care physicians and AIDS: Attitudinal and structural barriers to care. *Journal of the American Medical Association*, 266, 2837–2842.
- Gielen, A. C., O'Campo, P., Faden, R. R. and Eke, A. (1997) Women's disclosure of HIV status: experiences of mistreatment and violence in an urban setting. *Women and Health*, 15, 19–31.
- Gillett, J. (2003) Media activism and Internet use by people with HIV/AIDS, *Sociology of Health and Illness*, 25, 6, 608–24.
- Glaser, B.G. and Strauss, A.L. (1967) *The discovery of grounded theory*. NY: Aldine de Gruyter.
- Granovetter, M. (1973) The strength of weak ties, *American Journal of Sociology*, 78, 1360–80.
- Greene, K., and Faulkner, S. (2002). Expected versus actual responses to disclosure in relationships of HIV-positive African-American adolescent females. *Communication Studies*, 53, 297– 331.
- Greene, K., Derlega, V.J., Yep, G.A. and Petronio, S. (2003) *Privacy and Disclosure of HIV in Interpersonal Relationships: a Sourcebook for Researchers and Practitioners*. Mahwah, NJ: LEA [Lawrence Erlbaum Associates].
- Gruskin S. et al (2007) *Provider-Initiated HIV Testing and Counseling in Health facilities- What Does this mean for the Health and Human rights of pregnant women?* Developing World Bioethics 8 Blackwell Synergy Boston USA.
- Hacking, I (1975) *The Emergence of Probability*, Cambridge: Cambridge University Press.
- Hacking, I (1990) *The Taming of Chance*, Cambridge: Cambridge University Press.
- Haraway, D. (1991) *Simians, Cyborgs, and Women*. NY: Routledge.
- Hatch, E., and Lazaraton, A. (1991). *The research manual: Design and statistics for applied linguistics*. Boston, MA: Newbury House.
- Hays, R. B., McKusick, L., Pollack, L., Hilliard, R., Hoff, C., and Coates, T. (1993). *Disclosing HIV*

- seropositivity to significant others. *AIDS*, 7, 425– 431.
- Herek, G.M., Capitanio, J.P. and Widaman, K.F. (2002) HIV-related stigma and knowledge in the United States: prevalence and trends, 1991–1999, *American Journal of Public Health*, 92, 371–77.
- Hering, S. (2000). The Internet: a liberating medium? The illness narratives of those affected by AIDS as shaped and presented in virtual support groups on the Internet. Master's thesis, Department of Sociology and Anthropology, Bar-Ilan University.
- Hira H et al. (1989) perinatal transmission of HIV-in Zambia. *BMJ*. 1989 Nov. 18; 299 (6710): 1250-2.
- Holt, R., Court, P., Vedhara, K., Nott, K. H., Holmes, J., and Snow, M. H. (1998). The role of disclosure in coping with HIV infection. *AIDS Care*, 10, 49– 60.
- Indyk, D. and Rier, D.A. (1993). Grassroots AIDS knowledge: implications for the boundaries of science and collective action, *Knowledge: Creation, Diffusion, Utilization*, 15, 3–43.
- Irungu TK et al (2008) HIV voluntary Counseling and testing in Nakuru, Kenya: Findings from a community Survey British HIV Association HIV medicine.
- Johnsone, M., Leaska, C., Elfordb, J., Borc, R. and Millerd R. (1997). Selective disclosure: a pilot investigation into changes in family relationships since HIV diagnosis. *Journal of Family Therapy* 19: 59–69
- Johnston, D., Stall, R., and Smith, R. (1995). Reliance by gay men and intravenous drug users on friends and family for AIDS-related care. *AIDS Care*, 7, 307– 319.
- Joint United Nations Program on HIV/AIDS/World Health Organization (UNAIDS/WHO) (2006), *Report on Global AIDS Epidemic. Geneva; UNAIDS/WHO.*
- Julianne M. Serovich; Tiffany L. McDowell; Erika L. Gafsky (2008) Women's Report of Regret of HIV Disclosure to Family, Friends and Sex Partners . *AIDS and Behavior*
- Kalichman, S. C. and Nachimson, D. (1999) Self-efficacy and disclosure of HIV-positive serostatus to sex partners. *Health Psychology*, 18, 281–287.
- Kalichman, S. C., DiMarco, M., Austin, J., Luke, W., and Difonzo, K. (2003). Stress, social support, and HIV-status disclosure to family and friends among HIV-positive men and women. *Journal of Behavioral Medicine*, 26, 315– 332.
- Kimberly, J. A., Serovich, J. M. and Greene, K. (1995) Disclosure of HIV-positive status: five women's stories. *Family Relations*, 44, 316–322.
- King, S.A. (1996) Researching Internet communities: proposed ethical guidelines for the reporting of the results, *The Information Society*, 12, 2, 119–27.
- Kitwe District Health Management Team (2008), Health Information Management System, Ministry of Health, Kitwe, Zambia.
- Kitzinger, J. (1995) 'Qualitative Research: Introducing Focus Groups', *British Medical Journal*, 311: 299-302.
- Klaw, E., Huebsch, P.D. and Humphreys, K. (2000) Communication patterns in an on-line mutual help group for problem drinkers, *Journal of Community Psychology*, 28, 535–46.

- Klitzman, R. and Bayer, R. (2003) *Mortal Secrets: Truth and Lies in the Age of AIDS*. Baltimore : Johns Hopkins.
- Krueger, R. and Casey, M. (2000) *Focus Groups: A Practical Guide for Applied Research*. Newbury Park: Sage.
- Lazarus, R. S. and Folkman, S. (1984) *Stress, Appraisal and Coping*. Springer, New York.
- Leaska, C., Elford, J., Riva, R.B., and Johnson, M. (1997). Selective disclosure: a pilot investigation into changes in family relationships since HIV diagnosis. *Journal of Family Therapy* (1997) 19: 59–69.
- Levy, A., Laska, F., Abelhauser, A., Delfriassy, J., Goujard, C., Boue, F. and Dormont, J. (1999) Disclosure of HIV seropositivity. *Journal of Clinical Psychology*, 55, 1041–1049.
- Lisko, E. A. (1998) Legal implications of study results showing continued failure to disclose HIV status to sexual partners. <http://www.law.uh.edu/healthlawperspectives/HIVAIDS/980213LegalImplications.html>
- London L. et al (2007) Even if you're positive you still have rights because you are a person: Human rights and the Reproductive choice of HIV- positive persons. *Developing World Bioethics* 1471-8731 pp11-22 Blackwell publishing 2008.
- Maman, S. and Medley, A. (2004) Gender dimensions of HIV status disclosure to sexual partners: rates, barriers, and outcomes. A review paper. Geneva : Department of Gender and Women's Health, World Health Organization.
- Maman, S., and Medley, A. Gender Outcomes. A review Paper. WHO 2004. NLM classification:WC 503.7:2.
- Mansergh, G., Marks, G., and Simoni, G. (1995). Self-disclosure of HIV infection among men who vary in time since sero-positive diagnosis and symptomatic status. *AIDS*, 9, 639– 644.
- Manzi M. et al (2005) High acceptability of voluntary counseling and HIV-testing but unacceptable Loss to follow up in a PMTC HIV transmission program in rural Malawi; Scaling up requires a different way of acting. *Tropical Medicine and International Health* Volume 10 No. 12 pp1242-1250 December 2005 Blackwell Publishing.
- Marks, G., Richardson, J., Ruiz, M. and Maldonado, N. (1992) HIV-infected men's practices in notifying past sexual partners of infection risk. *Public Health Report*, 107, 100–106.
- Mason, H. R. C., Marks, G., Simoni, J. M., Ruiz, M. S., and Richardson, J. L. (1995). Culturally sanctioned secrets? Latino men's non-disclosure of HIV infection to family, friends, and lovers. *Health Psychology*, 14, 6– 12.
- Matovu K. B. Joseph & Makumbi E. Fredrick (2007) Expanding access to voluntary HIV counseling and testing in Sub- Sahara Africa: alternative approaches for improving uptake 2001-2007 *Tropical Medicine and International Health* Volume 12 No. 11 pp1315-1322 November 2007.
- Mavhandu-Mudzusi A. H. et al (2007) Nurses' experiences of delivering voluntary counseling and testing services for people with HIV/AIDS in the Vhembe District Limpopo Province, South Africa. *Nursing health sciences* 9, pp 254-262 Blackwell publishing Asia Pty Ltd.
- Mayer, K.H. (2004) Recommendations for incorporating human immunodeficiency virus (HIV) prevention into the medical care of persons living with HIV, *Clinical Infectious Diseases*, 38, 1, 104–21.
- Mays, V. M., and Cochran, S. D. (1987). Acquired immuno-deficiency syndrome and Black Americans: Special psycho-social issues. *Public Health Reports*, 102, 224– 231.
- Mendelson, C. (2003) Gentle hugs: Internet Listeners as sources of support for women with lupus, *Advances in Nursing Science*, 26, 299–306.

- Miller, R., Browning, S. L., and Spruance, L. M. (2001). An introduction and brief review of the impacts of incarceration on the African American family. *Journal of African American Men*, 6(1), 3– 12.
- Ministry of Health (2005) Annual Report: HIV/AIDS-Free ART, Lusaka, Zambia.
- Ministry of Health (2006) essential Competence ART, PMTCT and CTC Services, a reference guide for training and health Institutions, directorate of diagnostic and clinical care service, May, 2006, Ndeke house, Lusaka, Zambia.
- Ministry of Health (2005) Zambia Government National HIV/AIDS/STI/TB policy, Lusaka.
- Ministry of Health (2007) Children’s Clinic Card, Ndeke house, Lusaka, Zambia.
- Moneyham, L., Demi, A., Mizuno, Y., Sowell, R., Seals, B., and Guillory, J. (1997–1998). Development and testing of a contextually and culturally relevant measure of coping for use with women infected with HIV. *Omega*, 36, 359– 374.
- Moneyham, L., Seals, B. F., Demi, A., Sowell, R. L., Cohen, L. and Guillory, J. (1996) Perceptions of stigma in women infected with HIV. *AIDS Patient Care*, 10, 162–167.
- Mooney, K. M., Cohn, E. S. and Swift, M. B. (1992) Physical distance and AIDS: too close for comfort? *Journal of Applied Social Psychology*, 22, 1442–1452.
- National HIV and AIDS Strategic Framework 2006-2010 (2006). National HIV/AIDS/STI/TB Council, Zambia.
- Nettleton, S. (1997) Governing the risky self: how to become healthy, wealthy, and wise. In Petersen, A. and Bunton, E. (eds) Foucault, Health and Medicine. London: Routledge.
- Nettleton, S., Burrows, R. and O'Malley, L. (2005) The mundane realities of the everyday lay use of the Internet for health, and their consequences for media convergence, *Sociology of Health and Illness*, 27, 7, 972–92.
- Neumann L W (2000) *Research Social Methods* Boston Ellyn and Bacon.
- Ngwenya C. G et al (2008) HIV AIDS, Neumann L W (2000) *Research Social Pregnancy and reproductive autonomy: Rights and Duties* *Developing World Bioethics* 1471-8731 Vol. 8 No. 1 pp iii-vi.
- Nutbeam D. & Harris E. (2006) *Theory in a Nutshell; A practical guide to health promotion theories.* McGraw-Hill Australia.
- Nyblade L. et al. (2000) Women, Communities, and the Prevention of Mother to Child Transmission of HIV: Issues and findings from Community Research in Botswana and Zambia. July 2000.
- Nyblade L. & Macquarie K. (2006) Can we measure HIV/AIDS – Related Stigma and Discrimination? Current Knowledge About Quantifying stigma in Developing countries ICRW/Policy Project USAID.
- Parsons, J.T., Schrimshaw, E.W., Bimbi, D.S., Wolitski, R.J., Gomez, C.A. and Halkitis, P.N. (2005) Consistent, inconsistent, and non-disclosure to casual sexual partners among HIV-seropositive gay and bisexual men, *AIDS*, 19, Supplement I, S87–S97.
- Parsons, J. T., VanOra, J., Missildine, W., Purcell, D. W., and Gomez, C. A. (2004). Positive and negative

- consequences of HIV disclosure among seropositive injection drug users. *AIDS Education and Prevention*, 16(5), 459–475.
- Pennebaker, J. W., Colder M. and Sharp, L. K. (1990) Accelerating the coping process. *Journal of Personality and Social Psychology*, 58, 528–537.
- PEPFAR (2008) “The Power of Partnerships: The U.S. President’s Emergency Plan for AIDS relief. 2008 Annual Report to congress.”
- Petersen, A. (1997) Risk, governance and the new public health. In Petersen, A. and Bunton, E. (eds) Foucault, Health and Medicine. *London: Routledge*.
- Pignatelli Salvatore et al (2006) Factors predicting uptake of voluntary counseling and testing In real-life setting in a mother-and-child centre in Ouagadougou Burkina Faso *Tropical Medicine and International Health* Volume 11 No. 3 pp 350-357 March 2006 Blackwell Publishing.
- Radin, P. (2006) ‘To me, it's my life’: Medical communication, trust, and activism in cyberspace, *Social Science and Medicine*, 62, 591–601.
- Reeves, P.M. (2000) Coping in cyberspace: the impact of Internet use on the ability of HIV-positive individuals to deal with their illness, *Journal of Health Communication*, 5, Supplement, 47–59.
- Rhodes, T. and Cusick, L. (2000) Love and intimacy in relationship risk management: HIV positive people and their sexual partners, *Sociology of Health and Illness*, 22, 1, 1–26.
- Rier, D.A. and Indyk, D. (2006) Flexible rigidity: Supporting HIV treatment adherence in a rapidly-changing treatment environment, *Social Work in Health Care*, 42, 3/4, 133–50.
- Rob Noble (June 2007) Preventing mother-to-child transmission (PMTCT) Worldwide. AIDS & HIV information from AVERT. Org.
- Robinson, K.M. (2001) Unsolicited narratives from the Internet: a rich source of qualitative data, *Qualitative Health Research*, 11, 706–14.
- Rosenstock I.M. (1966) Why people use health services. *Milbank Memorial Fund Quarterly* 44, 94–127.
- Rossi, A., and Rossi, P. (1991). Normative obligations and parent-child help exchange across the life course. In K. Pillemer and K. McCartneyb (Eds.), *Parent-child relations throughout life*. Hillsdale, NJ: Lawrence Erlbaum.
- Rothenberg, K. H. and Paskey, S. (1995) The risk of domestic violence and women with HIV infection: Implications for partner notification, public policy, and the law. *American Journal of Public Health*, 85, 1569–1576.
- Rounds, K. A. (1988). AIDS in rural areas: Challenges to providing care. *Social Work*, 33, 257– 261.
- Russell Armstrong (2008) *Mandatory HIV testing in pregnancy: Is there ever a time?* Developing World Bioethics 8 Blackwell publishing South Africa.
- Saengtienchai, C., and Knodel, J. (2001). Parental caregiving to adult children with AIDS: A qualitative analysis of circumstances and consequences in Thailand (Rep. No. 01–481). Ann Arbor : Population Studies Center, University of Michigan.
- Serovich, J. M. (2000). Helping HIV-positive persons to negotiate the disclosure process to partners, family members, and friends. *Journal of Marital and Family Therapy*, 26, 365– 372.
- Serovich, J. M., Kimberly, J. A. and Greene, K. (1998) Perceived family member reaction to women's disclosure of HIV-positive information. *Family Relations*, 41, 15–22.
- Serovich, J.M. and Mosack, K.E. (2003) Reasons for HIV disclosure or nondisclosure to casual sexual

- partners, *AIDS Education and Prevention*, 15, 70–80.
- Shehan, C. L., Constance, R. Bradshaw, U.P., Bender, J., Arce, N., Bender, B (2005) To tell or not to tell: Men's disclosure of their HIV-positive status to their mothers' *Family Relations* 54 (2) 184–196.
- Sheon, N. and Crosby, G.M. (2004) Ambivalent tales of HIV disclosure in San Francisco, *Social Science and Medicine*, 58, 2105–18.
- Sherr L, Barnes J, Elford J, Glaitan A, Miller R, Johnson M. (1997) Women with HIV disease attending a London clinic. *Genitourin Med*;73:274-9.
- Shilts, R. (1987) *And the Band Played On*. NY: St. Martin's.
- Siegl, D., and Morse, J. M. (1994). Tolerating reality: The experience of parents of HIV-positive sons. *Social Science and Medicine*, 38, 959– 971.
- Signorile, M. (1995) HIV-positive, and careless, *New York Times*, 26 February.
- Simoni, J. M., Demas, P., Mason, H. R. C., Drossman, J. A., and David, M. L. (2000). HIV disclosure among women of African descent: Associations with coping, social support, and psychological adaptation. *AIDS and Behavior*, 4, 147– 158.
- Simoni, J. M., Mason, H. R. C., Marks, G., Ruiz, M., Reed, D. and Richardson, J. L. (1995) Women's self-disclosure of HIV infection: rates, reasons and reactions. *Journal of Consulting and Clinical Psychology*, 63, 474–478.
- Simoni, J.M. and Pantalone, D.W. (2004) Secrets and safety in the age of AIDS: does HIV disclosure lead to safer sex? *Topics in HIV Medicine*, 12, 4, 109–18.
- Sinkala, M., McFarlane Y. et al. (2005) Scale-up of PMTCT services in Zambia. USAID / MOH.
- Sixsmith, J. and Murray, C.D. (2001) Ethical issues in the documentary data analysis of Internet posts and archives, *Qualitative Health Research*, 11, 423–32.
- Smith, J. E., Landau, J., and Bahr, G. R. (1990). AIDS in rural and small town America. *AIDS Patient Care*, 4, 17– 21.
- Sowell, R. L. Seals, B. F. Phillips K. D. and Julious C. H.. (2003) Disclosure of HIV infection: how do women decide to tell? *Health Education Research*, Vol. 18, No. 1, 32-44, February 2003.
- Sowell, R. L., Cohen, L., Demi, A. and Moneyham, L. (1992) Family Responses to AIDS/HIV Infection: Stressors, Resistance Factors, and Adaptational Outcomes. Cooperative Agreement between Centers for Disease Control and Prevention and AID Atlanta, Inc. (N641 CCU 408293) (1992–1996).
- Sowell, R. L., Seals, B., Moneyham, L., Guillory, J., Demi, A. and Cohen, L. (1996) Barriers to health-seeking behaviors for women infected with HIV. *Nursing Connections*, 9, 5–17.
- Sowell, R. L., Seals, B. F., Phillips, K. D. and Julious, C. H. (2003) Disclosure of HIV infection: how do women decide to tell? *Health Education Research*, 18 (1) 32-44.
- Stein, M. D., Freedberg, K. A., Sullivan, L. M., Savetsky, J., Levenson, S. M., Hingson, R. and Samet, J. H. (1998) Sexual ethics. Disclosure of HIV-positive status to partners. *Archives of Internal Medicine*, 158, 253–257.
- Stempel, R. R., Moulton, J. M., and Moss, A. R. (1995). Self-disclosure of HIV-1 antibody test results: The San Francisco General Hospital cohort. *AIDS Education and Prevention*, 7, 116– 123.
- Street, R.L. (2003) Mediated consumer-provider communication in cancer care: the empowering potential of

- new technologies, *Patient Education and Counseling*, 50, 99–104.
- Suler, J. (2004) The online disinhibition effect, *CyberPsychology and Behavior*, 7, 321–6.
- Sullivan, K. M. (2005). Male self-disclosure of HIV-positive serostatus to sex partners: A review of the literature. *Journal of the Association of Nurses in AIDS Care*, 16(6), 33–47.
- Thompson, E. A. (2000). Mothers' experiences of an adult child's HIV/AIDS diagnosis: Maternal responses to and resolutions of accountability for AIDS. *Family Relations*, 49, 155–164.
- Thorne, C., Newell, M-L. and Peckham, C. S. (2000) Disclosure of diagnosis and planning for the future in HIV-affected families in Europe *Child: Care, Health and Development* 26 (1) , 29–40.
- Umberson, D. (1989). Relationships with children: Explaining parents' psychological well-being. *Journal of Marriage and the Family*, 51, 999–1012.
- UNAIDS, (1970) Revised HIV Estimates, Fact Sheet; November 2007.
- UNAIDS/WHO (2006) Epidemiological Fact Sheet - 2006 Update, Zambia.
- UNAIDS/WHO (2008a) Report on the Global AIDS Epidemic; July 2008.
- UNAIDS/WHO, (2008b) Report on the Global AIDS Epidemic; July 2008.
- UNAIDS/WHO (2008c) Core Slides: Global Summary of the HIV and AIDS Epidemic, 2007; July 2008.
- UNAIDS/WHO, (2008d) Understanding the Latest Estimates of the 2008 Report on the Global AIDS Epidemic; July 2008.
- UNDP (2005) Human Development Report.
- USAID (2003) Women's Experiences with HIV Serodisclosure in Africa: Implications for VCT and PMTCT Report of a USAID Technical Meeting USAID Office of HIV /AIDS Washington, DC April 2, 2003
- UNAIDS, (1970) Revised HIV Estimates, Fact Sheet; November 2007.
- Vaux, A., Phillips, J., Holly, L., Thomson, B., Williams, D., and Stewart, D. (1986). The Social Support Appraisal (SS-A) Scale: Studies of reliability and validity. *American Journal of Community Psychology*, 14, 195–219.
- Walther, J.B. (2002) Research ethics in Internet-enabled research: human subjects issues and methodological myopia, *Ethics and Information Technology*, 4, 205–16.
- Wilfert C (2002) Prevention of mother-to-child transmission of HIV: reflections on implementation of PMTCT in the developing world. *Acta, Pediatrics*, 91: 863-865.
- Whalen, C. C., Antani, M., Carey, J., and Landefeld, C. S. (1994). An index of symptoms for infection with human immunodeficiency virus: Reliability and validity. *Journal of Clinical Epidemiology*, 47, 537–546
- Wolitski, R. J., Bailey, C. J., O'Leary, A., Gomez, A., and Parsons, J. T. (2003). Self-perceived responsibility of HIV-seropositive men who have sex with men for preventing HIV. *AIDS and Behavior*, 7(4), 363–372.
- Wolitski, R.J., Rietmeijer, C.A.M., Goldbaum, G.M. and Wilson, R.M. (1998) HIV serostatus disclosure among gay and bisexual men in four American cities: general patterns and relation to sexual practices, *AIDS Care*, 10, 599–610.
- World Health Organization Brief meeting report (2005) Antiretroviral drugs for the treatment

of HIV infection in infants and children in resource-limited settings: Recommendation for a Public health Approach; Geneva, Switzerland.

World Health Organization (2002), Global situation of the AIDS pandemic end 2002, Weekly Epidemiology Record. 2002; 77: 417-24.

Yamane Taro (1967) statistics An Introductory Analysis 2nd Ed. New York Harper and Row.

Yep, G. A. (2000) Disclosure of HIV infection interpersonal relationships: a communication boundary management approach. In Petronnio, S. (ed.), Balancing the Secrets of Private Disclosures. LEAS Communication Series. Lawrence Erlbaum, Mahwah, NJ, pp. 83–96.

Zierler, S., Cunningham, W. E., Andersen, R., Shapiro, M. F., Nakazono, T., Morton, S., Crystal, S., Stein, M., Turner, B., St Clair, P. and Bozzette, S. A. (2000) Violence victimization after HIV infection in a US probability sample of adult patients in primary care. American Journal of Public Health, 90, 208–215.

Zierler, S., Witbeck, B. and Mayer, K. (1996) Sexual violence against women living with or at risk for HIV infection. American Journal of Preventive Medicine, 12, 304–310.

APPENDIX I: INFORMED CONSENT

TOPIC: A CROSS SECTIONAL STUDY ON ACCEPTANCE LEVEL AND DETERMINANTS OF HIV COUNSELING AND CHILD TESTING AMONG MOTHERS PARTICIPATING IN A PREVENTION OF MOTHER TO CHILD TRANSMISSION IN ITIMPI, BUCHI, CHIMWEMWE, NDEKE, LUANGWA, AND, ZAMTAN CLINICS, OF KITWE URBAN DISTRICT.

INTRODUCTION

I Mavis Mulele Chingezhi; a student of Masters of Public Health at the University of Zambia kindly requests for your participation in the research study mentioned above because it is important to know the factors that influence acceptance to HIV child test in PMTCT. Before you decide whether or not to participate in this study I would like to explain the purpose of the study, any risks or benefits and what is expected of you. Your participation in this study is entirely voluntary; you are not obliged to participate. No privileges will be taken from you if you decide not to participate. You will be asked to sign consent in the presence of someone if you agree to participate.

PURPOSE OF THE STUDY

The study will help to obtain more information on acceptance to HIV child testing in PMTCT. This is very important as this information will assist to provide feedback to the Ministry of Health in order to influence decision making or policy formulation. This in turn will increase compliance and finally reduce morbidity and mortality due to delayed diagnosis of HIV/AIDS in children.

PROCEDURE

Once you have signed the consent, and agreed to be asked questions, you will be asked questions concerning HIV child testing. You will then be accorded a chance to make suggestions on how you think the level of acceptance of HIV child testing can be increased to a satisfactory level.

RISKS AND DISCOMFORTS

There are no risks and discomforts except the time spent on answering questions, which will take approximately 30 minutes.

BENEFITS

No immediate benefits will be achieved but by participating in the study you will be able to provide us with information that will assist relevant authorities and policy makers to formulate strategies and policies that will help improve adherence to HIV child testing. This will in turn reduce morbidity and mortality due to undiagnosed HIV/AIDS in children. However no monetary favors will be given in exchange for information.

CONFIDENTIALITY

Any information you will give and your research records will be confidential as permitted by the law. Your personal information will not be released without your written permission unless required by law, and you will only be identified by a number. With confidentiality the Ministry of Health, University of Zambia Research Ethics Committee or the School of Medicine may review your records.

CONSENT TO PARTICIPATE IN THE STUDY

I-----have been fully informed of the purpose of the study, the benefits, risks and discomforts and confidentiality. I willingly agree to participate.

Sign----- Thumb print-----

Date-----

Witness (name) -----

Sign-----

Please Note

1. Your participation in this study is voluntary.
2. You are free to refuse or withdraw from participation.

PERSONS TO CONTACT FOR PROBLEMS OR QUESTIONS

1. Mavis Mulele Chingezhi, University of Zambia, Department of Community Medicine, P.O. Box 50110, Lusaka. Cell: 0955758678.
2. Prof. S. Siziya, University of Zambia, Department of Community Medicine, P.O.Box 50110, Lusaka. Cell: 0955752646.
3. Mr S Nzala, University of Zambia, Department of Community Medicine P.O. Box 50110, Lusaka. Cell: 0977636932
4. Research Ethics Committee, Ridgeway Campus, P.O. Box 50110, Lusaka
Tel. 260-1-256067, e-mail:unzarec@zamtel.zm

APPENDIX II: BUBGET BUDGET ESTIMATE

| ITEM | NO | UNIT COST | TOTAL |
|-------------------|-----------|------------------|--------------|
| STATIONARY | | | |
| Flash Disc | 1 | 500,000.00 | 500,000.00 |
| Bond paper | 7 | 25,000.00 | 175,000.00 |
| File/File clips | 5/5 | 15,000/5000 | 100,000,00 |
| Pens | 10 | 2,500.00 | 25,000.00 |
| Staplers | 4 | 45,000.00 | 180,000.00 |
| staples | 1 | 15,000.00 | 15,000.00 |
| Pencils | 8 | 1,500.00 | 12,000.00 |
| Rubbers | 5 | 500.00 | 2,500.00 |

| | | | |
|--|-----------------------------|--------------|----------------------|
| Note book | 4 | 10,000.00 | 40,000.00 |
| Tippex | 2 | 15,000.00 | 30,000.00 |
| CDs | 2 | 10,000.00 | 20,000.00 |
| Bags for interviews | 4 | 70,000.00 | 280,000.00 |
| Data spread sheet | 4 | 15,000.00 | 60,000.00 |
| Data processing | | | 1,500,000 |
| Printer toner | 1 | 1,000,000.00 | 1,000,000.00 |
| SUBTOTAL | | | 4,039,500.00 |
| SERVICES | | | |
| Ethics committee | 1 | 250,000.00 | 250,000.00 |
| Data Entry | 1 | 750,000.00 | 750,000.00 |
| Data analysis | 1 | 1,800,000.00 | 1,800,000.00 |
| Photocopying Proposal | 100pages (times)6copies | 250.00 | 300,000.00 |
| Photocopying Questionnaire | 5pages (times)200copies | 250.00 | 250,000.00 |
| Photocopying Report | 150pages (times)6 copies | 250.00 | 225,000.00 |
| Binding proposal | (times)6 copies | 20,000.00 | 120,000.00 |
| Binding Report | (times)6 copies | 60,000.00 | 360,000.00 |
| SUBTOTAL | | | 4,055,000.00 |
| PERSONNEL | | | |
| Lunch allowance | | | |
| (a)Principal Researcher | 1(times)60 days | 50,000.00 | 3,000,000.00 |
| (b)Research Assistant | 3(times)60 days | 30,000.00 | 5,400,000.00 |
| Transport | | | |
| (a)Principal Researcher (Lusaka to Kitwe) | 1 | 2,500,000.00 | 2,500,000.00 |
| (b)Research Assistants | 3(times) 60 days | 20,000.00 | 3,600,000.00 |
| SUBTOTAL | | | 14,500,000.00 |
| EQUIPMENT | | | |
| Laptop | 1 | 6,000,000.00 | 6,000,000.00 |
| Printer | 1 | 1,500,000.00 | 1,500,000.00 |
| SUBTOTAL | | | 7,500,000.00 |
| TOTAL | | | 30,094,500.00 |
| Contingency (10%) | | | 3,009,450.00 |
| GRAND TOTAL | | | 33,103,950.00 |

JUSTIFICATION OF THE BUDGET

STATIONARY

The reams of bond paper will be used for the research proposal development and the final report. Paper will also be required to make extra copies of the proposal for submission to the Research Ethics committee and the board of graduate studies. The questionnaire will also need to be photocopied.

The flash disc is for copying, storing and safe keeping of research data.

The bags are for the researcher and research assistants to ensure that the interview schedules and the questionnaires are kept safely.

Other accessories such as pens, pencils, rubbers, stapler, staples and note books are required for the routine collection of data.

PERSONNEL

Data collection will be conducted throughout the day and data collectors will need lunch allowance to buy their lunch. The researcher will need 4 assistants to administer the questionnaire and conduct the interviews. These will need bags, transport money to move to and from their respective homes. They will also need to be trained before they start the actual work.

TYPING SERVICES

Typing services will be required to enable the investigator type and photocopy the proposal, questionnaire and the report.

CONTINGENCY FUND

Contingency fund which is 10% of the total budget is required for and extra costs due to inflation and any eventualities.

APPENDIX III QUESTIONNAIRE

THE UNIVERSITY OF ZAMBIA

SCHOOL OF MEDICINE

DEPARTMENT OF COMMUNITY MEDICINE

SEMI-STRUCTURED QUESTIONNAIRE

TOPIC: ACCEPTANCE TO TEST THE HIV STATUS OF CHILDREN BORN OF HIV POSITIVE MOTHERS ON PMTCT.

DATE.....

SERIAL No.....

INSTRUCTIONS FOR INTERVIEWER

1. Introduce yourself to the respondent and explain the reason for the interview.
2. Do not write name of respondent on the questionnaire.
3. Tick the most appropriate response to the question in the space provided.
4. Request the respondent to sign consent before you start the interview.
5. All the information provided by the respondent should be kept in strict confidence.
- 6 The respondent should be free to ask questions during the interview.
7. Respondents should not be forced to be interviewed.
8. Thank the respondents at the end of the interview.

SECTION A: DEMOGRAPHIC DATA

FOR OFFICIAL USE ONLY

1. Age of respondent.....years

[]

2. Marital status []
- 1) Single
 - 2) Married
 - 3) Divorcee
 - 4) Widow
 - 5) Separated
 - 6) Cohabiting
3. What is your highest completed level of education? []
- Completed years _____
- 1) None
 - 2) Primary
 - 3) Secondary
 - 4) College
 - 5) University
4. What is your occupation? Specify _____ []
5. How many children have you given birth to? _____
6. How many are alive? _____ []
8. Do you feel bad about knowing your HIV status? []
- 1) Yes
 - 2) No
9. Do you know the HIV status of your child? []
- 1) Yes
 - 2) No
9. How do you feel about knowing your child's HIV status? []
- 1) Comfortable
 - 2) Uncomfortable
10. Who do you stay with? []
- 1) Alone
 - 2) Spouse
 - 3) Relatives
 - 3) Friends
11. Do you receive support from anywhere? []
- 1) Yes
 - 2) No
12. Where do you receive support from? []
- 1) Family members
 - 2) Community based organization
 - 3) Friends
 - 4) Others specify _____
13. How is the support? []
- 1) Escort to the clinic
 - 2) Take care of the child
 - 3) Monetary support
 - 4) Others specify _____

14. Are you happy with the support you receive? []
 1) Yes
 2) No
15. Would you want your child to be tested for HIV? []
 1) Yes
 2) No
16. If yes, at what age would you want your child to be tested? []
 1) At 6 weeks
 2) At 12 months
 3) At 18 months
 4) At any other age, specify _____

SECTION B: BARRIERS TO CHILD STATUS-TESTING ACCEPTANCE

17. How far is the nearest clinic? []
 1) <30 minutes walk
 2) 30 minutes to 1 hour walk
 3) More than 1 hour walk
18. Depending on your answer above what applies to you? []
 1) The distance is not ok so I do not intend to bring my child for an HIV test
 2) The distance is reasonable so I could bring my child for an HIV test
29. When you go to the clinic how is the reception from the health workers? []
 1) Welcoming
 2) Not welcoming
20. Depending on your answer above what applies to you? []
 1) This is likely to affect my decision to bring my child for an HIV test.
 2) This is unlikely to affect my decision to bring my child for an HIV test.
21. How long do you wait at the under five clinic before you are attended to? []
 1) <30 minutes
 2) 30-60 minutes
 3) Above one hour
22. Depending on your answer above what applies to you? []
 1) This is likely to affect my decision to bring my child for an HIV test.
 2) This is unlikely to affect my decision to bring my child for an HIV test

SECTION C: BARRIERS AND BENEFITS OF CHILD HIV STATUS-TESTING ACCEPTANCE

Remember that you have made a decision to test or not to test your child for HIV, please indicate the factors behind your decision

| Barriers and Benefits | Yes | No |
|-----------------------|-----|----|
|-----------------------|-----|----|

| | | |
|--|--|--|
| Staff has made me understand the importance of testing so I will take my child for the test | | |
| Staff has made me not understand the importance of testing so I will not take my child for the test | | |
| Increased support and encouragement from spouse relatives and friends so I will take my child for the test | | |
| Peace of mind so I will take my child for the test | | |
| Results take long to come out so I will not take my child for the test | | |
| In my view , I will take my child because early diagnosis ensures early treatment | | |
| In my view, I will take my child because the test result will allow me to modify and plan my life | | |
| In my view, I will not take my child because It will increase anxieties of an unhealthy life | | |
| In my view, I will not take my child because It will lead to being isolated by friends and family | | |
| In my view, I will not take my child because It will lead to being called names | | |
| In my view, I will not take my child because It will lead to fights with my partner | | |
| In my view, I will take my child because I am unlikely to be blamed | | |
| In my view, I will not take my child because the shortage of staffing will affect my time management | | |

THANK YOU VERY MUCH!!!

Appendix IV: Summary of Pearson Chi-square values for the cross-tabulations between barriers and willingness to take the child for HIV status test.

| Chi-square type | Distance to the nearest clinic and willingness to take the child for HIV test | | |
|----------------------------|---|------|---|
| Pearson Chi-square without | P=0.85 | df=2 | P is greater than 0.05, hence a relationship exists between the barrier and willingness to take the |

| | | | |
|--|---|------------------------------|--|
| layer variable | | | child for a test. |
| Pearson Chi-square with layer (age) variable | 11-20yrs;P=0.63, 21-30yrs P=0.27, 31-40yrs P=0.001, | df=2 df=2 df=2 | P for this range of age is still greater than 0.05, therefore, the relationship P for this range of age is still greater than 0.05, hence, the relationship. P for this range of age is less than 0.05, hence significant. |
| Chi-square type | Reception at the clinic and willingness to take the child for an HIV test | | |
| Pearson Chi-square without layer variable | P=0.281 | df=1 | P is greater than 0.05, hence a relationship exists between the barrier and willingness to take the child for a test. |
| Pearson Chi-square with layer (education) variable | None; P=Nil, Primary; P=0.27, Sec; P=0.00, College; P= Nil, | Nil df=1 df=1 Nil | No statistic computed because reception at the clinic is constant. P for this level of education is greater than 0.05, hence, the relationship P for this level of education is less than 0.05, hence no relationship. No statistic computed because reception at the clinic is constant. |
| Chi-square type | Waiting time at the under 5 clinic and willingness to take the child for an HIV test | | |
| Pearson Chi-square without layer variable | P=0.028 | df=3 | P is less than 0.05, hence, the null hypothesis that no relationship holds. |
| Pearson Chi-square with layer (education) variable | None; P=0.83, Primary; P=0.31, Sec; P=0.27, College; P= 0.36, | df=1 df=2 df=3 df=1 | P for this level of education is greater than 0.05, hence, the relationship. P for this level of education is greater than 0.05, hence, the relationship. P for this level of education is greater than 0.05, hence, the relationship. P for this level of education is greater than 0.05, hence, the relationship. |

Appendix V: Summary of Person Chi-square values for the cross-tabulations between benefits and willingness to take the child for an HIV test.

| | | | |
|------------------------|---|--|--|
| Chi-square type | Take child due to understanding the importance of the test and willingness to take the child for an HIV test | | |
| Pearson Chi- | | | |

| | | | |
|--|--|------------------------------------|--|
| square without layer variable | P=Nil | df=Nil | No statistics computed. |
| Chi-square type | Take child due to increased support and encouragement and willingness to take the child for an HIV test | | |
| Pearson Chi-square without layer variable | P=0.77 | df=1 | P is greater than 0.05, hence, the relationship. |
| Pearson Chi-square with layer (age) variable | None; P=Nil, Primary; P=0.77, Sec; P=0.88, College; P= Nil, | Nil df=1 df=1 Nil | No statistic computed because willingness to test the child and take the child due to the benefit are constants. P is greater than 0.05, hence, the relationship. P is greater than 0.05, hence, the relationship. No statistic computed because willingness to test the child and the benefit are constants. |
| Chi-square type | Take the child due to peace of mind and willingness to take the child for an HIV test | | |
| Pearson Chi-square without layer variable | P=0.82 | df=1 | P is greater than 0.05, hence, the relationship. |
| Pearson Chi-square with layer (age) variable | None; P=Nil, Primary; P=0.09, Sec; P=Nil, College; P=Nil, | df=Nil df=1 df=Nil df=Nil | No statistics computed because the benefit and willingness to take the child are constants. P for this level of education is greater than 0.05. No statistics computed because take child due to peace of mind is a constant. No statistics computed because the benefit and willingness to take the child are constants. |

Appendix V: Continued

| | | | |
|---|---|------|--|
| Chi-square type | Take child because early diagnosis ensures early treatment and willingness to take the child for an HIV test | | |
| Pearson Chi-square without layer variable | P=0.87 | df=1 | P is greater than 0.05, hence, the relationship. |

| Chi-square type | Take child to allow for planning/change of life and willingness to take the child for an HIV test | | |
|--|--|--------|--|
| Pearson Chi-square without layer variable | P=0.74 | df=1 | Comment P is greater than 0.05, hence, the relationship. |
| Pearson Chi-square with layer (age) variable | None; P=Nil, | Nil | No statistic computed because willingness to test the child and benefit are constants. |
| | Primary; P=0.71, | df=1 | P is greater than 0.05, hence, the relationship. |
| | Sec; P=0.88, | df=1 | P is greater than 0.05, hence, the relationship. |
| | College; P= Nil, | Nil | No statistic computed because willingness to test the child and benefit are constants. |
| Chi-square type | Take child to avoid blame and willingness to take the child for an HIV test | | |
| Pearson Chi-square without layer variable | P=0.20 | df=1 | P is greater than 0.05, hence, the relationship. |
| Pearson Chi-square with layer (age) variable | None; P=Nil, | df=Nil | No statistics computed willingness to take the child is a constant. |
| | Primary; P=0.20, | df=1 | P for this level of education is greater than 0.05, hence, the relationship. |
| | Sec; P=0.44, | df=1 | P for this level of education is greater than 0.05, hence, the relationship. |
| | College; P=Nil, | df=Nil | No statistics computed willingness to take the child is a constant. |