

**QUALITY OF LIFE AND COPING STYLES OF HIV POSITIVE  
COMPARED TO HIV NEGATIVE WOMEN IN ZIMBABWE  
PARTICIPATING IN THE PREVENTION OF MOTHER TO CHILD  
TRANSMISSION OF HIV PROGRAM**

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**DEDICATION:**

This dissertation is dedicated to the late **Chenesai Patricia Kurewa**; “I could have done more to improve your quality of life”.

To my daughter **Gertrude Tsungai** and my son **John Takudzwa** it was not easy being so far away from you. Praise God for taking care of us all!

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## **GLOSSARY OF TERMS USED**

AIDS	Acquired immunodeficiency syndrome
ANC	Antenatal clinic
ARV	Antiretroviral
CBO	Community based organizations
CDC	Center for disease control
COC	Combined oral contraceptive
HAART	Highly active antiretroviral therapy
HIV	Human immunodeficiency virus
HRQOL	Health related quality of life
MOS	Medical outcomes survey
MTCT	Mother to child transmission
MOH &CW	Ministry of Health and Child Welfare: Zimbabwe
MTP	Medium term plan
NAC	National AIDS council
NACP	National AIDS Coordination Program
Nevirapine	Antiretroviral drug
NGO	Non governmental organizations
PMTCT	Prevention of mother to child transmission
POP	Progesterone only pill
QOL	Quality of life
RHC	Rural health center
SF	Short form questionnaire
SPSS	Statistical package for social sciences
STI	Sexually transmitted infections
UNO	University of Oslo: Norway
UZ	University of Zimbabwe: Zimbabwe
VCT	Voluntary counseling and testing
WHO	World health organization
WHOQOL	World Health quality of life questionnaire
ZDHS	Zimbabwe demographic heal

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## 1. ABSTRACT

Quality of life and coping styles of HIV- positive compared to HIV negative women in Zimbabwe participating in the prevention of mother to child transmission of HIV program.

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**Objectives:** To describe the quality of life of women participating in the prevention of mother to child transmission of HIV (PMTCT) program and how it has influenced their coping towards risky sexual behaviors.

**Methods:** A cross-sectional study with a total of 273 women, 189(69%) HIV positive and 84(31%) HIV negative. These are women in their reproductive age ranging from 17 to 41 years, mean age of 27.7 years who delivered their index babies under the (PMTCT) program in Zimbabwe. A questionnaire was interview administered to the women from three months postpartum. The modified questions were derived from the Medical Outcomes Survey- HIV (MOS-HIV). This instrument is used to assess functional status and well-being, measuring subject perceptions of overall health, physical, role and social functioning and mental health. Coping was assessed according to Lazarus and Folkman's concept of problem focused and emotion focused strategies and the available social supports. Risky sexual behaviors were assessed by asking about contraceptive use, condom use, future pregnancies, and disclosure of HIV status and knowledge of sexual partner's HIV status.

**Results:** HIV infection risk increases with age with those above 24 years most infected 86% versus 46% for the younger women ( $p<.01$ ). Being single and formally employed exposed one to higher risk of HIV infection. Women were significantly compromised in mental health and family functioning domain, with the HIV positive reporting highest in the "poor" facet 43% ( $p<.01$ ), 45% ( $p=0.01$ ) respectively. Among the HIV positive women, 22% did not use any contraceptive method versus 14% among HIV negative ( $p<.01$ ). Moreover as many as 47% HIV positive and 87% HIV negative women did not use condoms currently ( $p<.01$ ). 24% HIV positive had not disclosed status and 11% were divorced due to disclosure of status. 13% HIV positive women expressed desire to have more children versus 49% among HIV negative ( $p<.01$ ). Most available type of support was informational ( $p=0.01$ ) with the family as the highest unit providing ongoing support 40% HIV positive versus 54% among HIV negative ( $p=0.03$ ).

**Conclusion:** There is need to target interventions that address and promote mental well being and provision of adequate mental health services. The family unit needs to be strengthened and equipped with resources, so as to be able to cope with the demands of the HIV infected family members. Health education should be targeted on reduction of sexual risky behaviors by involving male partners. At antenatal booking male partners should be encouraged to be screened for HIV. Interventions that enhance women's social networks and encouragement of health promoting behaviors should be developed and evaluated constantly for their effectiveness. There is need for further analysis, identifying barriers and facilitator's women experience in practicing health promoting behaviors. Quality of life evaluation is an important outcome measure which can identify areas of need for the HIV positive people especially in poor resource countries where HIV laboratory markers are beyond the reach of many.

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## **2. BACKGROUND**

### **Global Burden of HIV/AIDS**

According to the 2002 UNAIDS report on the global HIV/AIDS epidemic 40 million people in the world are infected with the human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS). Out of these individuals 28.5 million people living with HIV/AIDS at the end of the year 2001, are in sub-Saharan Africa. This comprises an estimated 18.5 million women and 3 million children under the age of 15 years all living in sub-Saharan Africa.<sup>1</sup>

### **Mother to Child Transmission of HIV**

Mother to child transmission (MTCT) of HIV is the most significant source of HIV infection in children below the age of 10 years. MTCT can occur during, before and after delivery. In the absence of specific interventions the estimated rate of MTCT ranges from 15 to 40 percent, the differences between populations being largely associated with the prevalence of breastfeeding<sup>1</sup>. Infant mortality of up to 50 percent in the first two years of life has been documented in sub-Saharan Africa among children born to HIV infected women.

## **3. ZIMBABWE**

### **Country Profile**

Zimbabwe has an estimated population of 11 634 663 people, 5 631 426 males and 6 003 237 females, according to the last Zimbabwean census conducted in the year 2002. It is a landlocked country in southern Africa and shares its borders with Zambia in the north; South Africa in the south, in the west is Botswana and Mozambique in the east.

The country is demographically divided into ten provinces further divided into 58 districts comprising of both rural and urban areas. More than half of the population lives in the rural areas with the rest residing in the urban and peri-urban area.

There are two major ethnic groups which comprise of the two major languages *shona* and *Ndebele*. People from other African ethnic groups constitute about 13 percent and 3 percent are of European and Asian origin respectively.

## **Infrastructure of the Health Care System**

The new government at independence adopted the Primary Health Care approach, which was enunciated by the global community at Alma Ata in 1978. A National Policy was developed, ``Planning for Equity in Health`` to ensure that all Zimbabweans had access to health care.

The policy saw the government building 246 rural health centers (RHC)/clinics, refurbishing and upgrading of 450 existing RHCs to provide maternal and child health care. At such centers delivery of uncomplicated births are carried out, offer of family planning services, immunizations, environmental and curative care. By the year 1987, at least 85 percent of the population lived within 8 kilometers of a health facility. The public health system is the largest provider of health services in the country, with the private health sector serving only about 7 percent of the population, most of who are based in urban areas<sup>2</sup>. Due to increased costs in health services a significant proportion of the population consult traditional healers<sup>3</sup>.

Family planning services have been available in Zimbabwe since 1953, with an established service from the grassroots in the rural villages to the central hospitals in the cities. In 1985 the government resolved to promote family planning not just for child spacing and welfare reasons but also to limit the family size (number of children born to a woman). The Child Spacing and Family Planning was renamed the Zimbabwe National Family Planning Council (ZNFP). It facilitates its own training programs and had at one time 34 clinics and 800 trained community- based distribution agents covering almost 50 percent of the rural population<sup>4</sup>.

The country has a good road and railway network system connecting the various areas both rural and urban.

## **WOMEN'S SITUATION in Zimbabwe**

Before independence women were socially and legally minors, thus their rights were subordinate to men, being father, husband or brother. After independence in 1980 women struggled to liberate themselves socially, politically and economically by lobbying the government through various women's organizations. They triumphed in the passing of the Legal Age of Majority Act of 1982, which made 18 years the age of majority for both men and women<sup>5</sup>.

To date Zimbabwean constitution permits discrimination against women on the basis of customary law, under which women are designated minors. Gender inequalities are significant in every aspect from the basic necessity like education, demonstrated in the table below:

**Table 1: School enrollment according to Gender**

Indicators	Males %	Females %
Primary school enrolment ratio (1995-1999) 1-7 years in school	87	86
Secondary school enrolment ratio (1995-1997) 8-13 years in school	52	44

*Source: UNICEF; State of the World's Children 2002. New York*

The major ethnic groups in Zimbabwe, the Shona and Ndebele are patriarchal societies, which impose strict controls on female sexual behavior and a more lenient attitude towards male counterparts.

It is culturally acceptable for men to have more than one wife or girlfriend and yet women are expected to be monogamous with their husbands. Research has shown that 14.3 percent of the women in Zimbabwe are in a polygamous marriage both formal and informal. This has been shown to decrease with the woman's educational level<sup>4</sup>.

### **Socio-economic status of the women**

Close to 35 percent of households in Zimbabwe are headed by women or girls. They are the traditional caregivers and take on additional responsibilities when family members become ill. When family breadwinners are ailing or die, girls are often the first to be taken out of school to help with care, carrying out household chores and undertaking income generating activities<sup>6</sup>. Women constitute the majority of communal farmers and generally gain rights to land and other important resources through men, mostly a spouse or father. The piece of land is normally allocated to men by the district council; although some changes are being made a woman has no independent legal right or access to land.

They contribute labor to their husband's land, and those married can be allocated a plot by the spouse. Single or divorced women depend on land. In their family homes but it is not always guaranteed that they will be allocated the land<sup>7</sup>.

In the case of death of the husband it used to be an expected norm that the widow be inherited within the family so as to enable her to have access to the late husband's property, disregarding whether she also contributed in acquiring it or not. However due to the advent of HIV this practice has since changed but still there remains immense pressure within family circles for the informal inheritance so that the widow can continue to stay at the late husband's homestead peacefully. This scenario is equally true in urban properties in the absence of a will the woman has to go to court in the presence of the late husband's relatives who have give their blessing that she can be the heir to her husband's property and they sign for it<sup>8</sup>. It is quite rare for the women to participate in community development decision making, and few of them hold influential positions at the local and central levels. This limits opportunities for them to establish developmental priorities that can meet their needs. There has been a declining trend in formal sector employment growth since independence with 55 percent of women being unemployed in 1997<sup>9</sup>. There is no available published information on the recent statistics of employment status of women in particular in Zimbabwe. The majority of the women in the urban areas are in the informal sector where they do cross border trading into the neighboring countries South Africa and Botswana. Others are in the buying and selling business and pose as vendors in the urban townships.

In 2002, Zimbabwe's central statistical office reported that inflation had reached an all time high of 123.5 percent, thereby pushing all prices of basic necessities of food and clothing up. This affects the women most since they are the family care takers who have to plan and provide meals to their families<sup>10</sup>. Urban housing is severely limited due to increased rural –urban migration caused by poverty whereby people come to the cities in the hope of finding employment. As a result there is overcrowding. squatting and overstretching of infrastructure especially water and sanitation facilities.

## **Sexual and Reproductive Health**

Ages for sexual debut are reported to be 18.7 for women and 19.7 for men, according to the Zimbabwe Demographic Health Survey of 1999. Casual sex is not sanctioned for women but it is common practice that men will have had several sexual partners before marriage. Research has demonstrated that there is a large degree of tolerance for men's having concurrent sex partners, but not for women<sup>11</sup>. Zimbabwe's contraceptive prevalence is much higher than the regional averages, with figures of 54 percent for all methods and 50 percent for modern methods. The regional statistics including North Africa are 25 and 20 percent respectively<sup>12</sup>. Despite almost universal knowledge of HIV/AIDS in Zimbabwe women have been found to have a different perception on how they construct their risk to HIV. They view their own personal protection as secondary to their role as a wife, service provider or girlfriend<sup>13</sup>. In the past couples in Zimbabwe communicated about sex and sexuality through third parties such as uncles and aunts, thus, making open discussion difficult. Prostitutes and casual sex partners are considered "dirty" and wives are supposed to be "clean", this means a condom becomes taboo to be used in a formal relationship<sup>14</sup>. Some ethnic groups encourage women to abstain from sex for several weeks before and soon after delivery and the men are supposed to respect that arrangement.

According to the 1999 ZDS, 4.3 percent of the women had used a condom during last sexual intercourse with a spouse or cohabiting partner and 42 percent used a condom with a non cohabiting partner. This was 6.5 percent and 70.2 percent for the females and males respectively. Both men and women in the urban areas were likely to use a condom in the last sexual act with any partner compared to their counterparts in the rural areas<sup>4</sup>

## **The HIV/AIDS Pandemic in Zimbabwe**

The great strides in achieving health goals have been put into disarray because of mainly the high prevalence of HIV/AIDS in the country. At the end of 2001 UNAIDS estimated that 2.3 million adults and children were living with HIV/AIDS in Zimbabwe. Out of the infected adults 1.2 million that is 60 percent were women and 240 000 were children below the age of 15 years<sup>1</sup>.

The adult HIV prevalence in Zimbabwe was 33.7 percent the third highest in the world. The HIV/AIDS epidemic is largely driven by heterosexual transmission which accounts for 92 percent of the infections. MTCT is also a major contributor accounting for 7 percent of the infections. Transmission via blood products is very rare since Zimbabwe introduced universal screening of blood and blood products in 1985. Transmission via men who have sex with men maybe under estimated due to the government's stance against homosexuality practices.

Between 1997 and 2000, HIV prevalence among women attending antenatal clinics (ANC) rose from 29.0 to 35.0 percent. Preliminary findings from the 2001 ANC survey indicate that HIV prevalence was 31.3 percent in the urban areas and 33.2 percent in the rural areas (CDC HIV surveillance report). Zimbabwe has conducted HIV sentinel surveillance among ANC women since 1991.

Knowledge of HIV/AIDS is high in Zimbabwe yet some significant gaps remain, particularly among the people residing in the rural areas and it still remains a highly stigmatized disease in the country<sup>13</sup>.

The advent of HIV/AIDS has further strained the coping mechanisms through its enormous and complex impact on households. This is because it severely affects the most economically active members of the household, thus income and consumption patterns change dramatically<sup>15</sup>. Traditionally strong family ties and informal mechanisms beyond the extended family have helped households cope with adult mortality or other shocks. Due to HIV/AIDS most of these coping strategies are no longer available as the extended family net and local support networks are increasingly under pressure<sup>15</sup>. When family breadwinners fall ill or die, it is usually the girls who are first to be taken out of school so as to help care for the sick, carry out household chores and undertake income generating

activities. There are limited forms of social protection to lessen the impact of adult deaths in Zimbabwean households.

At the end of 2001, an estimated 780 000 AIDS orphans were living in Zimbabwe. The percentage due to AIDS rose from 16.0 percent in 1990 to 76.8 percent in the year 2001 and is projected to rise to 88.8 percent by 2010. Many children affected by AIDS are experiencing neglect, exploitation, psychological trauma and physical abuse. AIDS orphans live in poorer conditions, partly because more are taken care of in rural, elderly, female or child headed households, which themselves are already or tend to be poorer<sup>15</sup>.

The Food and Agricultural Organization (FAO) estimated that Zimbabwe lost 9.6 percent of its agricultural labour force in the year 2000 due to HIV/AIDS<sup>16</sup>. Zimbabwe spends 60 percent of its health budget on HIV/AIDS, with up to 50 percent bed occupancy in hospitals being infected with HIV. An estimated 67 percent of adult (ages 15 to 49) TB cases are HIV positive.

## **Zimbabwean National Response to the HIV/AIDS Epidemic**

After the first AIDS case was identified in 1985, the government's initial response involved the universal screening of blood and blood products for HIV. This initiative has been very successful because now HIV transmission via blood products is very rare.

In 1987, the Ministry of Health established the National AIDS Coordination Program (NACP). The HIV sentinel surveillance program was implemented in 1991. A one year emergency Short Term Plan (STP) aimed at creating public awareness about HIV/AIDS and training of health personnel in different aspects of HIV/AIDS prevention and control was implemented from 1987 to 1988.

This was followed by the first Medium Term Plan (MTP) from 1988 to 1993. MTP1 focused on consolidating and expanding interventions initiated during STP, motivating appropriate behavior change among specific population groups, counseling and caring for people with HIV/AIDS and monitoring the epidemic through epidemiological surveillance.

In recognition of the worsening AIDS situation and the need to mobilize other sectors to participate actively in the fight against AIDS a multi-sect oral approach was adopted. This led to the development and implementation of multisectoral second Medium Term Plan (MTP2) from 1994 to 1998. The main objectives of MTP2 which were to be realized through a set of strategies and interventions were to reduce;

1. Transmission of HIV and other sexually transmitted infections (STI).
2. Personal and social impact of HIV/STI.
3. Socio-economic consequences of the epidemic.

The second Medium Term Plan (MTP) for the prevention, control and care of HIV/AIDS identified the need for development of a comprehensive policy on HI/AIDS as a major priority which had to be addressed. In recognition of the importance of an HIV/AIDS policy, a unit was established within the National AIDS Coordination Program (NACP) to spearhead the implementation of this strategy.

The government introduced the National Policy on HIV/AIDS in December 1991. The National AIDS Council was created in May 2000 to implement the policy. An AIDS levy was introduced in 1999 to supplement the health ministry's HIV/AIDS budget and steps have been taken to make the disbursement of the funds more transparent.



In June 2002, the government enacted a declaration of a six –month period of emergency (HIV/AIDS) to increase availability of and access to generic AIDS drugs. Zimbabwe’s policy in accordance with international guidelines places no restrictions on travel by HIV-positive persons.

Zimbabwe relies heavily on funding from international donors for its HIV/AIDS programs. Non governmental organizations (NGO) s and community based organizations (CBO) including churches and faith based organizations provide a significant amount of HIV/AIDS prevention, care and support.

The national AIDS policy considers counseling to be a vital component of HIV/AIDS prevention and care. The female condom was launched in July 1997, although its usage is limited by both its cost and lack of knowledge about it and reported difficulties in using it.

A phase one trial of buffer gel has been completed in Zimbabwe and there is ongoing research to test the diaphragm as a potential prevention method for HIV. These are aimed at empowering the women in terms of controlling their sexual behavior. The feasibility is questionable given the poor socio-economic status of the women target group.

Zimbabwe’s first Prevention of Mother to Child Transmission of HIV was initiated in 1999 and this is now fully fledged with 181 health centers including 43 out of the 58 district hospitals offering nevirapine to HIV positive pregnant women free of charge.

### **Women and HIV IN Zimbabwe**

In the year 2000 Zimbabwe undertook the first fully implemented antenatal clinic (ANC) survey since 1997. Anonymous blood samples were collected over a three-month period from 6 121 women ages 15-44 at their first ANC appointment across 19 sentinel sites covering all provinces. Summary of the prevalence's are in the tables below

**Table 3: ANC HIV prevalence's year 2000.**

Ages in years	HIV Prevalence (%)
15 to 19	27.8
20 to 24	35.1
25 to 29	40.1
30 to 34	43.5
35 to 39	31.2
40 to 44	15.6

Educational level and HIV prevalence among ANC women:

<b>Educational level</b>	<b>HIV Prevalence %</b>
None	26.6
Primary	37.1
Secondary	34.3
Tertiary	11.1

HIV prevalence and Employment status among ANC women:

<b>Employment Status</b>	<b>HIV prevalence %</b>
Formal	35.5
Non formal	34.7
Housewife	35.1
Student/Other	27.6

*Source: AIDS&TB Program, Zimbabwe Ministry of Health and Child Welfare (with support from Zimbabwe-CDC AIDS Program). National Survey HIV Prevalence among women attending Antenatal Clinics in Zimbabwe; 2000.*

**TABLE 4: ANC HIV prevalence year 2001**

Ages in years	HIV prevalence (%)
<15	8.3
15 to 19	19.5
20 to 24	28.9
25 to 29	36.5
30 to 34	39.9
35 to 39	31.0
40 to 44	23.4
45 to 49	18.2

*Source: Kububa P et al “First suggestion of decline in HIV Prevalence in Zimbabwe?” International Conference on HIV/AIDS, Barcelona, July 7-12; 2002.*

The ANC survey for 2000 revealed a prevalence of 34.5 percent among married women, with urban areas having a prevalence of 31.6 percent and rural areas 26.8 percent respectively. National ANC prevalence rates declined from 35 percent to 29.5 percent. These declines were also observed in all age cohorts with the exception of the 40 to 44 years age group and remained highest among the 30 to 34 years. Mortality rates among Zimbabwean women in the working age population was found to peak at 5.7 percent of the age cohort 30 to 34 years, with 5.5 percent dying due to AIDS<sup>17</sup>.

The majority of women, despite knowing that their husbands are at high risk of HIV do not raise the issue of condom use for fear of being perceived as accusing their husbands of infidelity and depriving them sexual pleasure. They are therefore not able to negotiate safer sex by insisting on condom use, the timing of sex and the conditions under which it occurs. Those women who raise the issue of condom use are often subjected to increased risk of physical violence and will lose the support of the spouse even economically. Studies have shown that even when women are educated about HIV/AIDS issues, their economic dependence on men left them in a state of helplessness when it comes to negotiating safer sex.

Their subordinate socio-economic status affects their vulnerability to acquiring HIV and when infected it becomes difficult for them to access care and support services<sup>18</sup>.

### **Mother to Child Transmission of HIV Epidemic in Zimbabwe (MTCT)**

Basing on background information that MTCT risk is 15 to 45 percent, it is estimated that 10 to 12 percent of infants in Zimbabwe are infected with HIV. Almost 600 000 Zimbabwean women give birth annually and of these 200 000 are HIV positive and 30 percent of them transmit the HIV virus to their babies. This translates to an estimated 60 000 babies born with HIV infection annually<sup>19</sup>.

This has grave implications on child health and survival in Zimbabwe. Infant mortality rate (IMR) which had declined to a rate of 61 per 1 000 live births by 1978 had risen again to 80 by 1997<sup>19</sup>. The childhood death rate increased from 8 to 20 per 1 000 between 1988 and 1997. It is therefore estimated that by the year 2005 HIV will account for 60 percent of childhood mortality which will be four times more than what it would have been without HIV/AIDS.

An ongoing study in the country (Zvitambo) found an overall HIV prevalence rate of 32.5 percent among pregnant women enrolled in the program and 40 percent among those aged 25 to 35 years old<sup>20</sup>. The statement by UNICEF that “AIDS in children is an emergency; an emergency out of control” is very appropriate to the Zimbabwean situation.

### **Prevention of Mother to Child Transmission of HIV(PMTCT)**

#### **Antenatal Care Package**

Voluntary counseling and testing (VCT) is offered to pregnant women attending the antenatal clinic. Initially when the program started it used to be on an individual pre-test counseling. Due to increased number of women the health personnel got overwhelmed so its now group counseling in the form of a health education talk given by the midwives and counselors together. Confidentiality is then maintained at individual post test counseling and issuing of HIV results.

**ANC HIV/AIDS Talk:**

Information is given on the importance of being screened for HIV while pregnant so as to be able to get nevirapine drug which will prevent the child from being infected by HIV. The women are then taught about how HIV is transmitted from the mother to the baby, during pregnancy, during labor and delivery and during breastfeeding. They are given a chance to ask questions and are also encouraged to sensitize and bring their sexual partners for counseling and testing.

Other sexually transmitted infections are discussed in terms of the harm they can cause to the unborn baby especially syphilis. Women are encouraged to book early of at least from 12 to 16 weeks so as to be able to undergo all the tests and ensure safe delivery of the baby.

Bloods are then collected, those who opt to know their results then go through and individual post test counseling by a trained counselor. For those that turn out to be HIV positive nevirapine is then given usually if they are 7 months and above. They are taught about the signs that they should look for when in labor so as to take the tablet. When they have taken the tablet at onset of labor they should note the time so as to give accurate information to the midwife at whatever center they are to deliver the baby. Emphasis is put on being honest in case they vomit just after taking tablet or delivery occurs less than an hour of taking tablet. In that case the child will then have to get an extra dose. If transferred to a referral center they should remind the concerned midwife about the tablet. They should insist in getting the tablet as long as it is within 72 hours of delivery.

Counseling is encouraged for all women since it is vital information given in a country of high HIV prevalence. It is encouragement to take courage and undergo HIV testing which is done using a rapid test and the results are available immediately. The issue of a negative result and the “window period” is explained and women advised to bring their partners for testing as well and to disclose their results so as to practice safe sex.

Rights are also discussed in terms of one’s health in being tested for HIV, to disclose results in order to live positively and protecting each other from infections. It is the right of the child to live a full life. The women have to focus on their own rights rather than concentrating on the spouse’s decision. It is also encouraged that they should discuss their sexual life with reference to other STI’s with their partners.

Husbands, in some instances are tested at their work places without consulting their wives so the women are encouraged to be forthcoming and utilize the opportunity to know their status at no cost.

The aim is for those counseled to live according to the advice given, in the sense that pregnancy and delivery also lead to deterioration in health despite being HIV positive, since the body needs extra nutrients for the baby and there is blood loss.

Mothers are counseled on safe feeding options, like exclusive breastfeeding for at least up to six months where alternative feeding is not possible. Support for mothers on their feeding options is encouraged.

HIV negative women are counseled on the need to stay negative and the increased risk of MTCT during breastfeeding incase they seroconvert. Counseling emphasizes condom use especially during breastfeeding.

Family planning counseling also stress on the preceding risk of deteriorating health in future pregnancies and use of condoms in reducing viral load especially during lactation. Male condoms are offered free of charge and female condoms are available at a cost.

Getting male involvement and support of male partners and family members is encouraged as they are the significant others and influence the women's decisions in all aspects of PMTCT.

## **COMPLEXITY of PMTCT in Zimbabwe**

### **Antiretroviral therapy:**

The cornerstone of the PMTCT program is the availability of nevirapine treatment to prevent HIV infection to the infant<sup>19</sup>. However in Zimbabwe like in most developing countries there are no antiretroviral drugs for the mother beyond the immediate postnatal period. In general medication is difficult to access due to unavailability and prohibitive costs. Most of the prophylactic treatments come in limited amounts and are associated with research initiatives.

The women within these projects may have opportunities to participate and benefit in such initiatives which are short term and therefore not sustainable.

**Breastfeeding:**

Infant feeding is a major concern, where there is no provision of infant formula. Even if it was available it would again create stigma due to cultural deviation from the normal practice of breastfeeding. The cultural demands and beliefs in terms of breastfeeding becomes a complex situation for those who decide to formula feed.

In the MTCT pilot projects in Africa it was highlighted that women's lack of decision making capacities and men's reluctance to know their own HIV status make it difficult for women who test HIV positive to fare well in their desire to practice positive living<sup>21</sup>

**Counseling and continued care**

Counseling is a new phenomenon in Zimbabwe which came with the advent of HIV/AIDS. The national policy on HIV considers counseling to be a vital component of HIV/AIDS prevention and care. WHO, in its 2002 report, it was estimated that 97 375 people in Zimbabwe had received VCT in the year 2001. Thus only 10 percent of the population in need of VCT was receiving it mainly from the public/NGO VCT sites.

Continuity of care focus on the individual, within a resource strained country where often the mental health needs are already overwhelmed and not a priority, creates a complex situation for those in need. This type of care is affected by both the shortage of funds and to some extent lack of evidence based information of the problems highlighted and their impact on the particular women concerned.

The head of PMTCT programs in the ministry highlighted in her report, that staff could not cope with the demands of counseling at antenatal care centers offering nevirapine<sup>22</sup>.

It becomes more complicated for the same facility to attend to the various psychosocial needs after delivery. This leaves the woman with a whole set of external pressures which she has to tackle in isolation sometimes even from family members.

The opportunity to prevent HIV infant infection relies on the identification and treatment of pregnant women with HIV, and this forms the base for PMTCT programs breakthrough. There are enormous repercussions for such programs for the mother, father, index infant and wider family concerned<sup>23</sup>. Given the time pressure on decision making at the time of pregnancy, continuity of care becomes crucial and there is need for psychosocial support at this early traumatic stage.

The birth of a baby and living with HIV is taxing enough for the women and thus issue of supportive groups and individual counseling become an essential element.

**Stigma:**

Despite high levels of HIV/AIDS awareness in the country, it has remained a highly stigmatized disease. People with HIV are shunned and treated with contempt, as immoral and labeled as having a disease of “shame”<sup>24</sup>. There is documented evidence whereby community leaders, chiefs, headmen and others made public discriminatory statements during graveside speeches at funerals. The situation in Zimbabwe in most cases is whereby the first time HIV testing is offered to a couple is when the woman attends the antenatal clinic. When she gets tested and turns out to be HIV positive there are bound to be concerns that both the family and her partner will assume that she is the one responsible for bringing the virus. Thus she will be labeled as the source of infection in the relationship.

This becomes complex bringing a sense of guilt, stigma and blame at a time when the key issue is to respond to the presence of the virus. The reaction following an HIV positive result is mostly directly or indirectly related to stigma which leads to fear, a reluctance to interact with HIV positive individuals. There is evidence of avoidance and fear of abandonment and abuse on the part of the woman concerned.

In October 2002, the head of the PMTCT program highlighted how HIV/AIDS- related stigma acted as an impediment to VCT and other PMTCT services<sup>22</sup>.



#### **4. QUALITY OF LIFE**

The interest in health-related quality of life assessments reflect a more serious concern for that broad definition of health “a state of complete physical, mental, and social well being and not merely the absence of disease”<sup>25</sup>. Since then many other definitions of both “health” and “quality of life” have been attempted, often linking the two for quality of life (QOL). They frequently emphasize components of happiness and satisfaction with life.

In the absence of any universally accepted definition, it is clear that QOL means different things to different people and takes on different meanings according to the area of application<sup>26</sup>. In the context of clinical trials the concern is with evaluating those aspects of health that are affected by disease or treatment for disease. This can sometimes include other indirect consequences of disease such as financial difficulties.

To distinguish between the QOL in its general sense and the requirements of clinical medicine and clinical trials, the term health-related quality of life (HRQoL) is often used in order to avoid ambiguity.

HRQoL is still a loose definition and has a multidimensional concept, but it is generally agreed that the relevant aspects may vary from study to study. These can include general health, physical functioning, role functioning, social well being and functioning, sexual functioning and existential issues<sup>26</sup>.

The concept of HRQoL can be differentiated from the broader concept of “quality of life” in that it usually includes a global measure comprising all aspects of human experience and the personal assessment of one’s experience with them. On the other hand HRQoL has a narrower focus on those aspects that can be readily affected by health care<sup>27</sup>.

The World Health Organization Quality of Life Instrument (WHOQoL) measures people’s individual perception of their positions in life, in culture and value systems in which they live and in relation to their goals expectations, standards and concerns. This instrument was developed in a wide range of languages and many different cultural settings yielding comparable scales across cultures<sup>28</sup>. It assesses individuals in six domains that are, physical health, psychological state, level of independence, social relationship and their relationship to salient features of the environment and spiritual state.

The instrument addresses quality of life at two levels of questioning that is perceived objective and subjective evaluation. Its limitation is that it has not been tested and adapted as widely as the HRQoL, medical outcomes survey (MOS-HIV) and Short Form 36 (SF36).

The MOS-HIV is a brief comprehensive health status measure that was developed in 1987 and has been used extensively in studies of HIV/AIDS. It includes ten dimensions health perceptions, pain, physical role, social and cognitive functioning, mental health, energy, health distress and QOL. MOS-HIV was one of the first disease targeted measures for the HIV/AIDS population and is still widely used in clinical trials and other evaluation studies<sup>29</sup>.

HRQOL research in HIV/AIDS including studies using the MOS questionnaire have been mostly conducted in clinical trials and have been reportedly shown to be a valid and reliable instrument for assessing QOL in HIV populations<sup>29</sup>. In the HIV investigation domain HRQOL has become a useful component of treatment assessment and helps researchers, clinicians and those infected to better understand the effects of disease, its treatment and role of interventions.

Although women represent the fastest group affected by HIV/AIDS, their presence in QOL and HIV research have been recently demonstrated<sup>27</sup>. The life circumstances of HIV infected women in developing countries are characterized by being young, above that they take on household activities, caring for children and dealing with other external family and community pressures.

Interventions targeted at alleviating the effects of HIV come in peace meals thereby not addressing the full impact of HIV infection issues among women. HIV infection has been demonstrated to manifest itself differently in women than in men. Considering the extra social and maternal roles taken by women it is necessary to assess how the quality of life of the HIV infected women is affected using validated instruments.

The goal of every intervention is to improve the QOL of the targeted individuals. With the advent of HIV now being a chronic condition there is increased recognition of the importance of including QOL assessment as an outcome measure in HIV interventions.

Most QOL studies have been carried out in the developed countries and have thus dealt with populations with completely different life styles from that of the developing countries<sup>27, 29, 47</sup>. This limits the extent to which the findings can be generalized to the populations in different settings. Few studies have focused or assessed the QOL of HIV infected populations in the developing countries<sup>40, 44, 46</sup>.

The fact that the widely used validated instruments that measure HRQOL like the MOS and the Short Form (SF) are not available in local languages limits the level at which their findings can be compared with studies using a different language. Thus a need has arisen for validation and adaptation of standardized instruments in local settings so that they can be part of every health intervention and results can be compared from local to international findings from similar studies.

The majority of the HIV positive women are in their reproductive ages and there is a high sero-prevalence rate of HIV infection during that period<sup>29</sup>. HIV infection in pregnancy constitute a unique interaction among patho-physiology, individual and cultural experiences that may influence perceived quality of life<sup>45</sup>.

It has been demonstrated that all aspects of QOL are affected even in asymptomatic HIV infection, especially in the emotional and psychological factors<sup>29,44</sup>. QOL assessment helps to highlight some of these salient manifestations of HIV that can not be communicated to the clinician, or that may not be easily detected by carrying out a medical examination.

Most published QOL studies have assessed women consulting a health facility for treatment or psychotherapy. Findings from such studies can not be generalized to other populations as these are people already getting specialized care and have the same help seeking behavior which leads to selection bias<sup>29,40,44</sup>. Some of the studies included samples of women who were infected by HIV through a different mode of transmission mostly injection drug users. This is not common in the developing country which makes it difficult to compare them with women infected through heterosexual transmission.

Most studies assessed QOL on HIV infected persons only without a control group thereby limits the extent one can conclude that the findings are not applicable to the true in the general population<sup>40,48,49</sup>.

Use of questionnaires and quantitative methods helps in highlighting the extent of the limitations and the estimated number of people experiencing limitations and thus aids in identification of areas of need and targeting of resources that alleviate suffering.

PMTCT is a major breakthrough intervention to save unborn infants from HIV infection. Much attention has been given to the counseling, uptake of the HIV test, infant feeding and its dilemmas. Few studies if any have followed up these women to find out about their health in the post partum period more so in the developing countries where there is no readily available antiretroviral treatment for them before and after pregnancy. It is essential to assess how the health of these HIV infected women is affected after delivering under the PMTCT program where the focus is for them to deliver a healthy baby without a plan of care for the mothers.

This study seeks to evaluate the health of these mothers using modified questions derived from the MOS-HIV, since it has been validated and widely used in different settings and was found to be a valid and reliable instrument cross-culturally<sup>29</sup>. A control group the HIV negative women who delivered under the PMTCT program were included so as to enable comparison between the two groups.

## **COPING**

Coping has been defined as cognitions and behaviors that individuals use to manage a stressful situation and its attendant negative emotions. That is anything that a person does to address the stressful encounter regardless of how well or badly the outcome may be. The situation appraised will be taxing and exceeding one's resources<sup>30</sup>. Lazarus and Folkman identified two ways of coping with stressors that is, problem focused coping being those strategies directed at altering the cause of stress and developing a more satisfying situation. This type of coping has been demonstrated to be used most frequently in situations where something can be done about the stressor and the person has control of the situation.

Emotion –focused strategies are directed at reducing the emotional distress prompted by the problematic situation. This has been found to be used effectively when control over outcome is limited and the stressor is considered unchangeable and inescapable, one has to live with it.

In their widely accepted model, they identified eight basic types of coping- confrontive coping, distancing, self-control, seeking social support, accepting responsibility, escape avoidance, planful problem solving and positive reappraisal. The broader the span of coping strategies a person employs, the better the chances for adjustment and perceived quality of life.

Chronic illness is a condition that taxes an individual's resources and HIV infection is one such illness accompanied by a host of stressors ranging, from social stigma to uncertainty of illness progression<sup>50</sup>.

The relationship between illness and coping is complex in whether it is determined by the person or by the situation one is encountering, or some interaction of the two. There are various factors that have been studied for consideration when studying coping, like personality traits, appraisal, and nature of illness or stressors themselves. The way in which a person handles or faces a stressor is linked often to how they perceive and interpret the situation. This has also been found to be influenced by a number of factors like, presentation of the stressor and its attributions, the influence from one's social group, personal values, personality traits, availability of the coping mechanisms and previous experiences<sup>31</sup>.

Receiving an HIV positive diagnosis often leaves a person in a crisis with strong emotional reactions like fear, anxiety, disorganization or anger, denial, bargaining, depression, pessimism, helplessness, hopelessness, withdrawal and acceptance<sup>32</sup>. There is uncertainty towards one's future and that of loved ones, thus leading to anxiety and distress. Often there are fears of how others will react, dealing with stigma, physical and mental decline which can lead to suicidal tendencies.

When experiencing a stressful event, the extent of stress is defined by the relationship between the importance of the event in terms of commitments of what values and goals are at stake and the availability of coping resources. Psychological stress comes in when that which is at stake is substantial and the coping resources are appraised as not adequate to meet the demands of the situation<sup>30</sup>.

For women living with HIV, the biological impact of the infection interacts with profound personal, social and economic constraints that expose them to high risk of emotional distress due to limited access to care and social support.

The women's situation becomes more complex and stressful when they are in their reproductive age group where decisions have to be made with regards to contraception and childbearing<sup>50</sup>.

Pregnancy and HIV constitute a unique interaction among patho-physiology, individual response and cultural experiences that influence the way the woman has to cope with her situation.

The decisions she has to make towards contraception and repeat pregnancy have complicated implications not only on her health as a woman but also for the prevention of HIV infection in infants and protecting spouses and would be sexual partners from HIV infection. Given this combination of stressors and the alarming statistics of women infected with HIV in their reproductive ages, there is limited information about the psychological impact of HIV infection during pregnancy and in the post partum period<sup>4</sup>.

The few studies that have investigated how HIV infected women cope with their situations have utilized women with different life styles like the injection drug users and most of them are from affluent societies that have access to antiretroviral therapy, psychotherapy and available public social supports<sup>50,51,52</sup>. Other wise the bulk of coping and HIV infection studies have focused on men<sup>53,54</sup>.

These studies have demonstrated the use of various coping strategies and how they can buffer the impact of HIV infection on emotional well-being and quality of life and the particular strategies that can alleviate general psychological distress. They focused mostly on the psychosocial aspects of coping and conceptualized coping in a way that does not consider the entire spectrum of possible strategies that affect the day to day lives of people. Such findings have limitations in generalizing them, especially to women from the developing countries who face unique stressors. These are not only due to bio-psychosocial differences, but more so due to the high prevalence of HIV infection and low socio-economic environments.

The overall findings regarding outcomes of emotion focused and problem focused strategies in dealing with HIV infection have been different with some studies reporting a positive impact of the former strategy. This was mostly in the emotion focused coping like seeking social support, spirituality and optimism that were related to improving psychological functioning in both chronically ill and HIV infected individuals<sup>52</sup>.

Better psychological adjustment has been associated with use of problem focused coping in chronically ill adults including HIV infected individuals<sup>54,55</sup>. The suggestion was that HIV infected people often cope better when using an emotion focused strategy since the disease does not have a cure, the solution based strategy of problem focus may not be effective<sup>56</sup>.

There is a general agreement that individuals having adequate social supports are more likely to have better mental and physical adjustment. The mechanism through which social supports protects against ill health is not very clear thus two hypotheses have been proposed:

1. The buffering effect explained by appraising the coping mechanisms and resources. A person usually assesses the coping requirements demanded by a situation and then the specific interpersonal relationships that are necessary to fulfill those needs. Social support becomes an underlying factor in appraising coping mechanisms as different situations and types of presenting symptoms will elicit coping requirements needing different types of support<sup>31</sup>.
2. The main effect hypothesis is where people with relatively strong social supports have better health than those with weak social supports irrespective of exposure to a stressor<sup>31</sup>.

This is the opposite of the buffering effect where people with strong social support have better health than those with weak supports but only under exposure to a stressor. The main types of social supports studied are tangible or material, informational, appraisal, self esteem and belonging support. Only the interpersonal relationships that provide the appropriate forms of support will operate as effective buffers<sup>42</sup>. The assumption is that a coping strategy is formulated after one appraises the situation in relation to the extent of the threatening or prevailing condition, and the available coping resources required in handling it. Therefore the choice of actions utilized will result in either physical or psychosocial well-being<sup>42</sup>.

The study of social supports has received little attention in developed countries with scanty social supports if any, yet they are the necessary tools of coping for communities overwhelmed with the burden of HIV infection and limited available social supports, psychotherapy and access to antiretroviral treatment.

There is need to identify the social supports available to the HIV infected women and those who are providing it. This will guide policy makers in allocating resources towards provision of social supports and strengthening those units identified as already providing this service.

It becomes imperative to find out how the women in high HIV prevalent areas appraise the threat of sexual behaviors that expose them to risk of HIV infection and infecting others for those already infected. Their response to this threat has been assessed as coping towards risky sexual behaviors for this study. The behaviors assessed being contraceptive use, condom use, future pregnancies, disclosure of HIV status and knowledge of sexual partner's HIV status.

Studies that have assessed coping with HIV infection in Zimbabwe have used samples of HIV positive women only using qualitative methods of focus group discussions and in-depth interviews<sup>60</sup>. This limits the extent to which one can generalize the findings due to lack of information on what the HIV negative are doing to cope with the situation and also quantifying the percentage of women alluding to utilizing a particular strategy.

Effectiveness of a coping strategy can be assessed in various ways, but the most important aspect in health is to assess physical, psychological and social functioning as appropriate outcomes of coping.

For this study it is only identification of coping strategies used in dealing with the stressor HIV infection that has been assessed without looking into their effectiveness. This baseline information is important as it can be used later to assess the effectiveness of the coping strategies identified as promoting psychological well-being. As a health outcome assessment strategies that are regarded as harmful to health will be discouraged and the ones that promote health behaviors will be strengthened.

This will also help target interventions towards reduction of strategies that have adverse effects to health and strengthen those that promote psychological well-being and improve quality of life.



## 5. STUDY RATIONALE

Industrialized countries have experienced dramatic reductions in HIV morbidity, mortality and MTCT due to the use of highly active antiretroviral therapy (HAART). HIV disease has been transformed into a chronic condition for those who can access treatment<sup>1</sup>.

Ideally MTCT prevention using antiretroviral (ARV) drugs in pregnancy and postnatally should prevent infant infection by HIV and prolong the life of the mother. In the developed countries HIV positive mothers continue after delivery with the ARV treatment they were taking before pregnancy.

In developing countries, women are not on such treatment before pregnancy. The current intervention programs where nevirapine is given to prevent infants from HIV infection during delivery do not offer any continued treatment for the mother beyond the immediate postnatal period<sup>34</sup>. PMTCT has been viewed as an intervention that uses women's bodies to deliver preventive treatment to the infant without anything to benefit the mother<sup>35</sup>. The anti-HIV benefits to the infant are clear but the benefit to the mother in the absence of HAART is questionable<sup>36</sup>.

In a resource constrained country of high HIV prevalence like Zimbabwe, in most instances the first time that HIV testing is offered to a couple is when the woman attends the antenatal clinic. After the test the woman takes the result to a society where stigma, blame, fear of relationship turmoil and isolation awaits for her. The woman has to make decisions, to learn about her status without consulting the spouse becomes risky, to discuss with him is difficult and to disclose an HIV positive result has worse consequences, as the concern is not only about her fate but that of the unborn infant<sup>37</sup>. Given the problems related to disclosure the HIV positive pregnant woman is increasingly driven into isolation even from family members. This marks high levels of stress which calls for psychosocial support an unmet need for the HIV positive women enrolled in PMTCT programs in Zimbabwe.

Few studies have followed up both mothers and infants in a setting where the intervention is to rescue the infants when it is not possible to rescue the mothers through ARV treatment. There is paucity of information about the health of these women during and after this intervention, their perceptions and how they are coping in the absence of a plan

of care and treatment<sup>38</sup>. Some women who have accepted this intervention continue to express hope that it will “cure” them, as well as protect their infants despite explanations to the contrary<sup>39</sup>. There is no published information in Zimbabwe of how the quality of life of women who have delivered under the PMTCT programs is affected and the type of coping strategies they use in relation to the stressors that come with testing HIV positive.

It is essential to register how these women are coping and assess the impact of such programs on the quality of life of the HIV positive women.

Most studies in health related quality of life and medical outcomes studies have been conducted in developed countries and this has received little attention in developing countries like Zimbabwe<sup>40</sup>. This study seeks to evaluate the impact of PMTCT on the quality of life in HIV infected compared to HIV negative mothers participating in the program. Assessing their coping strategies and quality of life will give an indication of the women’s needs, and in turn guide policy with regards to future plan of care for HIV positive women in the absence of antiretroviral treatment. Highlighting the coping strategies used will also help in building up or strengthening on the identified strategies that minimize risky sexual behavior and discouraging of those that will exacerbate the problem.

Identification of social supports available to the HIV positive women will help guide policy makers in targeting resources to the needy women, acknowledgement and strengthening of those units reported as already providing this essential need.

Interventions will then be targeted in strengthening health promoting strategies that reduce HIV transmission and discouraging those that have fuel the epidemic.

Assessment of the strategies used by the women to enhance their quality of life in the face of debilitating, stigmatizing and difficult life circumstances would enrich efforts to provide supportive interventions to women living with HIV/AIDS in Zimbabwe.

Information gathered from this study will be useful in identifying the effectiveness of the PMTCT intervention in improving quality of life of these women. This will help as an evaluation of the PMTCT program by giving basic information on what women are actually practicing after going through HIV testing and counseling in relation to risky sexual behavior. This will also contribute to the body of literature in the fields of quality of life and coping with HIV infection in pregnant women in poor resource countries.

## **6. STATEMENT OF THE PROBLEM**

Many women are living with HIV infection in Zimbabwe and the majority of them are in their reproductive age 15 to 49 years. At the end of 2001 it was estimated that 2.3 million Zimbabweans were living with HIV/AIDS, and out of the infected adults 1.2 million that is 60 percent are women<sup>1</sup>.

Zimbabwe' adult HIV prevalence rate is 33.7 percent, making it the third highest in the world. HIV prevalence among women attending antenatal clinics ranged from 26.4 to 39.6 percent<sup>18</sup>. Mother to child transmission of HIV is one of the major contributors in fueling the epidemic. According to Zimbabwean ministry of health statistics close to 600 000 women give birth annually and 200 000 of them are HIV positive. Out of the 200 000 HIV positive almost 30% of them have the potential to transmit the virus to their babies<sup>19</sup>. It is in response to the HIV epidemic that the government has welcomed interventions that can reduce mother to child transmission of HIV (PMTCT) to fight the epidemic. However due to the prohibitive costs of antiretroviral drugs (ARV), they can only be given to prevent transmission to the infant just before delivery and in the immediate postpartum period.

There are no ARV drugs available to these mothers beyond the postpartum period. There is no plan of treatment, care and follow up of these women after delivery.

It is therefore essential to register the coping strategies adapted by these individuals and assess how their quality of life is influenced by delivering under the intervention aimed at reducing mother to child transmission of HIV.

## **OBJECTIVES**

1. To investigate women's beliefs views and opinions about enrolling in the prevention of mother to child transmission of HIV program.
2. To describe how the program has impacted on the quality of life of the women participating in the program.
3. To describe how the program has influenced these women's coping behavior concerning contraceptive practices, future pregnancies and risky sexual behavior.
4. To describe the HIV positive's reception of community support

## **7. METHODOLOGY**

### **Study design**

A cross-sectional study comprising of women who delivered their index infants under the prevention of mother to child transmission of HIV (PMTCT), both HIV positive and HIV negative were invited to participate in this study. The women were selected from a “mother” project currently running in Zimbabwe titled “The role of sexually transmitted infections and micronutrient levels on MTCT of HIV: Motor and neurological development among infants exposed to single dose Nevirapine for the prevention of vertical transmission of HIV in Zimbabwe and Tanzania”. It is a collaborative study between the university of Zimbabwe and university of Oslo (UZ-UNO study).

Women were given information about this “baby” project as they reported for their follow up visits in the main study. They were then booked for the questionnaire interview at the clinic where they delivered, at their convenient time. Clinic records of the “mother project were used so as to obtain the addresses of the women and also to establish the HIV status and match study numbers for accuracy.

### **Study Area**

Women were selected from the three antenatal clinics where the mother project is taking place. Nevirapine is given to all HIV positive mothers who will have consented to an HIV test. The three clinics also happen to be the ones where pilot studies of PMTCT in Zimbabwe were launched in 1999, to assess its feasibility and acceptability.

#### **1. St Mary’s clinic**

The clinic falls under Chitungwiza municipality, which is a sprawling dormitory city approximately 24 kilometers out of Harare. It was constructed during the UDI (colonial era) to accommodate the black population and reduce the population density of Harare. It has an estimated population of about 321 782 inhabitants. The city is divided into four major sections each with its own municipal clinic run by a city health director who is a medical doctor by profession.

St Mary’s is one of the poorest among the four sections as its inhabitants are mainly rural people who refused to be relocated elsewhere when the city was being constructed. As a result the rentals are quite low and a lot of people opt to stay in this area to take advantage of the low costs.

This has however led to straining of the infrastructure which is also already very old and therefore burst sewage pipes are a common feature and most of the houses have no electricity. The clinic has a catchment's area of about 85 000.

## **2. Seke North Makoni**

Falls under Chitungwiza municipality and has a good infrastructure with electrified houses and piped water. It also offers maternal and child health together with treatment of uncomplicated cases.

## **3. Epworth**

This is a peri urban residential area situated 20 kilometers out of Harare and has its own administration comprised of a local board which is appointed by the ministry of Local government. It has poor infrastructure mainly due to lack of proper water and sanitation facilities.

### **Study population**

Women who delivered their index baby at these clinics under the UZ-UNO study were given information about the “baby” project, as they reported for their follow up visits and immunizations of their babies. They were then booked for the questionnaire interview after consenting to participate. Information to verify identity of the women was obtained from the clinic record of delivery. The records were also used to obtain addresses of those women who were not coming to the clinic for other reasons but would have delivered under this PMTCT project.

The women were followed up at their homes and invited by the lay counselors who were already employed under the UZ-UNO study. Interviews were performed at the clinic, so as to maintain confidentiality and to try and minimize the number of times the women would have to come to the clinic. Women were also free to be interviewed at the time of their convenience.

## **Enrolment**

### **inclusion criteria**

Women were included in the study if they:

- Received prenatal care and delivered under the PMTCT, UZ-UNO project
- They were HIV positive or HIV negative and having delivered their index baby from three months and above postnatally.
- They were at least 18 years of age and above
- They resided in Epworth, St Mary's, Seke, Chitungwiza and Harare
- They had no major complication or not too ill to be interviewed

### **Exclusion criteria**

Women were not included in the study if they:

- Did not enroll in the PMTCT program
- Their index baby is under three months of age
- Were confused or too ill to be interviewed
- Were not willing to participate in the study
- Resided outside the study areas.

## **Study Procedure**

This is a “baby” project from a “mother” study, a PMTCT program being collaborated between the universities of Zimbabwe and Oslo (UZ-UNO) and implemented in Zimbabwe for the past two years and running to date.

The researcher spent one week at each of the clinics to get a feel of how the program was being implemented. Observation was noted on how the clients were received and enrolled into the main project, what information they were given especially the pre and post test counseling component.

This gave an insight of what information to expect from the women and helped in the modification of the questionnaire so as to be sensitive to the information given to the women. It also created an opportunity for the researcher to get acquainted with the health personnel in the clinics especially the ones directly involved with UZ-UNO study.

It was essential to work closely with the personnel in the main study since the selection of clients depended on their cooperation in releasing the records and also physically identifying the mothers and introducing them to the baby “project”. This facilitated maintaining of confidentiality in terms of clinical records of delivery and HIV status of the women being shown to the researcher.

### **Training of research assistants**

During the week spend at each of the clinic the midwives were given the questionnaire to go through it and make written comments. The questionnaire was then discussed at length incorporating the midwives comments. They were then trained for three days through pilot testing on the lay counselors, who were also involved in the training so that they got the essence of what it involved since they were going to follow up and invite those mothers who for some reason were not coming to the clinics for the main study follow ups.

Emphasis was made on the issue of giving an opportunity the clients to respond to the questionnaire expressing their own experiences and maintaining confidentiality throughout the interview and afterwards since they are going to be seeing these women later. Recording of appropriate information as given by the client, giving the client time to ask after the interview and to give adequate responses according to the best of one’s knowledge.

### **Interview Procedure**

The midwives were involved in administering the questionnaire, though three quarters of the participants were interviewed by the researcher, who rotated around the three clinics on a weekly basis.

The objectives were explained to the participant, a written or oral consent for those not able to sign was given in front of a witness. Women were informed about the right to discontinue the interview if they felt uncomfortable to continue. They were reassured that it would not jeopardize their reception of clinical care or other services due to them in any way.

A structured interview was performed using a structured questionnaire. This had to be administered by an interviewer considering the literacy levels in the country.

Participants were interviewed within the clinic in a separate room from the one used for the main study.

Questionnaire included information on sociodemographic questions, ethnic identity, religious affiliation and educational level. Contraceptive use, condom use, desire for more children, disclosure of HIV status was also included together with expectations and benefits of delivering under PMTCT program.

Questions on quality of life aspects, reception of social support and coping behaviors were asked. The interview lasted 30 to 40 minutes depending if the participant interrupted with questions. After the interview the woman would be given an opportunity to ask questions which were answered to the best knowledge of the interviewer. Information was also given on health education, latest available events like the support groups and any other issues that were considered important to the mothers.

Advice was given to the participants where they expressed complete ignorance of issues pertinent to their health, like joining support groups and treatment for other infections which was being given free of charge as long as they belonged to the PMTCT program.

## **QUESTIONNAIRE**

### **-Quality of life questions**

Quality of life was measured using items from the Medical Outcomes Study HIV (MOS HIV) and other questions were derived from the health related quality of life questionnaire to be sensitive to this particular population. The reference period or time factor was after delivery in order to detect any differences and relate it to the post partum period. The items were modified to suit these particular clients in their situation as most of them were healthy individuals. Items included were: Overall health, physical functioning, and role functioning, social functioning, family functioning, social support mental health distress, pain and the overall quality of life.

Questions assessed directly how the women felt after delivery of this index baby and the limitations that they experienced, as this was the reference period of consideration. The responses ranged from “not at all” being the best state and “extremely” being the worst score.



The overall quality of life question is a single variable item taken from the original MOS-HIV. It asks the individual to rate their quality of life on a five point scale from “bad” to “excellent”. Item scores were reversed where necessary so that ultimately the higher scores reflected better health.

For each score standard scoring procedures were used in which item responses are summed up and scores converted into lowest range and highest. The lowest scores indicated “poor” functioning while the highest reflected “adequate” functioning and those who scored in between had “acceptable” functioning.

Physical functioning assessed the extent to which their health limited them from performing activities of daily living like attending to household chores washing and preparing meals for the family, and the responses were from not at all to extremely.

Role functioning assessed the extent to which health interfered with activities of daily living, and was addressed by five questions assessing if they were taking frequent rests when carrying out physical work, not accomplishing as much work as others, cutting down on the amount of time spent carrying out an activity and not able to carry out any physical work at all. The responses were yes and no, these were summed up and recoded into poor acceptable and adequate functioning for analysis. The reference period was since delivery this question would enable capturing information on the health status of the women in a more specific way.

Considering that this study population comprises of mostly unemployed and those informally employed it became necessary to ask a separate question about being able to work at usual paying job. This was meant to capture more specific information about the extent to which the women are able to take care of their personal needs as they are residing in a peri-urban area where they reported carrying out various types of work in order to earn a living. The response was in the “yes” or “no” format for the analysis to be easy.

The energy and fatigue scale was left out to avoid monotony almost asking the same thing. Pain was addressed as a single item assessing the amount of pain experienced since delivery from none, mild and moderate were combined to make one scale since its difficult to differentiate the two in the local language for this study and severe was retained as it is from the original scale.

Family functioning was assessed by four items asking one to rate the extent of family happiness, togetherness, support and understanding and amount of time when they are able to talk things over. The responses were from “poor” as the lowest and “excellent” for the best. These were added up and recoded into poor for lowest functioning and adequate for best functioning.

Sexual functioning was also assessed with a question of type of relationship, married, informal partner and not sexually active. Problems with sexual life was also solicited for and assessed in its original state of questioning.

Social functioning assessed how it had been affected since delivery this was addressed by two questions if not socially active at all since delivery being “poor”, and more socially active than before delivery as “adequate” functioning. The other item asked the extend to which physical health interfered with social activities like visiting friends since delivery and the responses were “always” for poor and “never” for adequate functioning. This was recoded so as to give it a positive response and then added up with the other question on social functioning and ranked from poor as lowest and adequate as highest functioning.

The mental health aspect was addressed by questions on anxiety, feeling depressed and being able to concentrate on one activity at a time after delivery. In order to have a positive response to enable analysis, the answers were transformed and recoded into three most applicable response, the scales used were “adequate” for the highest score of being well, “acceptable” as in between and “poor” as the lowest functioning.

### **-Coping strategies questions**

Variables addressing the two major groups of coping were asked in their original state five questions each from the ways of coping checklist which was developed and revised by Folkman and Lazarus (1980, 1985) and has been modified by various researchers were used. Since this study involved a control group the HIV negative the format of asking questions on coping had to be in a dispositional response format<sup>42</sup>. The interest was in how these women respond when they are confronted with difficult stressful events in their lives, for the HIV negative since for the HIV positive we assumed they would relate to the positive result as the stressor.

In assessing dispositional coping style the items are framed in terms of what the person usually does when under stress as opposed to what the person did or is doing currently which give situational responses. This approach was just to give an indication of how the women responded and would be validated by their actual behavior with regards to sexual behavior which might still expose them to risk of infection.

The emphasis was that there was no right or wrong answer that one should say what they generally do or feel when going through a stressful event, and for them to indicate what they personally do rather than what others would normally do. To avoid ambiguity the responses were either yes or no to the questions pertaining to a coping strategy.

For the emotion focused coping questions asked were on hoping for a miracle to happen, turning to prayer, trying to forget about the issue, associating stressor with misfortune or bad luck and concealing the problem to oneself not wanting others to know the gravity of the stressor.

Problem focused coping was assessed with questions on expressing anger to the one who caused the problem, criticizing and lecturing oneself, turning to work so as to avoid thinking about the problem, compromising or bargaining to get something positive out of the stressor and taking a risky. This was followed by an open ended question asking the type of risk taken if they answered positively to the question. The five questions for each category were computed and then added up to make one variable which was recoded into poor, acceptable and adequate for analysis. A general question on coping was asked as open ended and the responses were recoded into categories for analysis.

Social support was measured with the traditional scale on the three dimensions of support that is having a confidant, having someone to count on if help was needed, type of support available, provision of ongoing support and the frequency with which support was given. Network was assessed by a direct question on whether they belonged to a social group in the community.

An extra question on suicidal thoughts was assessed under coping, and the responses were always, sometimes and never. This was assessed as a single item.

Risky sexual behaviors are those that predispose one to HIV infection or infecting others for those already infected. These were assessed by asking about contraceptive use, condom use, future pregnancies, disclosure of HIV status to sexual partner and knowledge of partner's HIV status. The way they responded to that is evaluated as a coping strategy with regards to the HIV situation.

## 8. STATISTICAL ASPECTS

### Sample size

This was calculated basing on the number of women who had already enrolled into the study. A total of 1022 women had been enrolled and delivered under the PMTCT program. Of these 822 were HIV negative and 200 were HIV positive.

The formula used to calculate the study sample is based on a 5% margin of error and a non response of 5%.

$Z_p(1-p)$

W

Z value= 1.96)

Proportion=50%

W=error 5%

$$\frac{1.96 \times 1.96 \cdot .5(1-0.5) = 392 + 5\%}{.5}$$

$5 \times 392$

$100$

Total number of women to be interviewed is 396 participants.

The main focus of the study is the HIV positive women and therefore the target was to interview all of them if they had turned up. It turned out that the HIV negative were not very forthcoming for the interview and the same was true of the follow up in the main study.

It was difficult to get hold of the HIV negative as compared to the HIV positive women. Thus it turned out that the control group had fewer participants than the cases and the study population was 273 women comprised of 189 HIV positive and 84 HIV positive women.

## **9. Data entry and Analysis**

Data was entered into a data base using the software statistical program for social sciences (SPSS) for analysis. SPSS version 11. was used for analysis. Statistical difference between different groups was done using Chi square test. Statistical significance was considered at  $p < 0.05$ .

## **10. ETHICAL CONSIDERATIONS**

The study was approved by both the Norwegian Ethical Committee and the Medical Research Council of Zimbabwe. Identity numbers from the mother study were used on the questionnaires without any names on them. The consent forms with the participants signatures and names were kept under key and lock, and were only made available to people who were involved with the study.

## **11. RESULTS**

### **Socio-demographic characteristics of the women:**

A total of 273 women were enrolled into the study 189 (69%) HIV positive and 84 (31%) HIV negative. They had a mean age of 27.7 years with more than 75 percent of them being less than 32 years of age. (Descriptive statistics are shown in Table 1). More than half of the women were in a monogamous marriage 183(67%), 25 (9%) were in a polygamous marriage, 30(11%) were divorced, 23(8%) were widowed and 12(4%) were single mothers.

Most of the women were fairly literate having been in school for at least 1 to 7 years, 179 (66%) of them had been in school for 8 years and more, only 3(1%) had never been to school in their life and only 3 (1%) had gone up to tertiary level.

Only 29 (11%) of the women reported being formally employed, 100 (37%) were employed informally and more than half of the women 144 (53%) were not employed. Close to half (46%) of the women reported earning less than 20 000 Zimbabwean dollars that is equivalent to five United States dollars (5US\$) per month

The majority of the women are from the shona tribe 248(91%) which is the majority ethnic group in Zimbabwe and only 19(7%) were of the Ndebele tribe. All the women interviewed reported having had a live birth in their life and 156 (57%) of them had up to two children, only 29 (11%) had more than five children.

**TABLE 1:****Socio demographic characteristics of the women in the two groups**

<b>Variables</b>	<b>Frequency</b>	<b>HIV +ve</b>	<b>HIV-ve</b>	<b>P value</b>
	<b>N=273</b>	<b>N=189(%)</b>	<b>N=84(%)</b>	<b>X<sup>2</sup></b>
<b>Age</b>				
17-23	68	31(16)	37(44)	
24-27	69	49(26)	20(23)	<.01
28-31	69	59(31)	10(12)	
32+	67	50(27)	17(21)	
<b>Marital status</b>				
Single	12	11(6)	1(1)	
Divorced	30	22(12)	8(10)	0.03
Widowed	23	21(11)	2(2)	
Married-polygamous	25	22(12)	3(4)	
Married-monogamous	183	113(59)	70(83)	
<b>Education-</b>				
Number of years in school				
0	3	(1)	2(2)	
1-7	62	47(25)	15(18)	
8-11	179	122(65)	57(68)	N/S
>12	26	16(9)	10(12)	
<b>Employment status</b>				
Not employed	144	91(48)	53(63)	
Informal employment	100	71(38)	29(35)	0.01
Formal employment	29	27(14)	2(2)	



## **PMTCT issues**

The majority of these women knew of their HIV status with this pregnancy 83% for the HIV positive and 77% for the HIV negative and 17% and 23% respectively knew their HIV status before this current pregnancy. Almost all of them responded as understanding why they had to undergo an HIV test in their pregnant state with only 6% HIV positive and 7% HIV negative reporting ignorance about the reason behind the antenatal HIV test. Less than 20% of the women in both groups felt that the timing of being screened for HIV for the first time while pregnant was not good, with close to 30% both HIV positive and negative reporting that the information they were given about their HIV status was not enough.

For the reason for the HIV test there were no significant differences between the two groups with more than 60% mentioning that they were screened so that those positive could get nevirapine to prevent HIV transmission to the infant. Less than 10% referred to screening for other diseases as a reason for the HIV test with the rest giving various explanations from economical to complete ignorance about it.

A significant difference is observed on the reason for benefiting from the PMTCT program  $p < .01$ . For those who reported benefiting from the HIV screening, HIV negative scored highest 30% versus 13% for the HIV positive while the HIV positive scored highest on reporting benefiting from the treatment offered 38% versus 16% for the HIV negative. Women from both groups reported on the counseling and information received as the most important benefit they got from the program 39%. More HIV negative 13% versus 10% among the HIV positive reported that they did not see or realize any benefit from the program.

A significant difference is observed in being able to relate to others about the experiences gained from participating in the program,  $p = 0.02$ . HIV positive reported highest on not being able to talk about their experiences 25% versus 12% among the HIV negative. The HIV positive reported highest on stigmatization as the commonest drawback in limiting them from being at ease about HIV issues 13% versus 7% for the HIV negative.

### **Quality of life and HIV status**

A major limitation was observed in the mental health domain with 43% (N=81) of the HIV positive reporting poor mental functioning versus 19% (N=16) among the HIV negative ( $p<.01$ ). HIV positive reported highest on experiencing severe pain since delivery 11% versus 5% among the HIV negative ( $p<.01$ ). HIV positive women reported highest in “poor” family functioning 45% (N=85) versus 27% (N=23) among the HIV negative women ( $p=0.01$ ). (Table 2)

The majority of the women reported being limited in the physical and role functioning both HIV positive and the HIV negative, though it is not statistically significant

Almost all the women reported adequate social functioning 95% and 98% for the HIV positive and HIV negative respectively. Age has no significant association with all the quality of life domains except for daily functioning for the HIV negative where the older women above 32 years scored least in poor functioning 11% compared to 50% in the 24 to 31 year age group. However in physical functioning those older scored highest poor functioning of 82% and none of them reported adequate functioning. The same trend is observed in the family functioning with the older reporting highest in the poor facet 60% compared to 4% for adequate functioning.

In the 24-27 years old age group HIV positive women reported highest on “poor” mental health functioning 50% versus 25% among the HIV negative in the same age group. Marital status was significant with almost all the quality of life domains with married HIV positive women reporting highest “poor” daily functioning 36%(n=49) compared to single women 23%(n=12). Single women scored highest on adequate functioning 26% versus 16% among the married women ( $p=0.01$ ).

For the HIV negative the same trend is observed with 43% of the married women reporting poor functioning compared to 18% single women in that facet. Only 8% married women reported adequate daily functioning compared to 27% for the single women. Both HIV positive and negative married women reported higher poor physical functioning compared to single women.

Single women reported highest poor family functioning both HIV positive and HIV negative compared to their married counterparts ( $<.01$ ).

Married HIV positive women reported highest in poor role functioning 80% versus 69% among single women ( $p=0.01$ ). The same trend is observed for the HIV negative with the married women reporting highest poor role functioning compared to the single women. All women married and single HIV positive and HIV negative reported adequate social functioning. Single HIV positive women reported highest “poor” mental health functioning 67% ( $n=36$ ) versus 33% ( $n=45$ ) among the married women ( $p<.01$ ). The same trend is observed for the HIV negative with the single women scoring highest poor functioning 55% compared to 14% for the married women.

Educational level was significant with daily functioning with those with 8-11 years of education scoring highest on poor functioning 51% for the HIV positive versus 40% for the HIV negative ( $p=0.02$ ).

HIV positive women with less than 7 years of education reported highest on poor family functioning 63% ( $n=30$ ) with only 4% reporting adequate functioning. The same trend was observed for the HIV negative with 65% poor and none reporting adequate family functioning ( $p<.01$ ).

Both HIV positive and HIV negative women with less than seven years of education reported highest poor mental health functioning 54% and 35% respectively. Those with more than 12 years of education reported highest in adequate functioning for both HIV positive and HIV negative 68% and 90% respectively ( $p<.01$ ).

HIV positive women in the highest income bracket of Z\$41 000 and more reported highest “poor” daily functioning 51% ( $n=29$ ) compared with those earning less than 20 000 only 25% ( $n=19$ ) scoring poor functioning ( $p=0.03$ ).

For the HIV negative the same trend is observed with those earning Z\$41 000 and above scoring highest poor functioning 72% and none reporting adequate functioning in that income bracket compared to those earning less than Z\$20 000 scoring 38% poor functioning and 10% adequate functioning ( $p=0.01$ ).

HIV positive women in the lowest income bracket scored highest poor family functioning 52% ( $n=40$ ) compared to those with highest income 37% in the same facet”. For the HIV negative highest scores were in the “acceptable” domain.

Both HIV positive and negative women in the highest income bracket reported highest poor role functioning ( $p=0.01$ ). None earning above Z\$31 000 reported adequate functioning for the HIV negative.

HIV positive with high income reported highest adequate mental health functioning of 44% compared to 72% for the HIV negative.

HIV positive in the lowest income bracket scored highest for not being able to work 21% ( $n=16$ ) versus 7% ( $n=4$ ) among those in the highest income group ( $p=0.02$ ). The entire HIV negative women in the highest income bracket reported being able to work at usual paying job.

For both HIV positive and HIV negative those in lowest income reported high on not being able to work 21% ( $n=26$ ) versus those with the highest income 5% ( $n=4$ ) ( $p=0.01$ ).

The HIV positive and informally employed scored highest in mental distress with 55% scoring poor and 30% for the formally employed. For the formally employed 48% reported adequate functioning compared to 17% employed informally ( $p=0.02$ ).

For the HIV positive, 5% of those unemployed reported severe pain compared to 11% for those employed ( $p=0.01$ ). None of the HIV negative formally employed reported severe pain compared to 7% reported by those informally employed.

**Table 2: QUALITY OF LIFE and HIV status**

<b>Variable</b>	<b>Frequency N=273</b>	<b>HIV +ve N=189(%)</b>	<b>HIV -ve N=84(%)</b>	<b>p-value X<sup>2</sup></b>
<b>Mental health</b>				
Poor	97	81(43)	16(19)	
Acceptable	73	51(27)	22(26)	<.01
adequate	103	57(30)	46(55)	
<b>Pain experienced since delivery</b>				
None	128	72(38)	56(67)	
Very mild	76	59(31)	17(20)	<.01
Moderate	45	38(20)	7( 8)	
severe	24	20(11)	4(5)	
<b>Family functioning</b>				
Poor	108	85(45)	23(27)	
Acceptable	155	96(51)	59(71)	0.01
adequate	10	8( 4)	2(2)	
<b>Daily functioning</b>				
Poor	94	61(32)	33(39)	
Acceptable	134	92(49)	42(50)	N/S
adequate	44	35(19)	9(11)	
<b>Physical functioning</b>				
Poor	215	149(78)	66(79)	N/S
Acceptable	31	22(12)	9(10)	
adequate	27	18(10)	9(11)	

**Role functioning**

Poor	211	146(77)	65(77)	
Acceptable	41	30(16)	11(13)	N/S
adequate	21	13(7)	8(10)	

**Social functioning**

Poor	3	3(1)	-	
Acceptable	10	8(4)	2(2)	N/S
adequate	260	178(95)	82(98)	

### **Coping towards risky sexual behaviors**

HIV infection risk increased with age with those above 24 years of age more infected than the younger women age group 17 to 23 years. The single and formally employed carry a higher risk of being HIV positive ( $p < .01$ ) (Table 1).

HIV positive women reported highest on not using any contraceptive method 22% versus 14% among the HIV negative women ( $p < .01$ ), while 47% HIV positive and 87% HIV negative reported not using condoms currently ( $p < .01$ ). (Table 3). 6% HIV positive reported having an informal sexual partner versus 2% among the HIV negative, while 24% HIV positive reported not being sexually active versus 11% among the HIV negative ( $p = 0.02$ ). Lack of sexual interest was the commonest problem with sexual life with the HIV positive reporting highest 24% versus 14% among the HIV negative followed by partner's refusal to use condoms during sexual intercourse 14% and 12% respectively ( $p = 0.04$ ). A considerable number of HIV positive women expressed desire to have more children 13% versus 49% among the HIV negative ( $p < .01$ ). The HIV positive referred to their HIV status as the most important factor in their decision about future pregnancy 53% versus 6% among the HIV negative, while the HIV negative women wanted to add more children 38% versus 12% among the HIV positive ( $p < .01$ ). 24% HIV positive versus 10% HIV negative women had not disclosed their HIV status to anyone while those who disclosed did so to their sexual partners 61% and 85% respectively ( $p = 0.01$ ). Of the women who disclosed their status 11% among the HIV positive were rejected/isolated by their partners versus 2% among the HIV negative ( $p = 0.01$ ).

Though not statistically significant, 60% HIV negative versus 68% among the HIV positive women did not know the HIV status of their sexual partners.

**Table 3: Sexual Behavior**

<b>Variable</b>	<b>Frequency</b> N=273(100%)	<b>HIV +ve</b> N=189(%)	<b>HIV -ve</b> N=84(%)	<b>P-value</b>
<b>Contraception</b>				
None	53	41(22)	12(14)	
Pill(POP)	92	49(26)	43(51)	
Pill(COC)	43	25(13)	18(21)	<b>&lt;.01</b>
Depo Provera	28	20(10)	8(10)	
Condom	54	51(27)	3(4)	
Norplant	3	3(2)	0	
<b>Condom use</b>				
No	162	89(47)	73(87)	<b>&lt;.01</b>
yes	111	100(53)	11(13)	
<b>Sexual relationship</b>				
Married	206	133(70)	73(87)	
Informal sexual partner	14	12(6)	2(2)	<b>0.02</b>
not sexually active	52	44(24)	9(11)	
<b>Problems with sexual life</b>				
<b>After delivery</b>				
None	111	63(33)	48(57)	
Lack of sexual interest	57	45(24)	12(14)	
Not sexually active	25	21(11)	4(5)	<b>0.04</b>
Rejected by spouse	28	24(13)	4(5)	
Partner refuses condoms	36	26(14)	10(12)	
Current STI	16	10(5)	6(7)	



<b>Variable</b>	<b>Frequency N=273(100%)</b>	<b>HIV +ve N=189(%)</b>	<b>HIV-ve N=84(%)</b>	<b>p-value X<sup>2</sup></b>
<b>Desire for more children</b>				
No	185	150(79)	35(42)	
Yes	66	25(13)	41(49)	<b>&lt;.01</b>
Not decided	22	14(7)	8(9)	
<b>Reason for decision on more children</b>				
HIV-status/ ill-Health	106	101(53)	5(6)	
Economic hardships	32	13(7)	19(23)	
Enough children	38	25(13)	13(16)	<b>&lt;.01</b>
Spouse's decision	21	12(6)	9(11)	
More children	54	22(12)	32(38)	
Other reasons	22	16(8)	6(7)	
<b>Disclosure of HIV test result</b>				
None	54	46(24)	8(10)	
Partner/Spouse	186	115(61)	71(85)	<b>0.01</b>
Family member	31	26(14)	5(5)	
friend	2	2(1)	0	
<b>Reaction to disclosure</b>				
Supportive	164	100(53)	64(76)	
Rejection/Isolation	23	21(11)	2(2)	<b>0.01</b>
N/A	86	68(36)	18(22)	
<b>Knowledge of sexual partner's HIV status</b>				
No	179	129(68)	50(60)	<b>N/S</b>
yes	94	60(32)	34(40)	

### **Coping and social supports**

HIV positive confided most in another family member excluding the spouse 25% (n=46) versus 37% (n=31) among the HIV negative while the later confided more in the spouse 36% versus 24% among the former (  $p=0.01$ ).The most available type of support was informational 38% for the HIV negative versus 33% among the HIV positive ( $p=0.5$ ). The family was reported as the highest unit providing ongoing support 54% for the HIV negative and 40% for the HIV positive while non governmental organizations came second to the family 14% and 18% respectively. 10% HIV positive reported not receiving any kind of support from anyone versus the HIV negative not reporting in that category ( $p=0.03$ ). (Table 4)

Although not significant less than 20% of both HIV positive and negative women reported getting support always. HIV positive reported highest in belonging to a social group in the community 64% (n=121) versus 40% (N=50) among the HIV negative who do not belong to any type of group in the community ( $p=<.01$ ). Women in both groups reported having suicidal thoughts at times being more for the HIV positive 16% (n=31) versus 12% (n=24) among the HIV negative group.

Both HIV positive and HIV negative women reported giving a spiritual interpretation of their situations and 23% of them resorted to prayer (spirituality) ( $p=<.01$ ).

Only the HIV positive reported resorting to “lying” 7% (14) pretending not to know their status in order to avoid problems and cope with the situation. More than 5% in both groups felt “hopeless” in life and alluded to having given up in addressing their problems. Use of the two major ways of coping, emotion focused and problem focused was not statistically significant between the HIV positive and HIV negative though all women alluded to low use of emotion focused compared to problem focused strategy. (Table 4)

**Table 4: Coping and social supports**

<b>Variable</b>	<b>Frequency</b> N=273	<b>HIV +ve</b> N=189(%)	<b>HIV-ve</b> N=84	<b>P-value</b> <b>X<sup>2</sup></b>
<b>Confidant</b>				
none	53	42(22)	11(13)	
Spouse/Partner	75	45(24)	30(36)	
Family member	77	46(25)	31(37)	0.01
Friend	37	29(15)	8(9)	
Health personnel	31	27(14)	4(5)	
<b>Provision of ongoing support</b>				
none	19	19(10)	-	
Family	120	75(40)	45(54)	
Health personnel	47	32(17)	15(18)	
NGOs	46	34(18)	12(14)	0.03
Church	12	7(4)	5(6)	
friends	22	22(12)	7(8)	
<b>Type of support received</b>				
None	19	19(10)	-	
Informational	94	62(33)	32(38)	
Material resources	84	58(31)	26(31)	0.05
Emotional	54	36(19)	18(21)	
social	22	14(7)	8(10)	
<b>Family support</b>				
No	110	85(45)	25(30)	
yes	163	104(55)	59(70)	0.01
<b>How often is support given</b>				
Not at all	98	74(39)	24(29)	
Sometimes	130	85(45)	45(54)	N/S
always	45	30(16)	15(17)	

**Belonging to a social group**

No	118	68(36)	50(60)	<.01
yes	155	121(64)	34(40)	

**Suicidal**

Sometimes	41	31(16)	10(12)	N/S
never	232	158(84)	74(88)	

**Emotion focused coping**

Low	44	33(18)	11(13)	
Acceptable	129	81(43)	48(58)	N/S
adequate	99	75(39)	24(29)	

**Problem focused coping**

Low	89	70(38)	19(23)	
Acceptable	77	50(27)	27(33)	N/S
adequate	100	64(35)	36(44)	

**Fear of future(Concerns)**

Own health/Death	49	43(23)	6(7)	
Health/Death of index baby	19	17(9)	2(2)	
Care of orphaned siblings	51	50(27)	1(1)	<.01
Stigmatization	12	9(5)	3(4)	
Sero-converting to HIV	29	3(2)	26(31)	
Others	113	67(35)	46(55)	

## 12. DISCUSSION

It is important to note that this study has some limitations which could influence the outcomes. The HIV status used to describe this sample of women is based on the initial test which was done on the first antenatal day of booking which could be anytime from 12 weeks of conception to 36 weeks which was the enrollment cut off point. Considering that this is a high HIV prevalent area it is highly likely that a considerable number of the HIV negative women could have sero-converted to being HIV positive.

With regards to quality of life and HIV this sample is unique in that literature attests to the fact that HIV infection has been associated with low infertility<sup>43</sup> For this study more than three quarters of the women both HIV positive and negative reported having at least up to two children.

The absence of baseline data on the quality of life of these women before enrolling into the PMTCT program makes it difficult to conclude that the outcomes observed are due to the impact of the program or it could be equally true of the general population of women in Zimbabwe.

Despite the above shortcomings our data is in agreement with previous studies which reported considerable morbidity among the HIV asymptomatic people with mental health being the most affected<sup>44,46</sup>. Although the majority of studies on psychiatric aspects of HIV have been carried out in western countries they have shown an increase in psychiatric morbidity in the early asymptomatic stage of the disease.

In this study the HIV positive reported highest on poor mental health functioning and this can be explained in terms of the host of stressors that accompany the HIV positive result. In particular in a country where stigmatization is rampant these women are faced with dilemmas of infant feeding options and fear of being rejected following disclosure of status. This is an area of special concern which needs to be addressed outside the antenatal clinic. The same was observed by Larrabee and Sebit and their explanation was based on the extra roles women take as caregivers. The low-socio economic status of these women which is not controlled for in the analysis could also impact negatively on their psychological well-being. Since 24% had not disclosed their status to anyone, it means they have to handle it on their own thus leading to psychological distress.

Single HIV positive and negative women reported highest poor mental health functioning compared to the married women. This explains the isolation that these women could be experiencing if they do not have other social networks like having confidants belonging to social groups. While married women have their spouses to confide in and can get extra care and attention. On the other hand the informally employed HIV positive reported highest poor mental health functioning. This can be attributed to the type of work that they engage in, in order to earn a living. In most cases its manual work which is carrying heavy baskets of vegetables for sale, splitting quarry stones for sale is bound to cause mental distress as they ponder about how long they can sustain themselves in that situation.

The activities they engage in always pits them against law enforcement agents as they engage in illegal activities like fetching firewood from private property or selling items on prohibited premises. The lowest educated reported highest poor mental health and family functioning which can be due to the distinct social classes that exist in Zimbabwe. These discriminate against those with poor education and low socio-economic status. This also explains why they reported poor family functioning as they could be isolated because they are uneducated and poor.

The single women also reported poor family functioning which highlights the issue of women's dependents on male partners for both economic and social status. They could also be alienated being labeled as immoral and associated with promiscuity. In this study HIV negative women reported highest poor physical and role functioning which is inconsistent with previous studies<sup>45,46</sup>, which reported HIV positive reporting poor in those domains. Our explanation is that the HIV positive are already overwhelmed by their status and its stressors and would therefore not concentrate on physical symptoms as they have to carry out their expected roles to avoid being labeled and have little time to concentrate on appraising their physical and role function.

HIV positive women reported poor family functioning versus the HIV negative this can be explained in terms of either stigma or the women themselves could be withdrawing from the family circles to avoid being labeled or identified as infected.

Another explanation is that the family unit is already overburdened with the care of orphans and other sick family members and would not think of those who are busy falling pregnant which can add up as an extra burden in case their health deteriorated after delivery. It is also ironical that the family has been reported as the highest unit providing social support by both HIV positive and HIV negative, at the same time the HIV positive reported highest on poor family function. This can mean that for those who rely entirely on family support if they do not get it then they are left without any form of support at all which is bound to impact negatively on their health status.

The majority of the women both HIV positive and HIV negative reported being considerably limited in physical role and daily functioning. This is in agreement with other studies which revealed that women were severely compromised in various QOL components<sup>27,29,43</sup>. Married HIV positive women reported poor role functioning and physical functioning versus the single women. This differs with Sebit's findings where single women reported worst physical functioning<sup>40</sup>. This observation can be attributed to the fact that married women can afford to forfeit their role function since they can rely on their spouses for assistance and therefore can appraise their limitations while the single have to go it alone since there is no one to give them a listening ear and therefore have to persevere and carry on with life.

Health personnel handling HIV infected patients need to be conscious of these potential limitations which need special attention in order to alleviate suffering. The HIV positive women reported experiencing severe pain which is an area that health personnel can underestimate not seriously considering the discomfort that HIV people can be going through due to pain. It would be essential to make provision of pain killers and to be enquiring about any pain experiences whenever taking care of HIV infected individuals

There could be over reporting of physical and role functioning in anticipation of extra care and support in the form of treatment or financial aid considering the current harsh economic conditions in the country and increased donor activity in these communities.

Unlike other studies our women both HIV positive and HIV negative reported adequate social functioning. This can be explained by the universal value put on children especially in the African culture where bearing a child gives one social status and is regarded as a positive event in a life full of stressors.

It could also be that our women could carry on with their social activities despite reporting poor physical functioning. There is need to find out about these places of socialization and equip them with health information on HIV prevention and living positively for those already infected, this can promote health initiatives in trying to improve quality of life. Research has also shown that quality of life scores of child bearing women maybe much higher than those of the general population<sup>29, 46</sup>. Wu in his studies on quality of life assessment found that asymptomatic HIV infected persons reported better overall health, role and physical functioning.

The agreement of results inline with previous studies shows that MOS is a valuable instrument in measuring quality of life in this study population. It also supports the fact that quality of life in HIV infected persons can be affected in an almost similar way across different cultures.

The other differences can be explained in terms of socio-demographic factors, the stage of the disease, language used and access to treatment which is beyond the scope of this study.

Risk of HIV infection increased with age as the older age group above 24 years were more infected than the younger age group less than 23 years. This maybe attributed to the effectiveness of aggressive interventions targeted towards educating the youth about HIV prevention, although this is a small sample size to be able to make any conclusive statements.

A considerable number of the women both HIV positive and negative reported not using any contraceptive methods despite more than three quarters of them alluding to being sexually active at the time of the interview. This can mostly be attributed to the traditional belief that they would not conceive whilst breastfeeding. Another traditional practice was that women would abstain from sexual intercourse for some months in the immediate post partum period and their partners were supposed to respect that<sup>41</sup>. However this tradition has since been discouraged as it was also reported as one of the factors which drove men to engage in extramarital affairs while their wives were in this period of abstinence<sup>41</sup>.



This needs to be explored further as to why more than 10% of these women would not be on any contraceptive method. This should also send warning bells about how some cultural traditional practices can remain deeply ingrained in people's minds even if they are harmful to their health. There is need to continue assessing the extent to which such practices are still being followed and find ways of discouraging them.

This also questions how the women perceive the health education talks that they go through antenatally and postnatally. Moreover as many as 47% HIV positive and 87% HIV negative women reported not using condoms currently, when more than half of them in both groups did not know the HIV status of their sexual partners. For this study condom use is much higher for the HIV positive than reported in the previous studies, for the HIV negative it is 13% use of condoms as a protective measure against HIV infection versus 10% reported in a general population in one province, Manicaland<sup>41</sup>

These are issues of urgent concern as they expose people to high risk of transmission and fuel the epidemic through both heterosexual and MTCT transmission. There is need to assess the effectiveness of the counseling that this women have gone through. It also reflects on the attitude of associating condom use with infidelity and thereby not being used in a formal marital union. On the other hand it can also reflect on the limitations experienced by these women in being able to negotiate safer sex. There is need to further explore the factors that prevent women in such high HIV prevalent areas from practicing health promoting behaviors at individual, family and community level.

The other explanation could be in the fact that the HIV positive are not eager to disclose their status for fear of being stigmatized and divorced. Thus the issue of HIV may not be a subject to be discussed and therefore they can not be seen to deviate from the normal sexual practices. For the HIV negative they could be regarding themselves as free from the effects of the virus since they are negative and this can only reflect on limited knowledge about HIV transmission.

There is need to urgently address these issues which highlight the need for constant evaluation of interventions especially the counseling which should be part of continued care outside the health facilities especially in high HIV endemic areas.

This is because the health personnel are overwhelmed with other duties that they have to deliver and it would be asking too much for them to be reminding the women about positive living and the importance of having partners screened for HIV and disclosing status.

The other explanation could be that, the women might assume being cured by the nevirapine and therefore thus the reason why 13% of the HIV positive expressed desire to have more kids despite knowledge of their status. This figure is the same as that reported by women in the general population where 13% expressed urgent desire to replace the child they would have lost<sup>41</sup>, even through a miscarriage, stillbirth or abortion. Thus the value put on having a child surpassing the HIV status can not be underestimated.

This is a much higher figure compared to the one reported by Gregson in 1998 where he found that only 3% of the HIV positive expressed desire to have more kids<sup>41</sup>.

The HIV negative reported getting more social support than the HIV positive though informational support was the most available type of support. This needs attention as the HIV positive are the ones who require more support since their health is already compromised they need to be assisted in various aspects of their day to day lives.

Informational support may not be very helpful especially in low socio economic communities where people can not afford the basics like a plate of food on a daily basis. This would only be dealing with the emotional aspect of the problem depending on the content of the information given. Material resources or tangible support is what is required most with the HIV positive people in low socio economic environments. It would be beneficial to assess the type of information that they report receiving improve on it and give appropriate health messages to those who are providing this support who can in turn impart it to the concerned individuals.

It is also important to note that NGOs come second in providing social supports there is need to acknowledge this very important initiative and for policy makers to work closely with such institutions by giving them extra resources to enable them to cope with the high demands of the HIV infected people.

Most of the women alluded to confiding in the family members and spouses at most it is important to improve on these social networks find ways of involving them in being forthcoming for HIV screening and tackle issues of stigmatization and practicing positive living at family level. The family unit has to be strengthened with information and resources in mitigating the effects of HIV/AIDS and help those infected to live positively with encouragement from family members which will then be effective at community then national level.

It is the HIV positive who reported highest in being affiliated in support groups 64% these should be strengthened by giving them adequate information and empowering them in areas of problem identification, establishment of terms of reference, advocacy and representation in HIV/AIDS issues.

They should seek recognition from community to national level and should write petitions which they should forge forward to the policy makers through the appropriate channels of communication.

The HIV negative should also be encouraged to join these support groups considering that they reside in high HIV prevalent areas their chances of being infected are quite high and they can only get extra information through support groups.

There was no significant differences observed in both problem focused and emotion focused strategies which is in agreement with previous studies<sup>51</sup>. However there is high acceptable use of the emotion focused coping. This can be explained by the spiritual interpretation that the HIV positive women give to their status and this helps them deal with the emotional aspect of their situations. It could turn out to be an effective strategy in adapting to their situation but this is beyond the scope of this study. These women could also benefit from the fact that the church has been reported as providing support in the HIV/AIDS area and thus they could access help through spiritual support.

On the other hand most women responded to a general question by reporting that they resorted to lying and pretending not to have been ever screened for HIV in their life and this contributes to their mental stress since they have to think of excuses and ways of deviating from the truth throughout their life situations.

This study has managed to highlight the impact of going through an HIV screening test on the health of the women enrolled in the PMTCT program. Use of the MOS questions enabled comparison with other previous studies conducted in the same field.

This has revealed valuable information on the effects of HIV infection on the quality of life of these women and what they are doing after having gone through the test with regards to sexual behavior and the social supports available to them.

This will guide health professionals and other organizations involved in the care of HIV infected women in targeting services that can help alleviate suffering and tailor interventions that can meet women's needs. Policy makers should use this information to channel resources to areas of need strengthening those that promote quality of life and eradicating harmful life styles that are adverse to health.

### **13. LIMITATIONS OF THE STUDY**

The cross-sectional design of this study does not allow drawing up of conclusions regarding the direction of relationships of causality thus limiting the generalizability of the findings. This narrows the observations that come up as one can not say what could have contributed to it and thus may just give assumptions as explanations of causality.

The study population comprises of only women who have enrolled and delivered under the PMTCT program, this leads to a selection bias of a particular group of women who have the same type of help seeking behavior that of consulting the same clinics for pre and post natal care. Their representation of the general population is questionable thus limiting the extent one can generalize the results.

There is bound to be interviewer interviewee bias as these women are reporting for postnatal care at the same facility where they delivered the index baby and are being taken care of most likely by the same health worker who is now administering the questionnaire. The interviewer asks questions expecting a response in some way which reflects that the client has gone through proper counseling and should therefore be better informed and well adjusted to their condition. The interviewer has some background information about the woman most likely even the HIV status. This can influence the way she asks questions and also how the client response to the questions especially those pertaining to sexual relationships.

The issue of “courtesy bias” can also influence the responses since the interviewer is a health personnel the participant (patient) may respond in a manner just to please the nurse as they are aware of the expected behavior in a clinical setting, and thereby omitting what they actually do or how they actually feel to avoid embarrassment or just to be seen pleasing the interviewer.

Literature attests to patient perceptions varying according to the mode of data collection like in this case interview versus self administered questionnaire it is difficult to ascertain uniformity of expression and to what extent the interviewee is at ease to give reliable information especially in the case of sensitive topics like HIV/AIDS. The setting where the interview was conducted being in the clinic where certain norms and standards are prescribed and expected can have its own negative influence on the responses given.

Timing of the survey that is during the postnatal period which was quite varied for the women with some whose kids were already 18 months old and others only three months old it might be difficult to compare their status since delivery was the reference period of assessment. There are bound to be differences in the way they recall and how they perceived their health at the time of the interview.

Non response bias could also weaken the study findings considering that HIV/AIDS issues remain a sensitive topic in these communities.

The absence of documented baseline information on the quality of life of people in the developing countries and in particular for this community will limit the extent to which one can attribute the observations to the PMTCT program or maybe this is equally true of the general population. There could be or are bound to be other external factors that can influence the outcomes which can not be established in the scope of this study.

The number of controls is less than the cases which is very unusual with most studies and this also affects the comparisons in terms of actual numbers thus percentages have to be resorted to in most instances.

The HIV status is based on the initial test of first contact when they came for the antenatal booking. There are chances that more could have sero-converted at the time of this study since for most of them it was about six or more months since they were screened for HIV.

The absence of other disease markers used for the HIV people like CD4s and viral loads which are used along with quality of life evaluation are not included for this sample which limits the extent to which conclusions can be drawn using one parameter of patient subjective evaluation for health status assessment.

For the two major ways of coping the HIV negative had to imagine a stressful encounter whereas the HIV positive would refer to their situation this could influence the responses considering that the women are not very used to responding to questionnaires of that nature.

Few studies have used the MOS-HIV questionnaire with a control group in the developing countries thus it is difficult to compare the results with previous studies because the study done in Zimbabwe on QOL assessment used WHOQol on a sample of HIV positive patients only<sup>40</sup>.

## **14. MAIN CONCLUSIONS**

The HIV positive are severely compromised in the mental health aspect. This calls for urgent action in provision of psychotherapy and channelling of resources that address and promote mental well being. There is need to assess these women for psychiatric morbidity through provision of adequate mental health services.

Consideration should be put to the fact that these are nursing mothers and their psychological well-being is very important for the development of the index baby and other siblings.

Provision of such care need to be taken out of the antenatal care setting which is already overwhelmed with the services it provides to these women and their babies.

The family unit needs to be strengthened and equipped with resources that will enable it to cope with the demands of the HIV infected family members. Other players have to take the role of the family unit by identifying that which the family unit often provides and substitute for it. The family unit can also be equipped with important health information messages and psychosocial skills that they can use to handle the HIV infected as a health promotion technique. These messages can also help in reducing HIV transmission and encourage positive living for those already infected.

They should be involved in the plan of care by involving them in the antenatal stage encouraging women to talk about HIV screening and its importance especially before and during pregnancy. Information should be given to the “gatekeepers” who are influential in the way these women are going to prevent themselves from infection and protecting others from HIV infection.

The information should come from the women themselves after adequate knowledge about HIV/AIDS transmission its dynamics and the figures of those infected as a constant reminder of their vulnerability since they reside in high HIV prevalent areas.

The use of condoms as an effective barrier against HIV infection should be emphasized with main target being the male partners who should be screened together with their spouses through couple counseling and testing. They should be encouraged to disclose results so as to practice positive living and protect others from HIV infection.

HIV positive women should be discouraged from having more children with emphasis on the issue of deteriorating in health and the chances of having an HIV infected baby. Health education should be targeted towards reduction of risky sexual behavior. Interventions that enhance women's social networks and encouragement of health promoting behaviors should be developed and evaluated constantly for their effectiveness.

Traditional practices and beliefs that have adverse effects on health should be constantly assessed finding out to what extent they are still being practiced and lobbying should be done to eradicate them.

There is need for further analysis in identifying barriers and facilitators women experience in negotiating safer sex and practicing health promoting behaviors.

Quality of life evaluation has demonstrated to be an important outcome measure that can identify areas of need for the HIV positive people especially in poor resource countries where HIV laboratory markers are beyond the reach of many. This information can aid policy makers in channeling resources to the areas of need.



## **15. RECOMMENDATIONS AND future study topics**

1. The issue of incorporating quality of life evaluation with every intervention as an outcome assessment tool can not be overemphasized. It is essential that information is gathered about the impact of the intervention using a subjective format as this helps in understanding effectiveness of interventions and guides targeting of resources towards areas of need.
2. Communities should be familiarized with questionnaire interviews as they are quick, easy and cheap to perform. These should be adapted to local communities using images, or pictures for the illiterate communities to enable them to respond to questionnaires without being aided by an interviewer as this creates biases and misinterpretation.
3. Local instruments should be formulated that are more sensitive to the culture and needs of local communities in local languages. They should be validated in various settings and adapted so as to be able to compare them with other standardized instruments, which elevates the findings obtained.
4. A similar study should be conducted in a different setting in Zimbabwe in a more affluent community with educated elite women and a rural study area so as to be able to draw valid conclusions.
5. A longitudinal design should be used especially on reduction of risky sexual practices to find out barriers that prevent women from practicing health promoting behaviors.
6. There is urgent need to address psychosocial aspects of HIV in this community together with psychiatric morbidity of these women. Consideration should be given to the fact that these are nursing mothers and the mental status is pertinent to the development of the index babies and other siblings as well.
7. Resources should be targeted towards reduction of psychological trauma together with increased psychotherapy outside the maternal facilities. Communities should be involved from family level to the policy makers by highlighting the mental problems women are going through and identification of key issues in addressing the problems.

8. The family unit remains reported as the highest unit providing ongoing support to the women. There is need for strengthening this unit with information and resources to enable them to cope with the demands of the HIV infected family members.
9. Non governmental organizations doing a tremendous job in provision of ongoing support should be acknowledged by the policy makers, strengthened by allocating them part of the HIV/AIDS budget to boost their moral and encourage them to continue with this very important gesture.
10. Quality of life evaluation should be done as a continual process from baseline that is first contact with the woman as they book antenatally and then after three months postpartum, six months when most of them are supposed to be stopping breastfeeding and at eighteen months in order to ascertain the effectiveness or observe any changes.
11. There is need to follow up these women for at least five years to assess their morbidity and mortality pattern which can then be compared with the national maternal morbidity and mortality patterns. This will generate important information on the impact and effectiveness of PMTCT on the reproductive health of the women in the country.
12. The index babies need to be followed up to assess developmental issues and their morbidity and mortality pattern. It will be interesting to find out how they are perceived in the community especially when they enroll for preschool and in school with their special road to health card marked in an obvious manner which differentiates them from children born outside PMTCT programs.

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