

**FORMATIVE RESEARCH ON  
MOTHER TO CHILD TRANSMISSION OF HIV/AIDS IN ZAMBIA**

**A WORKING REPORT OF  
FOCUS GROUP DISCUSSIONS  
HELD IN KEEMBA, MONZE,  
November 1999**

by

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## Executive Summary

Mother-to-child transmission (MTCT) is by far the largest source of HIV infection in children below the age of 15 years. Nine out of ten of all HIV-infected babies globally live in Africa, which accounts for only 10% of the world's population. Mother to child transmission of HIV occurs during pregnancy, childbirth and during breastfeeding. The risk of a baby acquiring the virus from an infected mother, in the absence of preventive measures, ranges from 25% to 35% in developing countries. In Zambia, it is estimated that about 30 to 40% of infants born to women infected with HIV become infected themselves, with around 21,000 children becoming infected every year pre-partum, intra-partum or post-partum.

Drug therapies of AZT and Nevirapine are now available to decrease the transmission of HIV from mothers to their infants, in some cases by about 50%. In response to these advances in therapy, UNICEF, in collaboration with UNAIDS, WHO and others has supported pilot projects with the Ministries of Health in eleven countries to provide a short course of AZT to mothers. Zambia is one of the eleven countries and has recently begun implementing the pilot programme. One intervention in Chipata compound, Lusaka has already started and other interventions will begin in two other sites later this year. In order to effectively pilot the feasibility of the interventions to reduce mother to child transmission of HIV, formative research was proposed and conducted in the three sites selected for pilot. The formative research presented in this working report was carried out in November 1999, in Keemba, Monze, Southern Province.

The aim of the study was to assess and document the perspectives of women and their communities about mother to child transmission of HIV, VCT, treatment and breastfeeding options, and to identify community groups involved in support work and decision-making in order that a more responsive MTCT implementation strategy may be designed.

The specific objectives of the study were:

- To provide a better understanding of women and community views about MTCT of HIV;
- To assess local beliefs and perceptions about drug use during pregnancy and breastfeeding;
- To determine potential social, cultural and economic factors that are likely to affect women's participation in the MTCT program;
- To identify existing social and community networks relevant to the MTCT implementation;
- To recommend strategies that will assist with effective implementation of the MTCT programme.

Keemba lies to the north-western side of Monze town. It has an estimated population of 13,840 inhabitants who are predominantly Tonga. There are a total of 57 villages - each village headed by a headman. Two communities within Keemba were covered by the study – namely Keemba

centre and Chuungu. Chuungu lies to the south-east of Keemba centre, some 11 kms off the Lochinvar road.

Two primary methods of data collection were used in this study- namely focus group discussions and a participatory research activity. However, the fact that the moderators and the principal researcher resided in Keemba during most of the fieldwork (a period of eight days) gave some additional unstructured observational data. Six Focus Group Discussion (FGD) moderators drawn from the MTCT office in Lusaka and Monze were trained in FGD techniques over a period of one week. A total of 11 focus group discussions with pregnant women, breastfeeding mothers, local men and community leaders were held over a period of 8 days. A focus group guide, initially developed by ICRW in Botswana and then amended and adapted by the Zambian researchers, was used to lead and facilitate the data collection. All the focus group discussions were tape-recorded. The moderators were debriefed at the end of the fieldwork. Most of the focus group discussions were transcribed in the field, during the evenings or parts of the day. For participatory research, two meetings were held with one group of men and another one with women. Qualitative techniques have been used to analyse the data from the focus groups and participatory research activities.

The findings reveal that HIV/AIDS is perceived to be a huge problem in Keemba. The number of women, men and youths who are believed to be sick and "*just waiting for the day*" was said to be high. The bad condition of AIDS sufferers, the fact that more young people than old people die, the number of burials and the many orphans were given as cumulative evidence of the visibility and the scale of the HIV/AIDS epidemic in Keemba. HIV/AIDS was often referred to in rather veiled terms, for example talking of HIV/AIDS as *chiyuni* - the disease of the bird. Although this indicates that people in Keemba are not denying the existence of HIV/AIDS, underpinning these perceptions is a feeling of hopelessness when faced with such a multi-faceted and devastating disease. The reasons given for HIV being so prevalent in Keemba included sexual cleansing of a widow after her husband's death or having sex with a widow; women being forced into sexual exchange because of poverty; inter-generational sex; the sexual freedom of young people; the lack of prevention efforts; prostitution; migrant workers; and unmarried people not using condoms.

Against the background of morbidity arising from AIDS and other diseases, the community faced a number of problems with the health delivery system. They cited prohibitive health fees; shortage of drugs, equipment and supplies; staff shortages; and long distances to the health facilities as the problems affecting the community. The Keemba community members have to rationalise the use of available health services. Treatment is sought according to perceived severity and how patients respond to treatment. Household members perform various roles during illness episodes in the home. Illnesses in the household are discussed with household members and the extended family and perhaps treated within the household. The nearest health facility might next be approached and, depending on the progress of the illness, people would move further to bigger health care facilities. At any stage a traditional healer might be consulted depending on the type of illness, the severity of illness and response to treatment.

Compliance with folic acid and other medication during pregnancy is reportedly low, despite high ANC attendance. Women do not often deliver at the health care facilities. For pregnant women, the distance to the health facilities coupled with the absence of any reliable transport and the shortages of supplies are added incentives to deliver at home. At both the hospital and the health centre, women wishing to deliver are frequently required to bring their own gloves, cotton wool, baby clothes, syringes and needles, as well as pay for being admitted. The cost of some or all of these items on top of the health fees is extremely prohibitive for most women in Keemba. Most pregnant women therefore deliver at home, assisted by elderly women relatives. There are only three Traditional Birth Attendants in Keemba so most women do not have access to their services.

In relation to how large the actual MTCT problem was in Keemba, all except one group said that they thought almost three-quarters of mothers were HIV positive so the babies born were either all infected or more likely to be malnourished, sickly and not healthy. More and more babies were being born with *tukoto* – growths on the palate of the mouth or on the anus – a disease associated with malnourishment but which was rapidly becoming associated with HIV. Participants predicted that the main reaction of a woman to knowing she was HIV-positive during pregnancy would be anxiety that the pregnancy and the delivery would be likely to cause abortion or problems in delivery and even cause her death. They also spoke of depression and contemplations of suicide and abortion. The focus was on the health of the mother and not the child. All the groups were concerned more for the women than the unborn child. Becoming pregnant when sick with HIV/AIDS was mostly regarded with understanding and concern although some felt that pregnant woman with HIV/AIDS could be ostracised.

There are several strands to Keemba people's recognition of HIV infection in themselves or in others. There are certain symptoms that are strongly associated with HIV. The association between a TB diagnosis in Keemba and HIV is accompanied by accusations that health workers lie to patients about their true condition. Many people in Keemba apparently fear that they have HIV based on the community perception that many people in Keemba are HIV positive, the failure of health workers to disclose a patient's HIV positive status and on their own personal sexual history (for example, people's experience of sexual partners and spouses dying from HIV/AIDS). This limbo state of "knowing" without really knowing appeared preferable to actually knowing. Being told you are HIV positive can have some tragic consequences. On the other hand, participants speculated, being told you are HIV negative can be a catalyst for change. The private/public dichotomy is clear - HIV status is private because most people would wish to keep it secret yet ultimately one day they will fall sick and it can no longer be hidden.

Keemba people may not have had much exposure to date to VCT services and promotion but, perhaps prompted by the impending MTCT interventions which they have been informed about, they have clearly reflected on the implications of testing. It is clear that it is easier for men to decide to have a test and to disclose their status. Women are more circumscribed in their behaviour and expected to consult their husband or parents about wanting a HIV test, and they are more likely to be blamed. The fear of stigma against those suspected to have HIV/AIDS is deep rooted and widespread. Fear of stigma is so pronounced that even being seen with an african potatoe (a wild tuber) is tantamount to pronouncing that one is HIV positive. Nevertheless,

questions concerning incentives and disadvantages of testing focused more on incentives than disadvantages. It would be plausible to conclude that this was a community "ripe" for VCT. However, the set of questions about how men and women would react to a HIV positive test result were overwhelmingly negative in tone. This suggests that people's lack of experience in relation to testing made their answers to the first set of questions more hypothetical. Genuine fear of death, suicide, divorce, stigma and social segregation were paramount in how they felt people would react to being told they were HIV positive. Women found it more difficult to disclose their status to anyone, fearing recrimination. Men would also find it difficult to disclose their status but were thought to be more likely to tell their wives.

People had a concept of good counselling as that of "being told nicely" and being supported. The important components of VCT were: privacy and individual contact in a room on your own; no public disclosure; and continued support. They also saw counselling as an opportunity for education on prevention and care of PWAs and for obtaining medication. Such demands would put pressure on existing structures and resources. Participants had serious reservations about the confidentiality of resident health workers.

In Keemba, breast feeding ranges between six months to three years but normally last for one year six months. There are perceived benefits of breastfeeding and some of them indicated by the participants were that the babies grew better when breastfed. The period of breastfeeding was seen as a birth control by some of the participants. Some women were said to breastfeed for as long as three years as this was believed to be vital for child spacing. The women in Keemba see breastfeeding as part of the beauty of being a woman and the pride of childbirth. They see childbirth and subsequent breastfeeding as cementing marital relationships. Child bearing and breastfeeding also mean a lot to the family members. Some women use breastfeeding for abstinence from sex.

Alternative feeds are introduced early as a normal supplement to child nourishment. But there are situations such as maternal death where alternative feeds are introduced as a matter of necessity. A number of alternative liquid and solid foods are given to babies to supplement breast milk. These include maize meal porridge, chibwantu, (sweet beer), nshima mashed in soup or source made from kapenta, beans or sometimes beef and cow and goat milk. The other foods include eggs and fruits. Formula feeds are not popular in Keemba. The participants noted that formula was too expensive. It requires several tins of milk to enable a constant supply until the baby is big enough to rely on other foods. The community scorns women who do not breastfeed, seeing her as abnormal and accusing her of prostitution. The main concern is often the health of the innocent baby who might die of hunger.

<b>TABLE OF CONTENTS</b>	<b>PAGE</b>
Acknowledgements	2
Executive Summary	3-6
<b>Section I: BACKGROUND</b>	
Introduction	9
Feasibility of Prevention of HIV MTCT in Zambia	9-10
Rationale and objectives of the Keemba Formative Research Study	11
<b>Section II: THE CONTEXT</b>	
Background statistics on Southern Province	12-14
Tonga Ethnography	15-16
<b>Section III: STUDY POPULATION AND METHODOLOGY</b>	
Keemba – The Study Setting	18-19
Facilitators	19-20
Methodology	20-21
Study Population	21-23
<b>Section IV: GENERAL HEALTH ISSUES IN KEEMBA</b>	
Major health problems in Keemba	26
Perceived common illnesses	26
Treatment options	26-27
Treatment seeking	27-28
Treatment seeking during pregnancy and childbirth	28-29
Drug taking during pregnancy	29-30
Sources of sexual knowledge and information	30-32
<b>Section V: GENERAL PERCEPTIONS OF HIV/AIDS IN KEEMBA</b>	
Perceptions of the scale of the HIV/AIDS epidemic in Keemba	33-36
HIV transmission routes	36-38
Ways in which Keemba people protect themselves from HIV	38-39
Current sources of HIV/AIDS information in Keemba	39
<b>Section VI: HIV COUNSELLING AND TESTING</b>	
People in Keemba and their recognition of HIV infection in themselves or others	40-42
Experiences of those who have been tested for HIV	43
Private/Public dichotomy	43
Incentives and Disadvantages for having a HIV test in Keemba	43
Reactions to a HIV positive test	48-49
Preference for VCT site	49
Preference for VCT style	49-50
<b>Section VII: OPINIONS AND KNOWLEDGE ON MTCT IN KEEMBA</b>	
Reaction to a pregnant woman being asked for a HIV test in a clinic setting	51
Reactions of a pregnant woman to a HIV test result	55
Community's views on pregnant women with HIV/AIDS & how treated	55-56
Preventing pregnancy in HIV-positive women	56
Knowledge about MTCT	57-58

## TABLE OF CONTENTS CONTINUED:

## Section VIII: BREASTFEEDING

Length and the significance of breastfeeding	59-60
Alternative feeding	60
Community reaction to not breastfeeding	60-61

Section IX: LOCAL INITIATIVES FOR CARE AND SUPPORT	62-63
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## Section X: CONCLUSIONS AND IMPLICATIONS OF FINDINGS FOR MTCT

REFERENCES	68-71
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**Tables, Text Boxes, Pie Charts, Maps****Page**

Text Box 1: General Health and Population Statistics on Southern Province	13
Text Box 2: Maternal Statistics – National and Monze District	14
Text Box 3: FGD Topics	21
Text Box 4:	
Text Box 5: Symptoms associated with underlying HIV infection in Keemba	40
Text Box 6: Names for and comments about people suspected to be suffering from AIDS	42
Text Box 7: Main reasons given for having a HIV test	44
Text Box 8: Main disincentives for having a HIV test	44
Map 1: Keemba and Monze District, Southern Province	17
Table 1: FGD location, numbers and participants	23
Table 2: Feelings and Concerns about HIV testing in Keemba and Chuungu	45-47
Table 4: Feelings and Concerns about HIV testing in Pregnant women	53-54
Piechart 1: Daily Activities of Women in Chuungu	24
Piechart 2: Daily Activities of Men in Chuungu	26

## **SECTION I: BACKGROUND**

### **Introduction**

This research follows a decision that Zambia should be one of 11 countries to pilot the feasibility of an intervention to reduce the transmission of HIV from mother to child. The Central Board of Health (CBoH) - through a national Mother to Child Transmission (MTCT) working group<sup>1</sup> - selected three sites in Zambia for the pilot interventions.<sup>2</sup> Preceding the intervention in all three sites, the MTCT working group recognised the importance of conducting research in each site. The research would both give insight into the knowledge, attitudes, practices, behaviour and beliefs surrounding Voluntary Counselling and Testing (VCT) of HIV, mother to child transmission, pregnancy, childbirth and ante-natal and post-natal care at health centres; and, mobilise community participation and partnership for the pilot MTCT intervention programme (Mukuka 1999:9). Initially, Mukuka conducted formative research in Chipata Compound in Lusaka – the first pilot site – prior to the intervention starting in May 2000 (see Mukuka 1999).<sup>3</sup>

The formative research in Keemba presented in this working report was carried out in November 1999, and the MTCT pilot intervention is due to start in Keemba by the middle of 2000. Although the Keemba research focused on the same issues as the Chipata formative research, the two studies differ in methods, style and breadth. The Chipata formative research was a much broader study, using more methods and interviewing a broad range of people in the Chipata community (see *ibid*:12). Unlike the Chipata research, the Keemba research was designed and conducted by three social scientists (Nyblade, Bond and Ndubani) so both the resulting methods and material are more qualitative.

Nevertheless, both formative research studies are explicitly aimed at informing the MTCT pilot programme in Zambia by understanding the context within which women live and make decisions necessary to participate in such an MTCT prevention programme. The authors of this working report believe that consultation with women and others in the communities about the MTCT programme is critical to the success of the communication activities and services offered as part of these pilot projects.

### **Feasibility of Prevention of HIV Mother to Child Transmission in Zambia**

Mother-to-child transmission (MTCT) is by far the largest source of HIV infection in children below the age of 15 years (UNAIDS 1999). AIDS has been responsible for the deaths of 3

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<sup>1</sup> The Ministry of Health appointed the MTCT working group in August 1998.

<sup>2</sup> These three sites are: Chipata Compound in Lusaka; Keemba health centre and Monze mission hospital catchment area in Monze District, Southern Province; Mbala General Hospital and Tulemane health centre catchment area in Northern Province.

<sup>3</sup> Formative research was also carried out on MTCT and infant feeding in Ndola, Zambia, in December 1998 by the National Food and Nutrition Commission, Ndola DHMT, LINKAGES and SARA (USAID). See Draft Summary of Findings from the Formative Research Carried out in Lubuto, Main Masala and Twapia Clinic areas, (1999) Ndola December 7-9 1998.

million children and another 1 million are living with HIV today. Nine out of ten of all HIV-infected babies live in Africa, which accounts for only 10% of the world's population. In urban areas in southern Africa, rates of HIV infection are 20-30% and higher in women attending antenatal clinics.

Mother to child transmission of HIV occurs during pregnancy, childbirth and through breastfeeding. The risk of a baby acquiring the virus from an infected mother, in the absence of preventive measures, ranges from 25% to 35% in developing countries. In Zambia – one of the countries worst affected by HIV/AIDS in Sub-Saharan Africa – it is estimated that about 30 to 40% of infants born to women infected with HIV become infected themselves, with around 21,000 children becoming infected every year pre-partum, intra-partum or post-partum (CBoH 1999). A significant proportion of the other 60 to 70% of children who remain uninfected are at risk of becoming orphans (UNICEF 1999).<sup>4</sup>

Drug therapy is now available to decrease the transmission of HIV from mothers to their infants. Research from Thailand, Burkina Faso and Cote d'Ivoire has demonstrated a 50% reduction in transmission of HIV to a child from an infected mother when a short course of AZT is given to women during the last four weeks of pregnancy, during delivery and when combined with breast milk alternatives. And, more recently, a study in Uganda revealed similar efficacy to AZT of a drug called Nevirapine when given at the onset of labour.

In response to these recent advances, UNICEF, in collaboration with UNAIDS, WHO and others has supported pilot projects with the Ministries of Health in eleven countries to provide a short course of AZT to mothers and alternatives to breastfeeding. Zambia is one of the initial eleven countries and has recently begun implementation in Chipata community and will begin in the two other sites later this year.

The MTCT intervention has four main components (Mukuka 1999:9):

1. The integration of a minimum package of care (which includes AZT dosing) into antenatal and delivery services.
2. Involving the community.
3. Counselling on feeding practices
4. Advocacy and programme communication through sensitisation of health service managers, policy makers and the community on the scope of the problem and the possible solutions.

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<sup>4</sup> One of the burning issues around MTCT interventions in Africa is what are the consequences of “creating” more orphans if fewer children become infected as a result of the interventions but their parents are still likely to die before they are fully grown.

## **Rationale and Objectives of The Keemba Formative Research Study**

To respond to the need (specified in the four components) for discussion with women and communities about their concerns regarding measures to prevent MTCT of HIV, ICRW has worked in collaboration with the MTCT working group to conduct formative research in Keemba, Monze District, one of the MTCT prevention pilot sites. This work is being supported by GlaxoWellcome and UNAIDS. Parallel research has been conducted by ICRW and the Ministry of Health in Botswana, although the research there took place after the intervention had been implemented.<sup>5</sup>

The **aim of the study** was to assess and document the perspectives of women and their communities about mother to child transmission of HIV, VCT, treatment and breastfeeding options, and to identify community groups involved in support work and decision-making in order that a more responsive MTCT implementation strategy may be designed.

The **specific objectives of the study** were:

- To provide a better understanding of women and community views about MTCT of HIV;
- To assess local beliefs and perceptions about drug use during pregnancy and breastfeeding;
- To determine potential social, cultural and economic factors that are likely to affect women's participation in the MTCT program;
- To identify existing social and community networks relevant to the MTCT implementation;
- To recommend strategies that will assist with effective implementation of the MTCT programme.

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<sup>5</sup> In further analyses, comparisons between the two sets of data on Botswana and Zambia will be drawn.

## SECTION II: THE CONTEXT

### Background Statistics on Southern Province

In the last two years, there have been a number of national surveys and situational analyses on poverty and health in Zambia<sup>6</sup> which are relevant to this study. For the purpose of this report, we have selected a limited number of statistics and findings from rural Zambia, Southern province in particular, that help build up a picture of the context within which the MTCT intervention is to take place. These are presented in the following text boxes 1 and 2.<sup>7 8</sup>

The statistics portray that Monze District has a largely rural population and, as most of rural Zambia, it is characterised by poverty. The poverty situation has been worsened largely by the declining agricultural investment due to the economic hardships being experienced by Zambia. Southern province was once prosperous in farming and cattle rearing but the combination of recent droughts and constant outbreaks of livestock diseases have adversely affected the living standards of the people.

Although hard hit, as much of Zambia, by the HIV/AIDS epidemic, with a prevalence in the 15 to 49 year age group of around 14% and with a relatively high number of orphans, to date the population has not had easy access to VCT for HIV. Despite high ANC attendance, most deliveries take place at home assisted by relatives and not Traditional Birth Attendants (TBAs)<sup>9</sup>, maternal mortality is prominent and post-natal attendance poor. Exclusive breastfeeding is rarely practiced, with the great majority of mothers introducing food supplements on a regular basis in the first three months.

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<sup>6</sup> See HIV/AIDS in Zambia CBoH 1999; Orphans and Vulnerable Children Situational Analysis UNICEF 1999; LCMS 1998; A Study of Factors Associated with Maternal Mortality in Zambia CBoH & UNZA & UNFPA 1998; An Assessment of the Functioning and Quality of Reproductive and Child Health Services in Zambia, Zambia Situation Analysis Study CSO 1997; Demographic Health Services 1996. Full references in bibliography.

<sup>7</sup> A series of poverty studies in Zambia, funded by World Bank, have designated what constitutes poverty in a Zambian context. There is a fixed poverty line and a poverty index that allows national poverty surveys to calculate the incidence of poverty (see LCMS 1998:59-61). In 1998, persons who lived in a household with the monthly adult equivalent expenditure of less than K32,861 were considered as extremely poor (ibid).

<sup>8</sup> The statistics on orphans are believed to be an underestimate by the UNICEF Situational Analysis of Orphans and Vulnerable Children (1999:7). The number of orphan children in Zambia is hard to calculate but could be as high as 34% of those aged 15 and below (ibid). The HIV/AIDS in Zambia CBoH report (1999:35) gives a lower figure than LCMS – estimating that there are around 520,000 orphans in 1999.

<sup>9</sup> TBAs are usually older women who have had children themselves and have acquired skills by delivering babies and by being trained. There is a distinction between trained TBAs and untrained women who assist during home deliveries – there are far fewer of the former who often have small kits with scissors, clamps for the cords and cotton wool.

### **Text Box 1: General Health and Population Statistics on Southern Province**

#### **Population Statistics**

Population of Southern Province – 1,268,000 (81% rural; 19% urban) [LCMS 1998]  
Population of Keemba – 13,840 [Monze DHMT 2000]

#### **Orphan Statistics**

Percentage of Population aged 20 years and below who are orphans [LCMS 1998]:

Nationally – 16% (n=961,344)<sup>1</sup>

Rural areas – 15% (n=569,950)

Southern Province – 17% (n=135,086 – 62% father only dead; 22% mother only dead; 15% both parents dead)

In 1996, between 40% and 72% of households were thought to be caring for an orphan [Webb 1996]. In rural areas, double orphans are most likely to be looked after by a grandmother and single orphans by a surviving parent [UNICEF 1999].

#### **Poverty Statistics<sup>1</sup>**

Nationally, the highest proportions of persons who are poor are small scale farming households in rural areas: 84% of them are poor. In general, the percent of poor in rural areas is higher than in urban areas – 83% compared to 56% [LCMS 1998]

Southern Province Rural – 81% poor (66% extremely poor, 15% moderately poor) [LCMS 1998]

#### **HIV/AIDS Statistics**

Estimated HIV prevalence in 1998 [CBoH 1999]:

Nationally – 19.7%

Rural Areas – 13.6% of those aged 15-59 years

Southern Province – 15.7% of those aged 15-49 years

Monze – 14% of those aged 15-49 years (n=8,156 of which 4,473 are in Monze rural)

Percentage of Zambians who have been tested for HIV and know the results [CBoH 1999]:

Rural areas – 4.2% of women and 6.5% of men (compared to 7.6% and 8% in urban areas)

Number of AIDS deaths among children under the age of five for every 1000 live births [CBoH 1999]:

Nationally – 26 per 1000 births in 1999

#### **Other Health Statistics (other than maternal)**

##### **Malnutrition in Children**

Incidence of stunting, underweight and wasting of children aged 3-59 months [LCMS 1998]:

Rural areas – much higher than in urban areas (eg 56% compared to 47% stunted)

Southern Province – 47% stunted; 24% underweight; 6% wasting

Distance to health facility [LCMS 1998]:

Southern Province Rural – 50% of households live within 0-5kms; 34% 6-15kms; 17% over 16kms

Proportion of households who experienced at least one death during the last 12 months (1997-98):

Rural areas – 17% of households (compared to 12% in urban areas) [LCMS 1998]

Southern Province – 13% of households [LCMS 1998]

### **Text Box 2: Maternal Statistics – National & Southern Province**

#### **ANC Attendance Rates** [Maternal Mortality Study 1998]:

Nationally – 91.7%

Monze District – 94.3% (fourth highest in study)

#### First antenatal check up [DHS 1996]:

For 6 out of 10 births, before sixth month of gestation

For 1 out of 3 births, after sixth month of gestation

#### **Post Natal Attendance Rates** [Maternal Mortality Study 1998]:

Nationally – 20.2%

Monze District – 12.5%

#### **Place of Delivery** [Maternal Mortality Study 1998]:

Rural areas – most women deliver at home

Monze District – 44.8% at home; 27.6% in hospital; 6.9% at the health centre; 3.4% at TBA's place; 17% other

#### Assistance during Delivery [DHS 1996]:

Nationally, most commonly assisted by relatives (41%) and 6.6% of women deliver by themselves without anyone's assistance. Four percent assisted by doctor and 43% by a nurse or midwife.

#### Percentage of deliveries assisted by TBAs:

Nationally – 5% [CSO 1997]; 13% [Maternal Mortality Study 1998]

Rural areas – one study in Mongu rural, 10% [Faber et al 1994]

#### **Maternal mortality:**

Nationally – 649 maternal deaths per 100,000 live births [DHS 1996]<sup>1</sup>

#### Proportion of Women dying from maternal causes [Maternal Mortality Study 1998]:

Nationally – 18% in the study areas (26% during pregnancy; 13.3% during labour; 60.7% after labour) and 10% of maternal deaths estimated to be caused by HIV/AIDS)

Southern Province – 12.2%

Monze District – 17.9%

#### Cause of Maternal Deaths [Maternal Mortality Study 1998]:

Most common causes were haemorrhage (34%); sepsis (13%); HIV/AIDS (10%) and obstructed labour (8%).

#### Percentage of Maternal Deaths by Place of Delivery [Maternal Mortality Study 1998]:

For those women dying after labour, nearly 60% were delivering at home compared to about 33% delivering from health facilities. The relative of risk of dying was therefore highest for those who delivered at home and estimated to be 1.13.

#### Percentage Distribution of Maternal Deaths by Place of Death [Maternal Mortality Study 1998]:

Mostly in health institutions (49.6%); then at home (34.2%); then on the way to the health institution (12.1%).

#### Maternal Mortality Risks [Maternal Mortality Study 1998]:

Monze District – 3.02 (one of the highest in the study with seven other districts)

#### **Breastfeeding**

Nationally, breastfeeding very common (96% children aged 0-3 months breastfed) but exclusive breastfeeding is rare [LCMS 1998].

In rural areas, 66% of children are breastfed up to 21 months and then most of them are weaned [LCMS 1998]

Percentage of children being breastfed 0-6 months [LCMS 1998]:

Southern Province – 7% exclusively breastfed; 8% plain water supplement only; 85% other food supplements with 58% given these supplements at least three times a day.

## Tonga Ethnography

There is a rich body of ethnography on the Tonga that dates back to the late 1930s when an American anthropologist - Elisabeth Colson - began studying Gwembe valley Tonga culture. Colson, and later Scudder, mainly focused on the response of the valley Tonga to resettlement, and to social change in general (see Colson 1951, 1964, 1971; Colson and Scudder 1975). To date, Colson and Scudder have continued to carry out their research. In the 1970s, Keller did research on changing marriage patterns in Monze District (see Keller 1979). In the last decade, there has been a considerable amount of other research done on the Gwembe Tonga and the Tonga in Monze District. In the Gwembe valley, Clark looked at demographic change from the 1960s to the mid-1990s, and Cliggett studied elderly Tonga and how they cope and survive (see Cliggett 1997 and Clark et al 1995). Foster (1993), Bangwe (1997) and Waller (1997) carried out research amongst the Tonga in Monze District that focused on the impact of a series of shocks<sup>10</sup>, including HIV/AIDS, on a cohort of households. Mogenson (1995, 1997) did an analysis of the association of AIDS with a local disease called “*Kahungo*” in Choma District and Siamwiza did a historical analysis of drought in Southern province (see Siamwiza 1998). In 1998, Kamwanga, Siamwiza and Kasuta did research on the socio-economic impact of the Kariba Dam resettlement almost half a century after the event. This research was attached to a larger ZESCO-World Bank-DBSA Gwembe Tonga Rehabilitation and Development Project initiated by Scudder.

The relevance of this body of literature to Keemba and to the planned MTCT intervention is that it reveals pertinent details about social reality, response to crisis and HIV/AIDS such as:

- Fine ethnographic detail, based on longitudinal data, on kinship, marriage, gender roles, religion and medicine.
- How, in the past, the Tonga have responded to natural disaster (i.e. drought and disease), witchcraft, misfortune and change by turning to spirit possession and sorcery (Colson 1969, 1998). The nuclear family – particularly the relationships between fathers and sons and the position of wives – are undermined by the stress of such crises (ibid 1969).
- A history of alternative forms of treatment options, including government and missionary health services, diviners, herbalists, self-treatment with local medicines and offerings to the ancestors (Colson and Scudder 1975). People cope with a critical illness by consulting a whole range of treatments if necessary, although certain kinds of ailments are believed to be treated best by specific treatments (ibid; Colson 1971).
- Economic and rapid downturn since the mid-1970s resulted in what Scudder coined “community unravelling” (ibid 1983:16) – namely a rising incidence of violence and accusations of sorcery, increasing alcohol consumption, outmigration, family breakdown and declining fertility (ibid; Clark et al 1995; Colson 1979). This spiraling poverty is also evident from Foster’s, Bangwe’s and Waller’s work, where they argue that all households are facing “multiple shocks”, that most households are failing to meet their subsistence needs, that some households become progressively more vulnerable to disease, poverty and

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<sup>10</sup> These shocks were the 1992 drought, the cattle corridor disease and HIV/AIDS.

food security and that some households will face economic ruin and breakup. They also demonstrate that households are affected differentially, with some households able to exploit changes.

- The stress and disruption caused by the increasing debility of a person with AIDS in a household and how women are the most overburdened by caring for sick (Foster 1993, Waller 1997, Bangwe 1997). As the AIDS crisis escalates in Monze district, children are becoming overburdened with farming, domestic and livestock chores as adults in their households spend more time caring for sick household members and organising and attending funerals (Bangwe 1997). Indeed, Bangwe calculated that adults spend close to one quarter of their time on health, with clear expectations that attending funerals of neighbours and relatives should be reciprocated when their own households face a similar crisis.
- The strategies to cope with the impact of AIDS in Monze District are signaled by the latter group of researchers as: interhousehold support during funerals; linkages with kin (including urban kin) and other organisations; a large number of household members; crop diversification and inputs; reallocation and pooling of labour; food for work; selling livestock; and women's market gardening (Bangwe *ibid*, Waller 1997). Looking at the impact of death over time, Foster concluded that three to four generational HIV/AIDS afflicted households with larger family sizes were the most resilient.
- The association between AIDS and *kahungo*<sup>11</sup> is convincingly argued by Mogenson to be the articulation of a narrative about pollution, highlighting “disorderly death” (miscarriage negates life, AIDS is out of order as often strikes young adults who appear dead though living and is an absolute lack of control over death) and “disorderly sex” (sleeping with an unknown person, mixing too many bodily fluids) (Mogenson 1995, 1997). Mogenson argues that such local versions of AIDS should be taken seriously and that AIDS education should be an exchange of knowledge as opposed to a transfer of knowledge. She suggests participatory theatre as an appropriate intervention that could combine the elements of autobiography, village discourse, traditional healers and bio-medical information to reach collective expression. She closes her analysis by stating “People actively manage their own culture, and AIDS education should give, or rather make people aware, of opportunities they can choose between, in a management of culture which hinders the spread of AIDS” (*ibid* 1995:100).

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<sup>11</sup> Mogenson (1997:49) defines *kahungo* as a disease transmitted from a woman to a man when a man has physical contact with a woman who has miscarried or eats what she has cooked or has sex with her before she is cleansed or uses the toilet in the same place. Stepping where a foetus is buried can also transmit it. It is not contagious beyond the first contact. The symptoms are similar to AIDS – wasting, coughing, chronic illness. In urban areas, this disease is often referred to as *kafunga* and the belief in it is widespread in Zambia (Kamanga 1999; Bond 1998).

**Map 1: Keemba and Monze District, Southern Province**

## SECTION III: STUDY POPULATION AND METHODOLOGY

### Keemba - The Study Setting

Keemba is located on the north-western side of Monze town. Keemba is reached by going on the road to Namwala for about 18kms and then taking the Lochinvar road for a further 12 kms. Lochinvar is a national park on the Kafue flats. Keemba has an estimated population of 13,840 inhabitants who are predominantly Tonga. There are a total of 57 villages - each village headed by a headman. Two communities within Keemba were covered by the study – namely Keemba centre and Chuungu. The Keemba area is under the chiefdom of Choongo. Other than the chief, there are ward councillors and a Member of Parliament for the Keemba Constituency. The dominant religion in the area is Seventh Day Adventist (SDA) and this church appeared to be very influential with pastors often representing the views of the community.<sup>12</sup>

The local economy is based on charcoal burning, cattle trading, farming, transportation, fishing, traditional medicine (such as love potions<sup>13</sup>) and more clandestine activities such as poaching. The cattle are also used for ploughing and production of milk for sale. Charcoal burning, cattle trading and farming are the main economic activities. Charcoal burning is year round, even the area is so deforested that the men sometimes travel long distances to find forests to burn. Women are also involved in the charcoal burning trade, often traveling to town to sell. Indeed, the women in Chuungu recalled in detail the income and expenditure on farming and charcoal burning. Farming is mainly of staple crops<sup>14</sup> for home granaries and for sale during the rainy season. Keemba is considered relatively "rich" compared to Monze east because there is more rain, better soil and better marketing opportunities in Keemba.

Keemba centre consists of a primary school, a rural health centre (undergoing rehabilitation and extension under the microprojects scheme)<sup>15</sup>, shops, bars and some water pumps. The local bars appeared to do a good trade. The Lochinvar road runs straight through Keemba centre and mini-buses frequently seen travel to and fro. The amount of traffic suggests that there are quite a number of people traveling in and out of the area for much of the year, though travel during the rains would be more restricted.

Other than the rural health centres, there are seven health posts around Keemba. These are Chungu, Nachibuli, Hakwambwa, Makondo, Ganhwe, Kambaza and Mandondo. The health

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<sup>12</sup> Because of the considerable influence of the SDA church in the area, it is hard to hold any activities on a Saturday when the church holds its services.

<sup>13</sup> The use of love potions to enhance sexual attraction and potency is common in many parts of Zambia. Colson (1958:172, 173) writes that the Tonga use medicine to strengthen the body and increase attractiveness to curb adultery. Such love potions are also used in Chiawa (Bond 1998) and in town for "dry sex" and male potency (Nyirenda 1991). The moderators thought that these love potions probably increased male potency and sexual need and contributed to HIV transmission in the area.

<sup>13</sup> The staple crops in Keemba are mainly maize, sweet potatoes, groundnuts and cotton.

<sup>14</sup> Microprojects is a scheme co-funded by the World Bank and the Zambian government under the Social Recovery Project to allow communities to rehabilitate schools and clinics.

posts are visited by the health staff from Keemba health centre once a month, when family planning, under-five, ante-natal and other preventive activities are carried out. There are no fees charged at the health posts, unlike at the health centre where adults are charged K500 for consultation and children aged 6 to 13 years are charged K200. Children under five are treated free and ante-natal clinics are also free. There are seven Community Health Workers (CHWs) in Keemba of which five are active, and three TBAs.<sup>16</sup> CHWs and TBAs are often paid in kind for their services, for example with maize or (in the case of TBAs) *chitenge* cloth, although some communities will try to collect an annual fee of K500 for their CHW. There were also traditional healers in the area although the study participants did not talk much about them.<sup>17</sup>

The other community covered by the study was Chuungu. Chuungu lies to the south-east of Keemba centre, some 11 kms off the Lochinvar road, and reached by a grassy track. The centre of Chuungu consists of a delapidated primary school and health post – both in urgent need of repair, missing roofing sheets and infested with bats and termites. There is also a water pump near the school and the health post.

Participatory Rapid Appraisal activities conducted in Chuungu reveal the daily activities of men and women in Keemba, including the different work tasks of each sex and the greater direct responsibility women have for child care and food. This data is presented in two pie charts at the end of this section.

It should be stated that this was a small and time-constrained study limited both in coverage and location to Keemba centre and Chuungu only. Furthermore, Keemba is a unique setting, different in some respects from the rest of Monze and as such the data arising from this study ought to be analysed and interpreted within the Keemba context.

### **Facilitators**

Six Focus Group Discussion (FGD) facilitators drawn from the MTCT office in Lusaka and from within Monze District Health Management Team (DHMT) and the hospital were trained in FGD techniques over a period of one week at Monze College of Agriculture (ZCA).

It should also be noted that the fact that four of the six moderators were affiliated with either the Monze district health team or the Monze hospital may have either biased the responses of the respondents or helped the group open up to talk about the issues, recognising the moderators as people familiar with the area. The groups may have viewed these moderators as direct avenues to voice their concerns to the district health administration.<sup>18</sup> On the other hand, they may also

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<sup>16</sup> The planned MTCT intervention intends to train six more TBAs and two more CHWs.

<sup>16</sup> It is common in Zambia not to discuss traditional healers to outsiders or people perceived as coming from the health centre or the hospital. Traditional healing is still shrouded in secrecy (Ndubani 1998).

<sup>18</sup> For example, after one PRA activity in Chuungu, the participants took the opportunity to ask one moderator from Monze DHMT for information concerning funding for women's clubs.

have felt that they had to withhold certain information or views that were not in line with what the district health system has been teaching.

However, for the outside researchers it was useful to have people who knew the area and the language and the moderators said that their own attitudes and knowledge had been both changed and expanded through being involved in the research. For example, one nurse-midwife moderator said that she hoped to become more sympathetic to the needs of pregnant women in her own work after participating in the research.

During fieldwork, the moderators all stayed in an empty house attached to the health centre. The authors of this report were present at some stage during the fieldwork.<sup>19</sup> The facilitators were debriefed at the end of the fieldwork. The focus group transcriptions were done mostly in the field, during the evenings or parts of the day. The facilitators reviewed a preliminary draft of this report in May 2000.

## **Methodology**

Only two methods were used in the formative research presented in this working report – namely focus group discussions and a participatory research activity, although the fact that the moderators and a principal researcher resided in Keemba during the fieldwork (a period of eight days<sup>20</sup>) gave some additional unstructured observational data.

Focus group discussions are used as a data collection technique because: they approach sensitive subject matters in a more open and collective way than standardised questionnaires administered to individuals and they offer rapid, lower cost approaches to behaviour evaluation (Konde-Lule et al 1993:679). A focus group guide, initially developed by ICRW in Botswana and then amended and adapted by the Zambian researchers, was used to lead and facilitate the data collection. Owing to the complexity of the issues surrounding MTCT, the focus group discussion guides were broken down into two, with the intention of holding two separate discussions with each group of participants. For the Chuungu FGDs, the guidelines were condensed to allow for one, shorter FGD. The questions fell under the topics shown in the following text box 3 and were asked in the order they are presented.

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<sup>19</sup> Nyblade was there most of the time, Ndubani for one day at the beginning (having conducted the training of the facilitators) and Bond for two days – one at the beginning and one at the end.

<sup>20</sup> These eight days were from 24<sup>th</sup> to 31<sup>st</sup> October 1999.

### Text Box 3: FGD Topics

General problems in Keemba  
 General health problems in Keemba  
 General perceptions of HIV/AIDS and MTCT  
 HIV counselling and testing  
 Drugs and service delivery  
 Treatment of people living with AIDS (PWAs) by the community  
 Pregnancy and HIV sero-status  
 Breastfeeding

The Participatory Rapid Appraisal (PRA) activity was intended to give insight into daily life in Keemba. The PRA asked women and men to map out daily routines and health seeking behaviour onto a clock drawn on a large sheet of paper and pinned on a tree.

In the event, the bulk of the data came from only one data collection technique – focus group discussions – restricting our capability to strengthen key findings through comparison with data collected using different techniques or methodological triangulation.

The analysis for this report was done qualitatively, pulling out themes, patterns, experiences and quotations from the focus group transcriptions. However, in future analysis, the material will also be analysed using a programme called NUDIST which will help quantify some of the data and confirm this earlier analysis.<sup>21</sup> The focus group transcriptions are currently being reformatted for NUDIST.

### Study Population

Pregnant women, breastfeeding mothers and men from the general population as well as some community leaders were selected to participate in the research. Women focus group participants in Keemba were selected, with the help of the clinic staff, from women coming to attend the under-five clinic or ante-natal care (ANC) at the health centre. The days of the focus group discussions were timed to coincide with under-five clinics or ANC activities. The women that came to the health centre for these activities were asked to volunteer and then details of their age and residence were collected. Participants were then randomly selected based on their residence, to ensure that women were drawn from different parts of the Keemba clinic catchment area. Men in Keemba were selected by announcing the research through the local churches and asking those interested to report to Keemba health centre. While we were concerned about the highly self-selected nature of the men responding to the announcement, we were able to separate the men into 3 groups. The groups were stratified by age and by whether they were representatives

<sup>21</sup> ICRW has also used NUDIST to analyse the Botswana data. Having both the Botswana and the Zambian data entered into NUDIST will greatly help synchronise the data and draw out similarities and differences, broadening the scope and impact of the two studies.

of any of the local organizations to facilitate and encourage free discussions. In Chuungu, the participants were selected by the resident CHW.

Given the logistical constraints of conducting interviews throughout the large geographical catchment area covered by the Keemba health centre, the majority of the focus group discussions were held in Keemba. Recognizing that the participants living closer to Keemba area and the main road may not be completely representative of the population living at a greater distance, we also conducted two focus groups at Chungu health post. The first two interviews (breastfeeding women) were held in vacant rooms at the health centre. The rest of the interviews were held under trees a little distance from the health centre. The proximity of the interview site to the health centre appears not to have inhibited discussion as the groups did not hesitate to voice dissatisfaction with clinic services and staff.

The following Table 1 shows the number of focus group discussions held and who the focus group participants were.

The initial strategy to hold two focus group sessions with the same group of participants on separate days faced practical difficulties. The strategy worked only with breast-feeding women. Both the men and pregnant women said they could not return for a second interview on a separate day and suggested doing both discussions at one sitting. While we were concerned about both interviewer and participant fatigue due to the length of the discussions when they were combined (each discussion took roughly one and a half to two hours), this did not appear to have much of an effect. The men continued to participate actively throughout the two sessions, while the pregnant women were initially hesitant and so the length of the interviews was advantageous as by the second discussion they were participating more actively.

As reflected in the last column in Table 1, the focus group discussions varied in quality. This happened for a variety of reasons. Sometimes this was due to social reasons. For example, the reticence of a group of young pregnant women could be due to the fact that such women are unused to being outspoken, especially in a more formal setting and/or that the issue being discussed was of such a threat to their condition. Other times it was due to the quality of the facilitation and/or transcription. The moderators commented that overall they found the women more vocal and expressive than the men who were open but quieter – maybe this is a reflection of how close the MTCT subject lies to the hearts and lives of women.

**Table 1: FGD location, numbers and participants**

Number of FGDs held	FGD participants by number, type, sex & age (where noted)	Recruitment	Location of FGD	Assessment of FGD
1 – all questions covered	8 Men, members of community, aged 32 to 60 years, educational level Grades 7 to Form 2	Local churches Keemba centre	Under trees near Keemba health centre	Good – men very open and informative
1 – all questions covered	12 Men, members of community, ages not noted but all chosen because "young".	Local churches Keemba centre	Under trees near Keemba health centre	Excellent – the FGD that illicited the most information and discussion
1 – condensed version	6 Men, representatives of SDA church, CHWs, NHC, aged 36 to 57 years, educational level Grades 7 to Form 6, all married with children	Local churches Keemba centre	Under trees near Keemba health centre	Open & informative but limited by fact that as leaders well-informed with clear opinions & interests
1 – all questions covered	12 Pregnant Women, aged 14 to 27 years, 3 single & 9 married, 5 primigrava, educational level Grades 7-9	ANC clinic at Keemba RHC	Under trees near Keemba health centre	Fair – reticent group, 14 year old not talk at all
1 – all questions covered	11 Pregnant Women	ANC clinic at Keemba RHC	Under trees near Keemba health centre	Good – open & informative group
2 – all questions covered	Breastfeeding Women (number not noted)	MCH clinic at Keemba RHC	Vacant rooms at Keemba RHC	Very good – open & very informative giving much detail, best women's group
2 – all questions covered	8 Breastfeeding Women, aged 24 to 41 years, 1 single & 7 married, educational level Grades 7 to 11	MCH clinic at Keemba RHC	Vacant rooms at Keemba RHC	Fair – slow at first, then became more outspoken
1 – condensed version	14 Breastfeeding Women	Chuungu CHW	Chuungu Primary school	Good – fine detailed information and open
1 – condensed version	7 Pregnant Women	Chuungu CHW	Chuungu Primary school	Fair – patchy & restrained information

The Participatory Rapid Appraisal activities took place only in Chuungu with two groups of women (with 12 and 16 participants in each) and a very small group of men. In fact, the group of men only consisted of the Chuungu headmaster, the resident CHW and two other men from Chuungu area. Attempts to hold PRA activities in Keemba failed. Therefore the participation in the PRA was limited and they did not yield much data beyond giving an idea of the daily activities of women and men and some indications of the impact of illness on daily life.

While the study was able to gather much useful and timely information, there are a few limitations that should be noted. As already alluded to, this was a small and time-constrained study which limited both the variety and the quantity of data collection, the location for conducting interviews, the selection of focus group participants, as well as the time available to find and train interviewers.

**Pie Chart 1: Daily Activities of Women in Chuungu**

**Pie Chart 2: Daily Activities of Men in Chuungu**

## SECTION IV: GENERAL HEALTH ISSUES IN KEEMBA

### Major health problems in Keemba<sup>22</sup> – *”Tulamapenzi manji – We have many problems”* (a community leader)

Inadequate and poor water supplies and a lack of proper toilet facilities in the villages were felt by many to be responsible for disease outbreaks in the area. National statistics show that access to adequate and safe water and sanitation in rural areas of Zambia is as low as 35 percent (LCMS 1998).

In relation to problems at the health facilities, the following were listed: prohibitive health fees; shortage of drugs, equipment and supplies; staff shortages; and long distances to the health facilities. These are reflected in the following quotations:

*“Some of us lack the money to pay at the clinic so when we have a health problem – such as a toothache – we stay at home”.*

*“In most cases, community members are told to buy medicines including simple painkillers such as panadols”.*

*“The problems concern the hospital. When we go there, we are asked to pay and we come from very far away. Sometimes a child is sick and you try to take the child to the hospital but the child would get tired on the way and die before reaching the hospital. If you do reach there, you also have to find your own food”.*

The participants see increased funding by the government to the health institutions as the panacea to lessening the problems the facilities are facing - *“Perhaps the Government can provide adequate funding, increase staffing levels and provide transport”.*

### Perceived common illnesses

Malaria, diarrhoea, bilharzia, Tuberculosis and HIV/AIDS were cited as the most common illnesses. Almost all the participants in all the groups immediately agreed that HIV/AIDS was a big problem in the area, and this was discussed at some length.<sup>23</sup>

### Treatment options

The alternative treatment options in Keemba do not differ widely from those cited by Colson and Scudder for the Gwembe Tonga in the 1970s. They include: Monze mission hospital; the local

<sup>22</sup> Outside health, hunger, water scarcities, lack of income and shortage of seed and ploughing equipment were cited as the main problems in the area.

<sup>23</sup> The content of this discussion is included under people’s perceptions of HIV/AIDS in Keemba.

health centre; the health posts; CHWs; TBAs; traditional healers; and - more unusually - retired health workers.

Another local health structure – though not treatment option – is the Neighbourhood Health Committee. NHC were introduced in 1995 by government to replace the defunct Health Committees. Their role is to act as the link between the health centres and the local communities. As important as they are, recent trends show a diminishing interest among community members to participate in these committees due to lack of proper incentives and the politicisation of such bodies (Mwansa 1999). In Keemba, the NHC itself claimed to be active but many focus group participants did not know about their existence or understand their role.

### **Treatment seeking**

Treatment is usually sought according to perceived severity and how patients respond to treatment. For example, the distinction is made between a child sneezing that can be treated within the household, and a child having a high temperature that is serious enough to require treatment outside the household. Illnesses in the household are discussed with household members and the extended family and perhaps treated within the household. The nearest health facility (health post, CHW or health centre) might next be approached and, depending on the progress of the illness, people would move further to bigger health care facilities (health centre or Monze hospital). At any stage a traditional healer might be consulted depending on the type of illness, the severity of illness and response to treatment. Elderly relatives are also often consulted for traditional medicine.

*"CHWs do provide first aid help before referral in case of complications".*

*"If a child has a high temperature, you go and see the CHW who will give the child medication. If the child is very sick, the CHW writes a letter for you to take the patient to the health centre at Keemba".*

*"When treatment fails at the health centre we go to the hospital and if it fails there we go to traditional healers".*

During the Chuungu PRA activity, women explained that both routine (e.g. ANC clinics) and non-routine health activities disturb their daily routines forcing them to rise early and find money for transport. Husbands would often assist them with money for medicine and transport. Women were used to making a decision to travel to the clinic on their own, especially if the husband was absent charcoal burning. All twelve women in one PRA group had been the health centre at least once in the last three months, mostly because a child was sick.

In Keemba, household members perform various roles during illness episodes in the home. The parents or the grandmother often look after a child; a wife is often looked after by her husband, his parents or her family; and a husband is looked after by his wife and extended family. The participants said that men like too much attention when they are sick! *"Husbands like to seek*

*attention, to be looked after if it is a small illness. Yes, they fear sickness".* The little resources families are able to lay their hands on are often used to assist the sick family members.

These treatment seeking patterns are similar to those found elsewhere in Zambia and Africa. Other household members and family are involved in the decisions about where and how to treat the patient; the severity and type of illnesses determine what treatment option is chosen; and a failure to respond to treatment pushes the patient to alternative forms of treatment (Last 1992; Bond 1998; Ndubani 1998). Two forms of treatment (e.g. herbal and bio-medical) can be taken at the time in the search to get better – this is common with STDs for example (Faxelid 1998; Ndubani 1998).

### **Treatment seeking during Pregnancy and Childbirth**

In accordance with the statistics from the maternal mortality study on high ANC attendance in Monze District, most pregnant women are recalled as attending ANC at the nearest health post or Keemba RHC. The perceived benefits of ANC included being examined to see if the baby is well positioned or not and whether the baby is alive or dead.

*"The goodness is that when we come to the health centre, we have our blood pressure (BP) checked as well as the position of the baby in the stomach".*

However, the discussions revealed that although most of the pregnant women in Keemba are keen to go for ante-natal, they do not often deliver at the health care facilities. For pregnant women, the distance to the health facilities (especially to Monze hospital) coupled with the absence of any reliable transport and the shortages of supplies are added incentives to deliver at home. At both the hospital and the health centre, women wishing to deliver at the health facilities are frequently required to bring their own gloves, cotton wool, baby clothes, syringes and needles, as well as pay for being admitted. The cost of some or all of these items on top of the health fees is extremely prohibitive for most women in Keemba. As one woman simply stated, *"Not many people can afford them"*. There were stories of women being turned away in labour when they did not have one or some of the required items or of women not bothering to come if they did not have the items they were told they had to bring.

Some of these findings concur with those in the maternal mortality study conducted in 1998. For example, some of the reasons advanced for preferring home delivery were: long distances; lack of transportation including money to pay for transport; fear of medical fees; and lack of quality service especially the attitude of service providers who demanded that the women buy maternity essentials (Maternal Mortality Study 1998:88). In this cited study, lack of transport and long distance accounted for 43% of the reasons given for the delay to reach the health facilities. At the health facility, the same reasons accounted for 72% of the reasons given for delay in referring patients to the next level.

Other reasons for opting for home delivery over delivery in the health institutions that were not raised in this study but came out in the maternal mortality study include: ignorance of the benefits of

using the health facilities; lack of women staff in some health facilities; lack of privacy; and some traditions (ibid). In a rural area, women often find it hard to be attended to during delivery by a man since in a more tight knit community they are likely to know the clinical officer socially (Bond 1998; Freudenthal 2000). A study in Lusaka suggests that not having someone you know with you during delivery may also be a deterrent to delivering in a health institution (Maimbolwa 1999).

There are only three TBAs in Keemba – one is particularly active and renown. These three, and other TBAs in Southern Province, recently received training but did not receive any kits.<sup>24</sup> Most villages therefore do not have a TBA - *“From the villages that we come from they are not available. They could be there but we do not know them”*. Most women are therefore delivering at home usually assisted by women who are not trained TBAs. Indeed, most women in rural areas deliver without the assistance of any trained person (ibid). The moderators said that the untrained women were usually elderly women relatives of the woman delivering.

For those villages that have TBAs, the participants appreciated their contributions in helping with deliveries in the villages and said that when complications arose they escorted the women to the health centre. However, the participants recognised that nurses at health centres offered better delivery service in cases of complications believing that nurses were better able to determine what needed to be done in such cases whereas - *“TBAs ask you to push and sometimes this has had adverse effects on the pregnancy or on the baby”*. Nurses are also able to refer pregnant women to a major hospital for surgical operations.

No participant discussed the herbs that women take during delivery to induce contractions although according to the moderators, there are three different kinds of herbs commonly used, and the Maternal Mortality study indicated that the use of such herbs was very common.

It is interesting that although health facility deliveries may be better managed than home deliveries and the risk of delivering at home is greater, 56 and 57% of cases in health centres and hospitals respectively, were not adequately managed (Maternal Mortality Study 1998:87). Indeed, during the period of fieldwork, the researchers witnessed one case that was not adequately managed, with serious consequences, at Keemba RHC. It is unsurprisingly that, later in this report, our findings reveal women’s fears around delivery since it is clear that both women at home and in health facilities, are often not adequately supported, particularly when complications arise.

### **Drug-taking during Pregnancy**

The benefits of taking folic acid and other drugs during pregnancy were highly debatable. Some of the women’s groups said that they did not see any difficulties because the drugs were helping them. They said the men equally saw taking drugs as a good thing - *“They perceive it nicely because they know that once my wife becomes pregnant, she needs to go to the health centre”*. Discussions with community leaders also revealed that there were no problems with pregnant women taking drugs

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<sup>24</sup> The planned MTCT intervention intends to hold a refresher course for these TBAs and supply them with kits, as well as training a few additional ones.

from the health centre. They said that some of the drugs provided enough blood and other micro-nutrients whilst others are for malaria which is important to control during pregnancy. The in-laws also encouraged them to take medication provided it is not family planning tablets. If they suspected they were family planning tablets, they would interfere.

However, some participants within some groups were sceptical about taking drugs during pregnancy. They mentioned that drugs made the baby too big.

*"Some people discourage from taking drugs saying that the drugs will make the baby too big and can lead to difficult delivery and operation (Caesarean). As a result women do not take their drugs, they just store them at home".*

Normally a big baby is cherished but the fact that a "big" baby is seen as bad may be the reflection of the poor conditions most women deliver in. They will try as much as possible to avoid any occurrence of complications.

Forgetting to take the doses was another problem associated with taking drugs during pregnancy. Also some participants said the drugs had a bad smell and/or make them feel sick and this discouraged pregnant women from taking them. One participant said *"It depends on an individual's make up, some get high blood pressure, but as for me as soon as I take the drugs I vomit. I try another time thinking that it will be fine this time round but to no avail"*.

There are some significant points that emerge from these discussions. If women already find it hard to take even folic acid, what is the compliance going to be for the HIV-positive women recruited onto the MTCT intervention? Further, even if an intervention (such as folic acid) is obviously beneficial to the health of the unborn child, in a village context, women can see a healthy or big child as a problem due to the poor conditions that they deliver in. Again, the involvement of the household and the extended family in any health intervention is blatant, with in-laws wanting to know what medication is being taken and discouraging family planning. Family planning will be part of the MTCT intervention both to reduce HIV transmission and to prevent future pregnancies in HIV-positive mothers.<sup>25</sup>

### **Sources of sexual knowledge and information**

There appeared to be no formal teaching on sex – one participant explained, *"There is no time when such issues are taught apart from the Anti-AIDS clubs in schools"*. Sources of sexual knowledge were cited as the media, Anti-AIDS clubs, parents (occasionally) and peer groups. The Ndola formative research found the health centre as the main source of information even though general information about HIV was available through several other channels including the media.

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<sup>25</sup> We are not sure what the uptake of family planning currently is in Keemba and this is something that needs further enquiry. In May 2000, there had been no family planning pills in stock at Keemba RHC for three months.

Some of the participants said that ideally parents had a role to play in their children's sexual education. When a girl starts menstruating, her mother should explain to her about menstruation and caution her to be careful with boys now that she has become of age. The father should also tell his adolescent sons about the dangers of indulging in early sex. Interestingly, in these discussions the role of grandparents in discussing sex with their grandchildren was not mentioned.<sup>26</sup> In reality, some of the participants felt that actually the young boys and girls are never taught at all as one participant explained:

*"The way I see it myself is that they are not taught, they just learn from friends. Some parents only discover that their child is pregnant and they would often be at a loss as to how and when their child learnt about sexual matters. These days the times have changed, the devil (Satan) has entered people's hearts - young girls have known these things at an early age".*

In urban areas, parents are beginning to open up to talking to their children about sexual relations. Undoubtedly, AIDS has been the impetus for this change. In rural areas, such traditional norms seem more entrenched and the extended family is more likely to be in place to fulfil their traditional roles.

Colson (1958:273-75) writes about adolescent Tonga in the Gwembe valley in the 1950s that there are no specific instructions or formal teaching on sexual knowledge. Adolescents learnt about sex largely through settlement cases in the village, quarrels between parents, pregnancy and childbirth and heterosexual play between children of the same age. Girls are bathed ritually at menstruation and at the puberty ceremony girls are given advice on how to be a good wife. Full sexual life should not begin for girls until after the puberty ceremony. Today, adolescents probably learn from the same sources but also from their experiences of HIV/AIDS and from girls trying to access money for luxuries and schooling, and trying to enjoy life before they become tied down (Kambou et al 1998; Bond 1998b; Baggaley 1997).

Indeed, similar to Colson, in Keemba participants noted that adolescents started learning about sex when they enter puberty – *"it is hormones that force a young person to learn about sex and to know and practice sex"*. Puberty forces boys to desire girls who *"develop deep voices and also begin to chase after girls"*. Girls develop big breasts, enlarged hips and then begin to experience menses. Girls are thought to be taught mainly by friends at school about sex who then *"advise them to look for boys so that they can give them gifts and money to buy food"*. Likewise boys talk to their peers about sex, sexual experience and STDs.

Both boy's and men's sexual activity was described as uncontrollable. When men become sexually active *"he would want sex each time he meets you and this is how diseases come about because the person does not control himself"*. Men were said to be free to have three or four sexual partners.

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<sup>26</sup> Often grandchildren and grandparents have a joking relationship that allows them to discuss sexual matters, whereas parents and children have a restrained relationship that prohibits them giving their own children sexual advice (Bond 1998; Colson 1958).

The poor communication between parents and their children in the area of sexuality; the vulnerability of young girls in such a rural setting; and men's supposed inability to control their sexual urges are factors that would enhance the transmission of HIV. The key role of peer group in sexual knowledge and decisions is found elsewhere in Zambia and Africa, and can be successfully engaged in HIV prevention efforts (Mudenda 1992; Baggaley 1997).

## SECTION V: GENERAL PERCEPTIONS OF HIV/AIDS IN KEEMBA

### Perceptions of the Scale of the HIV/AIDS epidemic in Keemba

***”Jala maanda”*** – closed houses/whole house wiped out<sup>27</sup>

***”It wipes out the couples, no-one remains and the home is closed”*** (Kemba man)

This Tonga expression and practice captures the perception in Keemba that AIDS is a huge problem. The number of women, men and youths sick *”on and off”* who are *”just waiting for the day”*, sick people who get treated but do not get better, the bad condition of AIDS sufferers, the fact that more young people than old people die, the number of burials and the many orphans are given as cumulative evidence of the visibility and the scale of the HIV/AIDS epidemic in Keemba. Even the latency of the epidemic is referred to – *”Many people are infected”*, said one pregnant woman in Keemba, *”Even those who are not sick might be infected”*. Participants consistently said that a great number of people in Keemba are infected, as reflected in the following quotes:

*”It is all over”*

*”It is in our homes”*

*”There are orphans in every village, in fact the majority of children are orphans”*

*”If we look at what is happening, there isn’t a sabbath day which can pass without witnessing two or three deaths. Now these elders are no longer suspected of being witches. It is only this disease that is finishing people”*

*”The disease that cannot be cured has troubled us very much. We see many people going for treatment but they do not get cured. People who get sick never get any better. A person is taken to the hospital in and out but does not get better. Finally the bird takes him or her (dies)”*.

HIV/AIDS is often referred to in rather veiled terms, for example talking of HIV/AIDS as *chiyuni* - the disease of the bird.<sup>28</sup> This refers to one of the first poster campaigns used in AIDS education in Zambia where an eagle was depicted as swooping down on a scrawny figure with a slogan “Beware of AIDS!”. In the Chipata study, a number of local terms were also mentioned, for example, *Kaliondeonde* or “hang wire” (Mukuka 1999).

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<sup>27</sup> Traditionally the Tonga move site/house when a person dies and this expression probably refers to this practice – any reference in Colson\*

<sup>28</sup> Mogensen writes of research on AIDS amongst the Tonga in 1995 that “it is difficult to have any real conversation about AIDS – to say that someone has AIDS is a serious offence and AIDS is never talked about openly” (1995:39).

In Keemba, sometimes the scale of the problem would be apocalyptic. For example., *"All men are sick – all have the virus. Three-quarters of women are sick and have the virus"*; and *"10 out of 10 have it"*. A common metaphor for HIV in Keemba (appropriate for an economy partly based on charcoal burning) was that *"HIV is so common it is like smoke"*.

Although this indicates that people in Keemba are not denying the existence of HIV/AIDS, underpinning these perceptions is a feeling of hopelessness when faced with such a multi-faceted and devastating disease. *"We are finishing"*, one man said. *"It is beyond our control, so we have given up and stopped fearing"*, says another. Feeling that the problem is beyond individual, household or community control could make any change in sexual behaviour seem irrelevant. Both the ownership of the problem and the responsibility for the problem may be perceived to fall outside the realm of the community (Bond 1998:59; Ndubani 1998).

### ***"We have brought the disease on ourselves" – Keemba man***

The reasons given for HIV being so prevalent in Keemba include: sexual cleansing of a widow after her husband's death or having sex with a widow (who becomes *"more beautiful"* after her husband dies)<sup>29</sup>; sex being *"essential"* for men; women being *"forced"* into sexual exchange because of poverty; inter-generational sex; the *"sexual freedom"* of youths; the lack of prevention efforts; prostitution; migrant workers; and unmarried people not using condoms.

Another reason consistently given was that the health workers at the health centre and Monze hospital did not tell people the truth about their disease. This is captured in the following comment by a pregnant woman in Keemba – *"The clinic says you have 'TB of the bones' and does not say that you have AIDS or a STD....Meanwhile there are changes in the body"*. Indeed *"TB of the bones"* has become a synonym for AIDS in Keemba. *"Many people have died from TB of the bones"*, says one breast-feeding mother in Keemba. Other recent research in Lusaka shows the strong association between TB and HIV/AIDS in community perceptions and the subsequent stigma attached to being a TB patient (Bond 2000, Kamanga 2000).

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<sup>29</sup> Sexual cleansing is a Tonga ritual performed after the death of a married man. A close relative of the deceased, usually his brother or his brother's son, has sexual intercourse with the widow (or widows) to "cleanse" her of the spirit of the deceased. Failure to do so will make her "mentally disturbed" – in the words of one participant. A widow who is not cleansed possesses supernatural power that is feared by others. She carries the spirit of her dead husband and this spirit would cause harm to whoever sleeps with her. Such a woman would be vulnerable to witchcraft accusations. There has been efforts made to adjust the practice so the ritual occurs without sexual cleansing. The famous and much cited example of this is Chief Chikankata in Southern Province who, following interactions with the Salvation Army Community AIDS prevention programme in his area, replaced sexual intercourse with a rite (*kucuta*) that involved the widow jumping over a broom and sitting on the lap of her deceased husband's relative. More recent ethnography suggests that outside the jurisdiction of Chief Chikankata, sexual cleansing is still widely practised because people – both men and women and including the widows – fear the spiritual repercussions of not performing it (see Cliggett 1997). Participants in these focus groups and Cliggett's ethnography indicate that sexual cleansing occurs even when the community knows that the widow's dead husband has HIV.

From a gender perspective, what is striking about the perceptions about the prevalence of HIV/AIDS in Keemba is that although women, especially widows, are considered to be the "source" or "carrier" of HIV, men are equally blamed for the high prevalence of the disease. In fact the onus is more on the social and sexual behaviour of men who "the sower sowing seed", "chase widows", "have no respect", who have to have sex and "many girlfriends", and, whose inability to make money now "their cattle are finished"<sup>30</sup>, "overburdens" women with responsibility and "forces" them to go for business to town.<sup>31</sup> Likewise, the men contractors at the clinic "spread" HIV by giving money to local women. Hence, "the disease troubles us women" says a pregnant woman in Chuungu. More than once participants spoke of men "prostituting themselves". This tendency to apportion the responsibility for the high prevalence of the disease to men is different to the extreme blaming of women and the exoneration of men in parts of South Africa (DeClerque Madala 2000) and the tendency to blame women in other parts of Zambia (Bond 1998; Waller 1999).

The reasons given for high prevalence read like one of the earliest demographic models of the HIV/AIDS epidemic in Africa where Anderson et al (1991) pinpointed that who mixes with who and over what time period are key variables in determining the scale of the epidemic. Buve's and Foster's work (1995; 1994; 1993), based on research in and around Monze, showed that indeed sexual mixing patterns, the frequency of commercial sex and mobility were significant co-factors in the high prevalence of HIV. The community's own observations mirror such models and findings. Ten years earlier, in the lower Zambezi valley below Keemba, the Chiawa community widely denied that HIV/AIDS was a problem (Bond 1998). This recent research in Keemba indicates perhaps that local discourse now acknowledges the existence and frightening scale of HIV/AIDS but feel it beyond their control.

In relation to how large the actual MTCT problem was in Keemba, all except one group said that they thought almost three-quarters of mothers were HIV positive so the babies born were either all infected or more likely to be malnourished, sickly and not healthy. More and more babies were being born with *tukoto* – growths on the palate of the mouth or on the anus – a disease associated with malnourished which was rapidly becoming associated with HIV.<sup>32</sup> Thus HIV was a "big problem" for pregnant women, and if the child did survive the mother, then orphans were also a problem.

Indeed, the existence of many orphans was widely acknowledged. To care for, feed and educate these orphans was a problem. Once more the scale of the orphan problem was perceived as

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<sup>30</sup> As mentioned in the description of Keemba, the economy of the area has been hard hit by corridor disease that has killed many cattle.

<sup>31</sup> Such movement to town is associated with sexual exchange. Muchinge's study (1991) in Luapula of women fish traders shows how opportunities for sexual exchange arise at all stages of the journey except in the final business transaction in town where women are in their own domain and are not in need of any favours. In Keemba and Chuungu, people referred to sexual exchange between lorry drivers and women traders and in town where women trade in charcoal or love potions.

<sup>32</sup> *Tukoto* – sores around the anus – is a symptom apparently also now associated with HIV in adults.

immense – “*There are many orphans in every village – the majority of children are orphans*” said the breast feeding women in Keemba. And once again the reference to “*the home closed*” was made.<sup>33</sup>

### **HIV Transmission Routes – “*mainly sexual*”.**

Other than sexual transmission, the routes mentioned were: wound contact; blood transfusion; unsterile razor blades (used for tattoos or to cut umbilical cord); unsterile needles<sup>34</sup>. “*Sharing*” razor blades or needles was mentioned by the breastfeeding women in Keemba. These women made an interesting comment on how people were “*too proud not to share razor blades with those with long fingernails*”<sup>35</sup>. This comment shows the pressure on people in a rural community to share what they own. “*Bathing with someone with HIV/AIDS*” was one transmission route mentioned by the pregnant women in Keemba. This may arise from extreme notions of contagion or could be an innuendo for having sex with someone with HIV/AIDS.

Predominantly it was sexual transmission that all groups saw as responsible for transmission. “*It is mainly sexual*” one Keemba man stated pragmatically. Men’s lack of sexual control coupled with their innate sexual need is pitted against women’s financial need and inability to say “*No*” to sex. For example, references were made to the contract workers constructing the extension of Keemba health centre. Men were incapable of exercising sexual restraint and, unaccompanied by their wives, “*just enter anyhow (have sex) and that is how the disease is troubled us*”. Women explained, with reference to migrant contract workers, “*In the presence of money from these contractors, it is difficult to refuse sex from them*”. It is somewhat ironic that developments at the health centre should be perceived as contributing to HIV transmission.

Intergenerational sex (including that between young boys and older women) and sex with widows who are “*carriers*” of HIV are pinpointed as key. Sex with a woman who has not been cleansed after having an abortion or miscarriage was mentioned by one women’s group. This leads to a disease called “*kahungo*” – a disease similar to, and indeed Mogensen (1995) argues equivalent to, HIV/AIDS.

Knowledge and beliefs surrounding mother to child transmission came out under this theme. Most groups said that HIV was transmitted to children from “*infected parents*” through “*infected blood*” to the foetus in vitro – as a pregnant Keemba woman put it, “*the blood that has made the child has the infection and the child will be born with it*”. Some participants also believed that

<sup>33</sup> The moderators pointed at polygamy, travel, trading, drinking, the main Lochinvar road and the young girls moving to town and back as all contributing to HIV in Keemba. One moderator related how shock she was when young men proposed love to her during fieldwork. She saw this as an indication of the lack of self-control and respect in Keemba.

<sup>34</sup> One pregnant woman in Keemba said “*an injection in hospital*” could transmit HIV. This reflects realistic perceptions of the shortage of needles in hospitals and poor hygiene.

<sup>35</sup> “*Long fingernails*” refers to people who are extremely thin and wasted and whose fingers appear very long and spidery. In some parts of Zambia people who have improper sex, such as older women with younger boys, are believed to develop long fingernails (Bond 1998; Dover 1998; Colson 1958).

if a mother or her husband "moves a lot"<sup>36</sup> with other men or women, the baby is more likely to contract the disease. Most groups thought that a baby born with HIV would die from HIV - "Such a baby when born, is usually very small and with many problems. It is born very thin and continues to get thinner and thinner until death". However, transmission through breastmilk was mentioned by two groups (one men's group in Keemba and pregnant women in Keemba), and, the razor blade used to cut the umbilical cord by TBAs was cited as a risk factor by three groups – and one group acknowledged that TBAs and midwives themselves could get HIV by assisting a delivery.

**Vulnerable Groups – "Everyone is prone if sexually active...and even an unborn baby is at risk. Only person not at risk is a man whose umbilical cord fell on his penis and caused him to be impotent" – Keemba man.**

Most people were considered at risk of HIV infection as reflected in the quote above, the statement "There are too many people at risk here in Keemba", and the following comment from a breastfeeding woman in Chuungu – "Any person can suffer – anyone who misbehaves". Misbehaviour here would most likely be defined as having prohibited sex – ie sex outside marriage, sex before marriage, sex with an uncleansed woman and so on. All groups said that such "misbehaviour" was common in Keemba.

However, there are clearly certain age groups and categories that are more at risk than others, certain patterns of behaviour that make people more vulnerable and a strong belief that women are more able to resist infection than men. Young people – in particular girls – and/or unmarried are "prone". "Girls go to town, get infected, come back here..the same girl will have four boyfriends and HIV spreads. Girls are more infected than boys", one man in the community leader group explained. His observations are widely backed up by both epidemiological and social research in Zambia which shows that girls enter into sexual relations earlier than boys (often in pursuit of financial favours) and infection rates amongst girls aged 15-19 years are five times higher than that of boys of the same age (Kambou et al 1998; CBoH 1999). Participants noted that in Monze, many prostitutes had died from AIDS. People with TB and infants with *tukoto* are other categories particularly at risk.

Men's need for more than one woman is what make men vulnerable as expressed in the following Tonga metaphor related by a pregnant Keemba woman – "Men go for variety. There is a Tonga phrase that says you do not eat one type of food everyday, such as pumpkin leaves with groundnuts or okra all the time". Sometimes Tonga's are jokingly referred to as "Tonga bulls" – a bull always has to have several cows! Polygamous marriages<sup>37</sup> are perceived as particularly risky by two groups due to the lack of trust in such unions, the possibility that one

<sup>36</sup> "Moving a lot" is a colloquial term used in Zambia to refer to having many sexual partners. People are accused of being "movious".

<sup>37</sup> In 1958, in a census of 22 Tonga villages in the Gwembe valley, 23% of men were polygamous. The reasons for polygamy were widow inheritance and economic. Although polygamy causes jealousy and quarrelling, the co-wives do often offer each other assistance and comfort in times of illness and distress (Colson 1958:119-136).

infected person can legitimately spread HIV to others within the unit and the possibility of incest between young sons and young wives. Sexual cleansing is again identified as particularly risky. *"Sexual cleansing is what has killed us here"* exclaimed one community leader, relating a story about one woman who had four husbands die from HIV/AIDS.

Women – other than girls – and men are believed to be *"equally infected"* but more men than women are perceived to be dying. Women's power to resist succumbing to the infection arises out of their monthly cycle. Menstruation effectively cleanses women of dirt and the virus. This belief has also been documented in Chiawa and Chawama (Ndubani 2000). In Tonga this is expressed as *"kuyoya"* – literally translated this means *"women breathe"*. Mogenson explains this belief in more detail (1995:53). She writes that the strength of a man's blood is stable once he is fully grown whereas a woman's blood not only strengthens with age but also oscillates between strong and weak during her monthly cycle, being particularly strong *"when the blood of her menstruation is running"* (ibid). She writes further, *"In general it is believed that in a couple where both are HIV-positive, the woman will die much later than the man, because of her monthly menstruation"*.

The belief in the cleansing power of menstruation expressed here is a sharp contrast to some other groups in Southern Africa where menstruation is associated with women harbouring dirt (DeClerque Madala 2000). Bio-medically, women's immunity is believed to be compromised by pregnancy, hard labour and poor nutrition and women more easily contract HIV (Panos 1994), although women are also immunologically stronger. Perhaps women's central role in caring for people with AIDS and orphans (Waller 1997; Poulter 1996) makes them appear to be the survivors of the epidemic in the community.

### **Ways in which Keemba people protect themselves from HIV**

Aimed at eliciting what people were doing to prevent HIV prevention, most responses focused on what people were told to do or should do ideally to protect themselves. Thus church teachings on self-control, temperance, lawful marriage and disciplining sexual activities – ie sticking to one partner, remaining faithful to your spouse – were listed. Condoms at the health centre, informing sexual partners of your HIV status, parents talking to children about sex, stopping sexual cleansing, withdrawing before ejaculation, avoiding the use of dirty razor blades and avoiding pregnancy if HIV positive were also mentioned. As one Keemba man stated *"We have enough knowledge to control our sexual behaviour"*.

However, the actual difficulties of applying some of these measures to real life were captured in comments concerning the use of condoms. Condoms are available at the health centre *"for men"* but one men's group said they are not used because *"men are careless and women refuse to use them"*. Women explained their difficulties in using condoms arose from fear of being beaten up if they suggest one is used (since condoms are associated with prostitution) and from the need to have sex without a condom to *"feel skin"* and *"to get Vitamin A from sperm"*. An analysis of why condoms were unpopular in another rural setting in Zambia revealed similar beliefs and concluded that an underlying concept of the importance of fecundity made condom use rare

outside very casual sexual relationships and that good sex was not sex with a condom (Bond & Dover 1997).<sup>38</sup> Women were aware of and curious about "Femidon" – the female condom – but although some had asked the midwife to demonstrate how to use it, the midwife had refused because she said she would have to pay for the one she opened. The cost of Femidon – K1,000 – at Keemba health centre was considered prohibitive and they are not easily available in Monze.

### **Current Sources of HIV/AIDS information in Keemba**

It was overwhelmingly the health centre and/or health workers that were cited as the source of information on HIV/AIDS, in particular for women through under five clinics and antenatal clinics. This was also found in Ndola where the health centre staff were the main source of information on HIV/AIDS. One group of breastfeeding women in Keemba remarked that indeed "*our husbands are not taught as we are about HIV/AIDS*". This comment underscores the recent global initiative to involve men more in reproductive health education, especially family planning. Community health workers were mentioned by three groups as a source of information. Anti-AIDS clubs, friends, radio, churches and posters were also mentioned.

Asked where they would prefer to be taught, participants identified health centres, which are central and accessible, or schools which were identified as "*neutral*". The two mens groups in Keemba also suggested the church. The group of community leaders suggested that headmen and the chief should meet and discuss the issue together, commenting that it was a hinderance that the chief was so old. The moderators reiterated this point, believing it essential to involve the headman and the chief in the MTCT programme.

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<sup>38</sup> The MTCT intervention is promoting the use of condoms, even during pregnancy. Mukuka (personal communication: May 2000) says that this rationality of using condoms during pregnancy is hard for women in Chipata compound to understand.

## SECTION VI: HIV COUNSELLING AND TESTING

### People in Keemba's recognition of HIV infection in themselves or others

***"It is not a disease that people would announce like malaria....It is not treated like any other disease"*** (Community leaders, Keemba)

There are several strands to Keemba people's recognition of HIV infection in themselves or in others. These are: certain symptoms that are strongly associated with HIV; the failure of both the health centre and the hospital to be straight forward with HIV patients about their status; the fear and denial that shrouds infection with HIV at a community, household and personal level; and people's personal assessment of having HIV infection according to their own sexual history.

The symptoms associated with HIV infection are summarised in the following text box 5. Men and women in all groups mentioned most of these symptoms at some stage.

#### **Text Box 5: Symptoms associated with underlying HIV infection in Keemba**

- Combination of persistent symptoms – eg diarrhoea, fever, vomiting & body malaise
- Persistent and prolonged and "never ending" cough
- Diagnosis with TB
- Hair change or "Hair like *mukuwa* (white person)" ie soft, light coloured, weak
- Skin sores
- Weight loss until "only bones appear"
- Herpes zoster
- Big white eyes – ie anaemia or staring gaze which accompanies considerable weight loss
- *Kahungo*
- Long fingernails
- Illness that does not respond to treatment
- *Tukoto* – described as a growth on the palate of the mouth or anus in babies born to HIV positive mothers or anal growths in adults associated with HIV

The association between a TB diagnosis in Keemba and HIV is accompanied by accusations that health workers "lie" to patients about their true condition as reflected in the following quotations:

*"You are told that you have TB at the hospital but we know that it is AIDS"* (Breastfeeding women, Keemba)

*"We are tested at the hospital but not told that we have HIV. Instead we are told that we have TB. They do not tell us that it is HIV because they are worried that we would commit suicide. They tell us that it is TB of the bones"* (Breastfeeding Women, Chuungu)

*"The test results are recorded at the hospital. On the patient card the doctor's write "TB" but in the hospital record they write "HIV". These doctors cheat you!"* (Pregnant woman, Keemba)

Indeed, health workers do understandably find it hard to tell patients that they may have HIV and this serves to perpetuate stigma and denial. On death certificates, it is rare to find doctors writing "HIV" as the cause of death (Baggaley 1996). It is the experience of the UTH chest clinic that, faced with little treatment to offer most people with AIDS, health workers may indeed offer patients TB treatment even if a TB diagnosis is unconfirmed (ZAMBART 2000). In Lusaka, in local discourse, there are two types of TB - the "old TB" that is just TB and can be cured, and the "new TB" that is really HIV (Kamanga 2000). In Keemba, they also acknowledge that it is possible to "just have TB" which will get better "if you take the treatment". In Keemba. "TB of the Bones", as mentioned before, appears to be equivalent to the "new TB" in Lusaka discourse. The association *between* "TB of the Bones" and HIV is interesting since it is actually the one type of TB that has not increased with the advent of HIV (Ayles personal communication 2000).

Many people in Keemba apparently fear that they have HIV but either have no access to testing<sup>39</sup>, are not told their HIV status if they are tested or choose not to be tested. The fears they have are based on the community perception that many people in Keemba are HIV positive (as discussed earlier), the failure of health workers to disclose a patient's HIV positive status and on their own personal sexual history. For example, the community leaders told the researchers, "The health staff tested people in Keemba in 1997/8 – 42% were HIV positive...If that was 1998, now it is 1999 so the percentage would have increased. The health staff don't tell us who has HIV because they feel bad. So 42% of us are infected but we don't know who". This discussion is similar to one that one researcher had with a group of women near the clinic who said adamantly they had been told half of them were HIV positive. It is hard to establish on what experience these stories are based although there has been various research projects based at Monze hospital looking at HIV prevalence (see Buve & Foster 1993).

Coupled with people's experience of sexual partners and spouses dying from HIV/AIDS, such figures feed into fear that one is harbouring HIV. For example, "Someone's (sexual) partner is buried having died from persistent fever, diarrhoea, body malaise and cough, covering in skin sores and having hair like a *mukuwa*. Even if the survivor recovers, you can tell that he/she is still infected" (Keemba man). "Those that you share your money with die so you know that you have it" (ie other women whom one's husband or partner has sexual relations with and supports financially) (Breastfeeding woman, Keemba). As a result, "most people just fear and hope" (Keemba man) or "most people just wait for their turn" (Keemba man). Living in a country with high HIV prevalence where there is currently little treatment available for those living with HIV/AIDS, the latter two quotes succinctly capture how many Zambians live with the possibility of having HIV without actually knowing their status.

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<sup>39</sup> The lack of access to HIV test kits in many districts of Zambia is somewhat of an anomaly in a country that aims to promote VCT. At a recent Dutch Health meeting (April 2000), many district hospitals complained they had had no HIV test kits for over a year and were unsure how to obtain them. Currently, NORAD is supporting VCT in 20 sites in collaboration with the MoH and USAID is supporting VCT in 12 districts. Outside such targeted areas, HIV test kits are currently in very short supply. As far back as 1996, the MoH decided that most HIV diagnoses should be based on clinical symptoms to reduce costs.

At the moment people in Keemba *“just see and suspect”* that someone has HIV/AIDS – *“we stay with such people”* one Keemba man proclaimed. A woman in Chuungu remarked, *“That is the bad thing about us – we see someone is sick but do not say it is AIDS”*. Instead, innuendos are made about the illness behind the back of the sick person or family as captured in the following text box 6. Such comments are often stigmatising and/or blaming men’s infidelity, women or witchcraft. Two groups mentioned that people who *“know they have the virus always say they are bewitched”*. Saying that a person with AIDS is bewitched is a common response in Zambia, deflecting the blame away from the person themselves and introducing the possibility of being cured (Bond 1998, Yamba 1997).

**Text Box 6: Names for, and comments about, people suspected to be suffering from AIDS**

*“Oyu amumuchenjelele, mulilo, mulilo”* (This one be careful! It’s fire! It’s fire)  
*“Kusomona kwa inda”* (Diarrhoea has (walked) past)  
*“Musinzo wamana”* ( The journey has ended)  
*“Chamuzunda chitamani”* (He has been beaten by the unending thing)  
*“Nchecho chiyuni”* ( Look at the bird)  
*“Ulabamana bantu”* (He will make people finish)  
*“Mudibula nyika”* ( She is the killer of the world)  
*“She is the carrier”*  
*“Enda-enda”* (going, going, gone)

In such an environment – which we would argue is characteristic of many Zambian settings – it is perhaps unsurprising that very few people know their status and that those who do, are not open about their status. As the group of breastfeeding women in Keemba put it – *“We do not know anyone who knows they have HIV in Chuungu. No one knows – no-one”*. Most groups oscillated between claiming they had never known anyone to be tested to speculating that maybe *“someone might go on their own but they wouldn’t tell you”* to anecdotes about people who had been tested.

However, there is a difference expressed between being told that one has HIV and *“knowing”* that one has HIV. Hence, *“If those you slept (had sex) with die, you know (you have HIV)”* (Breastfeeding woman, Keemba), you *“know because you are sick and not getting better”* (Pregnant woman, Chuungu), *“He knows he is not ok but he is still busy going into other people’s wives”* (Breastfeeding woman, Keemba), and, you *“know as you walk”*<sup>40</sup> (Breastfeeding woman, Chuungu).

<sup>40</sup> People sick with HIV and/or STD are described as “walking” in a certain way. In Chiawa and Lusaka, people with STDs are ridiculed for “walking with parallel legs” (Bond & Ndubani 1997; Msiska et al 1996 1997). In Keemba, during fieldwork, people laughed at a man, suspected of suffering from HIV/AIDS, who walked slowly and painfully through the centre of Keemba, followed by his wife.

### **Experiences of those who have been tested for HIV.**

This limbo state of "knowing" without really knowing appeared preferable to actually knowing at this stage in the focus group discussions. Being told you are HIV positive can have some tragic consequences as reflected in the following case story related by one group of breastfeeding women in Keemba.

*"It happened here in Keemba that the relative to my father was told that he had HIV. I do not know who told him the result. When his parents went for church services on the sabbath day, he removed all the things in the house, drunk poison and set the house on fire. He died inside the house. He thought it was better to die than to suffer especially after seeing people with AIDS and the way they suffer without dying early though, for sure, those people await nothing but death".*

On the other hand, being told you are HIV negative can, according to one participant's experience, be a catalyst for change. One community leader relates, *"I had TB and was worried that I might also have HIV. So I tested at the hospital and found I was HIV negative. I discussed my result with my wife and since then I have not looked at another woman and we stick to one another".*

### **Private/Public Dichotomy**

*"HIV status is private in Keemba. No-one likes to have status known when still strong and they will keep it private. I have never known anyone to be public about their HIV status in Keemba. But it is public because of the signs and symptoms – even a child can tell that someone has HIV when they are very sick!" (Keemba man)*

The participants were asked whether HIV status was private or public in Keemba. The private/public dichotomy is clear from the quote above and was echoed in almost all the groups – HIV status is private because most people would wish to keep it secret yet ultimately, *"one day fall sick"* and it can no longer be hidden – *"others then give the diagnosis according to what they see and think"*. In Ndola, it was also found that HIV was a very private matter only discussed with close relatives (e.g. partner or parents). In Keemba there was reluctance to discuss with most relatives.

### **Incentives and disadvantages for having a HIV test in Keemba**

*"The goodness of being tested for HIV is not yet known in the villages" (Keemba man)*

Keemba people may not have had much exposure to date to VCT services<sup>41</sup> and promotion but, perhaps prompted by the impending MTCT interventions which they have been informed about,

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<sup>41</sup> Some moderators commented that many people did not even know a test existed for HIV prior to the MTCT meetings. By May 2000, VCT services had been set up at Keemba RHC and more women than men have come forward for testing. The resident midwife has set up a post-test club. Twenty-four women have been recruited for the intervention.

they have clearly reflected on the implications of testing. Their views about their feelings and concerns about HIV testing in relation to incentives, disadvantages, MTCT and reaction to a HIV positive test result are portrayed in some detail in the following text boxes 7 and 8 and table 2. In the Ndola study, people – more especially those with prolonged illnesses - expressed willingness to be tested.

**Text Box 7: Main reasons given for having a HIV test**

- Investigating the cause of chronic illness
- Medical procedure
- Marriage
- Concerns about sexual history (eg previous or current partner died)
- Prevention of further transmission
- Safeguarding wealth and children
- To live a healthy and longer life
- Access to treatment
- Access to education
- A desire to act on the knowledge of one's HIV status

It is clear that it is easier for men to decide to have a test and to disclose their status. As one woman explained "*Men have the ability to find out their status*". Women are more circumscribed in their behaviour – expected to consult their husband or parents about wanting a HIV test – and more likely to be blamed.

**Text Box 8: Main disincentives for having a HIV test**

- Undermining future plans
- Fear that the knowledge that one is HIV positive will shorten one's life
- Marriage problems (eg accusations, divorce)
- Women being pronounced guilty
- Lack of confidentiality within the medical profession
- Absence of treatment
- Fear of stigma and gossip.
- Depression
- Suicide



**TABLE 2: FEELINGS AND CONCERNS ABOUT HIV TESTING IN KEEMBA AND CHUUNGU**

<b>Disadvantages of having a HIV Test</b>	<b>Incentives to have a HIV Test</b>
<p>Do not wish to test because it "disturbs the future" (Keemba men)</p> <p><i>"Fear that if you knew your HIV status it would shorten your life"; "know your graves draws nearer"; "if deny, live longer" (Keemba men)</i></p> <p><i>"The spouse that goes for a HIV test first is guilty" (Keemba men)</i></p> <p><i>"A woman found HIV positive will be guilty of having spread the disease" (Keemba men)</i></p> <p><i>"Better to be ignorant of status" (Keemba men)</i></p> <p>Counsellors don't have confidentiality (Keemba men)</p> <p><i>"No cure, no drug, no life – only death around the corner" (Keemba men)</i></p> <p>People who know they are HIV positive will spread the disease (Keemba men)</p> <p>Fear the gossip and rumour (Keemba men &amp; women)</p>	<p>If wish to get married (Keemba men &amp; women)</p> <p>If health is poor (Keemba men &amp; women)</p> <p>In clinic or hospital if doctors want a test, have it done (Pregnant women Keemba)</p> <p>Want to know so know what is happening and choose what to do (Keemba men); <i>"Can live for ten years if HIV positive and look after yourself, or if HIV negative maintain yourself and abandon behaviour" (Keemba men community leaders)</i></p> <p><i>"Men have the ability to find out their status" (Pregnant women, Keemba)</i></p> <p><i>"Find out so avoid sources of infection and stop conceiving because you will lose child and it will reduce your life span and your quality of life" (Pregnant women, Keemba)</i></p> <p><i>"If former boyfriend or husband's girlfriend has died need to know. If HIV negative, then would want to stay alone" (Breastfeeding women, Keemba)</i></p> <p>Prevent spread (Breastfeeding women, Keemba).</p> <p><i>"Stop you finishing all wealth in search of a cure at traditional healers and instead could leave wealth to children" (Keemba men)</i></p> <p><i>"Gives you more understanding to break down misconceptions" (Keemba men)</i></p> <p><i>"Doctors can take care of you and you can live longer..can be advised and guided to live a healthy life" (Keemba men &amp; women); "know where walking, remain alive, live a little more and push the days" (Breastfeeding women, Chuungu); "if medicine, people would come forward" (Keemba men &amp; women)</i></p> <p>Learn about HIV through VCT (Pregnant women; Keemba)</p>

Adverse reactions to a HIV positive test result	Positive reactions to a HIV positive test result
<p><i>"If men know they have HIV, they will give it to others so that others follow him bragging '62 behind me are coming'"</i> (Breastfeeding women, Keemba)</p> <p><i>"You won't want to share the results because girls will run away. Your sexual activity will increase to show power, to show that you are a man. Ironically, you will continue more than ever to desire women"</i> (Keemba men)</p> <p><i>"To know you are HIV positive is a death sentence"</i> (Keemba community leaders &amp; pregnant women, Keemba); <i>"as good as dead"</i> (Pregnant women, Keemba); <i>"other will conclude that you are dead"</i> (Breastfeeding women, Keemba)</p> <p><i>"As a woman who wants to marry, you can't announce the results"</i> (Breastfeeding woman, Chuungu), <i>"As a woman continue to remarry and be cleansed"</i> (Pregnant women, Keemba)</p> <p>Commit suicide (Keemba men &amp; women)</p> <p><i>"Think a lot/too much"</i> (Keemba men); <i>"killed not by virus but by thoughts"</i> (Breastfeeding women, Chuungu)</p> <p>Get depressed/psychologically affected (Keemba men &amp; community leaders)</p> <p>Scared (Keemba men &amp; women) – <i>"heart will come out"</i> (Breastfeeding women, Keemba)</p> <p>Get sick quickly (Keemba men &amp; women)</p> <p><i>"A man cannot share his results, not even with his family because he has lost market. It is better to say you have malaria. So it remains his secret. 10/10 keep it to themselves"</i> (Keemba men)</p> <p><i>"Hide anal sores and others only see them when they die"</i> (Keemba men)</p> <p>Women cannot tell husband because she fears his reaction (Keemba men)</p>	<p><i>"If not married, start looking after yourself and stop spreading"</i> (Breastfeeding women, Keemba). <i>"Change and stop moving around"</i> (Community leaders, Keemba)</p> <p>Eat good food (Breastfeeding women, Keemba)</p> <p>Get medicine (Breastfeeding women, Chuungu).</p> <p>If pregnant, look for help because want to care for the child (Pregnant women, Keemba); men tell wives to stop having children (Breastfeeding women, Keemba).</p> <p><i>"Think about life and pray"</i> (Community leaders, Keemba)</p> <p>Men would tell wife as <i>"in the same house and should not have secrets"</i>, wives and girlfriends may fear they are infected but <i>"if love the man, may accept"</i> (Pregnant women, Keemba)</p> <p>May be supported by others – men turn to wife, <i>"reason together, plan the future and consult books and brothers, sisters and friends"</i> (Pregnant women, Keemba); <i>"family provide him with nice foods and tell him not to worry"</i> (Breastfeeding women, Keemba); women sent back to parents when dying and these relatives <i>"look at her nicely"</i> *(Pregnant women, Chuungu)</p> <p><i>"Wife will stop meeting (having sex) and go and be tested. If wife also HIV positive, use a condom. If negative, divorce husband, stay alone and live longer"</i>* (Breastfeeding women, Keemba)</p>

<p>Divorce – <i>“home will be destroyed because wife will leave”</i> (Keemba community leaders)</p> <p>Avoided/shunned by household members and close friends <i>“because you are going nowhere so you will be lonely”</i> (Keemba men); <i>“Relatives fear you and segregate you when it comes to eating and not want to stay with you”</i> (Pregnant women, Keemba); <i>“The majority will denounce you..and point fingers at you...At weddings leave you alone, give you your own plate and make up a song about you”</i> (Breastfeeding women, Keemba)</p> <p>Ridiculed by community (Pregnant women, Keemba); gossiped about in community (Keemba men, Breastfeeding women, Keemba)</p> <p>Family very disappointed by you (Breastfeeding women, Keemba)</p> <p>Lose respect and access to loans or votes (Keemba men)</p> <p>Embarassing and shameful situation (Keemba men &amp; women)</p> <p>Spouses blame each other and/or relatives of man blame the wife (Keemba men); relatives of husband accuse wife of <i>“killing relatives”</i> (Breastfeeding women, Keemba)</p> <p>No support - <i>“No-one to look after you”</i> (Breastfeeding women, Keemba)</p>	
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The fear of stigma against those suspected to have HIV/AIDS is deep rooted and widespread. An indication of the fear of stigma is the comment that one community leader made that even being seen with an african potatoe is tantamount to pronouncing that one is HIV positive.<sup>42</sup> An african potatoe is a wild tuber that is reputed to boost the immune system and thereby help people with HIV/AIDS in Zambia – some sellers would even say it cured HIV/AIDS and it has become a very profitable trade to be involved in. In Ndola and Chipata there was a strong social stigma for people found to be HIV-positive.

### **Reactions to a HIV positive test**

The responses to questions concerning incentives and disadvantages of testing focused more on incentives than disadvantages. It would plausible to conclude that this was a community "ripe" for VCT.<sup>43</sup> However, the set of questions about how men and women would react to a HIV positive test result were overwhelmingly negative in tone. This suggests that people's lack of experience in relation to testing made their answers to the first set of questions more hypothetical. Genuine fear of death, suicide, divorce, stigma and social segregation were paramount in how they felt people would react to being told they were HIV positive (see table 2). This fear seemed to be based on personal experience, personal fears about their own sexual history, the predominant stigmatising discourse in the community around people with HIV, lack of treatment and support for those with HIV and fear of death.

The reaction from men and women was predicted to be different. Men could react one way of the other – either "moving" around even more or feeling obliged to curb their behaviour. A major problem for men who tested HIV positive, said the community leader group, would be "*those women that they had hoped to have one day, they now won't be able to have*". Overall, men were accused of being likely to spread the disease further and of not wanting to change. Women were thought to find it more difficult to disclose their status to anyone, fearing recrimination. Men would also find it difficult to disclose their status but were thought to be more likely to tell their wives. Indeed, research in Lusaka has established that men are more likely to disclose their status and less likely to be divorced because of their status (Baggaley et al 1996; Zimba et al 2000). In Keemba, one group felt that a wife would get herself tested if her husband disclosed he was HIV positive. If she was negative, she would leave him but if she was positive, she would stay. However, if both of them are sick this would rather cement the relationship – "*you would stay together and look after each other*". The experience of a current household study in Chawama and Kamwala suggests that often women do stay with their

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<sup>42</sup> Likewise, being seen with an x-ray on public transport is associated with TB and thereby with being HIV positive.

<sup>43</sup> A baseline survey in Chawama compound in the mid-1990s established that the Chawama community was very open and receptive to VCT services. However, when the Kara Counselling VCT centre was first opened, the response was minimal. It has taken intensive community mobilisation, long term presence, and incentives (such as TB preventive therapy) to increase the number of people coming to be tested. In April 2000, 330 people were tested for HIV at Chawama VCT centre and in May 2000 335 people – this is the highest figure for all the Kara VCT sites in Lusaka. The total number tested for April was 764 and for May was 762, a relatively high figure. As more people get tested, the percentage of positives decreases – for example it would normally be around 25% of those tested but in April 57 of 330 (17%) were HIV-positive (R.Gimwala, ZAMBART, 2000).

husbands without being tested (ibid). Nyblade's work in Uganda shows the gap between speculating about how people react to a HIV positive result and how people actually do react. Her work showed, for example, that HIV positive men were assumed to react by spreading the disease further whereas in fact they were the only group who sometimes changed as a result of knowing their status by actually curbing their sexual behaviour for the sake of their own health (Nyblade 1999).

In Keemba, reflection, planning for the future, existing networks of compassion and support and being given advice about how to live longer were thought to be the main positive outcomes to receiving a HIV positive test result.

### **Preference for VCT site**

Only one women's group from Chuungu would consider going to Keemba health centre to be tested for HIV. All the other groups reiterated that being tested at the health centre or a health post would breach confidentiality and said they would prefer to be tested in Monze. As one men's group explained, "*Health workers at the health centre are resident and will tell others and force you into isolation and to withdraw from the community*". Examples of breached confidentiality in relation to STD results and fear that the same would occur with HIV was a recurrent theme in the discussions. The researchers heard many comments about how the community distrusted the current health staff at the clinic, and witnessed, during fieldwork, the tension between two health workers. This distrust and tension impinges on health services and has implications for the planned MTCT intervention. However, it should be noted that such distrust and tension is perhaps a common phenomenon in rural areas and has been documented in relation to STDs in Chiawa and Chawama by a visual anthropologist (see Freudenthal 2000). Nevertheless, it still remains a barrier to using Keemba health centre itself as a VCT site.

One suggestion was to have an outside counsellor who would guarantee more anonymity. Indeed, other experience of HIV testing in Zambia indicates that an outside counselling unit may be more appropriate and popular. The Population Based HIV Survey – carried out every two years in Zambia since 1995 – has documented their experiences of a progressively larger take up of VCT services in rural areas when a mobile counselling unit was used (Haworth et al 1999).

One story told again and again, with much hilarity, about how insensitively the health centre handles HIV confidentiality was on food distribution. The health workers received some high energy protein supplement (HEPS) to distribute to people with HIV/AIDS. They announced at the health centre that those with HIV/AIDS should come forward and collect it. "*No-one ever came forward yet the HEPS was still finished!*", one story teller exclaimed.

### **Preference for VCT style**

People had a concept of good counselling – "*being told nicely*" (Keemba man) or "*support like a pillar*" said another. Other important factors were: privacy and individual contact in a room on your own; no public disclosure; and continued support. They also saw counselling as an

opportunity for education on prevention and care of PWAs and for obtaining medication. Such demands would put pressure on existing structures and resources. This is the experience of Kara Chawama VCT centre where the current number of counsellors and space cannot cope with the increase in HIV tests – in April 2000, four counsellors saw over 500 clients (Ayles H personal communication May 2000).

Other suggestions were to not designate a particular day or hour or screening room for testing as this would breach confidentiality, and to try to get as many people as possible to test to “normalise” the procedure. Some men felt that people should be “forced” into testing and that the bible should be evoked to tell people about God’s anger and to compel people to be tested. Many participants felt that the availability of medicine for those with HIV would be the major incentive.

**SECTION VII: OPINIONS ON AND KNOWLEDGE ON MTCT IN KEEMBA****Reactions to a pregnant woman being asked for a HIV test in a clinic setting.**

*"You are concerned about the pregnancy so yes, you would agree to test if the doctor asks"*

**(Pregnant woman, Keemba)**

It is blatant from the responses to this set of questions (see table 3) that true consent for a HIV test from a pregnant woman in a clinic setting is hard to obtain. Women are used to having blood and urine tests at ANC clinics and have little power in such situations to turn down medical procedures especially when it concerns the health of the child they are carrying.<sup>44</sup> The possibility of receiving drugs for their own health and their child's health is an incentive hard to turn down. Being sick would be another incentive for agreeing to have a test.<sup>45</sup> However, undertaking a HIV test would make women feel frightened and even, some groups claim, suicidal. Women also fear the reaction of their husband and the lack of confidentiality at the health centre.

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<sup>44</sup> The power relation between a patient and a health worker within a clinic setting is usually unequal. In Zambia, quality of care is often compromised by shortage of staff, drugs and equipment, status, poor salaries and shortage of time (Faxelid 1998).

<sup>45</sup> It is possible that the current approach adopted by the MTCT intervention in Chipata, where women at ANC receive group counselling about the issue and intervention and can then later choose to seek individual counselling and an HIV test, might be an appropriate strategy for overcoming the unequal power relations between patients and clinical staff. Indeed, from the first month of the intervention, where a small number of women have been recruited, it would appear they are not being coerced into the intervention but their rights are being respected.



**TABLE 4: FEELINGS AND CONCERNS ABOUT HIV TESTING IN PREGNANT WOMEN**

<b>Reasons that a pregnant woman would NOT agree to be tested for HIV when asked in a clinic setting</b>	<b>Reasons that a pregnant woman WOULD agree to a HIV test when asked in a clinic setting</b>
<p>Depressed, sad (Keemba men); <i>"frightened, thinking about death"</i> (Pregnant women, Keemba); <i>"life over if HIV positive"</i> (Pregnant women, Chuungu).</p> <p><i>"Afraid because concerned about children who remain"</i> (Pregnant women, Chuungu)</p> <p>Consider suicide (Keemba men; Breastfeeding women, Chuungu)</p> <p>If not sick, would need to consult husband first (Keemba men &amp; Pregnant woman, Chuungu)</p> <p>Husband or partner annoyed and want to be consulted before the test and ready to blame it on behaviour of other men (Keemba men); husband could <i>"beat wife and not trust her"</i> (Pregnant women, Keemba)</p> <p>Lack of confidentiality at the clinic – <i>"Even if has syphilis, nurses point at you or tell their best friends and they tell others. Or others read it in the book"</i> (Breastfeeding women, Keemba)</p>	<p>If counseled &amp; offered medication to prolong life, will be <i>"happy"</i> (Keemba men); <i>"maybe agree because will help you if you have a disease"</i> (Breastfeeding women, Keemba; <i>"Tablets protect a bit so live a bit longer"</i> (Pregnant women, Chuungu); <i>"All of us could tell our husbands if we all had blood taken and there were drugs to protect the baby"</i> (Breastfeeding women, Keemba)s</p> <p>Already tested in pregnancy (eg asked for urine) so will agree (Breastfeeding women, Keemba); ANC check blood anyway so can test (Breastfeeding women, Chuungu)</p> <p>Under pressure to test due to pregnancy so <i>"look forward to results"</i> (Keemba men); <i>"concerned about pregnancy so agree to test if doctor asks"</i> (Pregnant women, Keemba); <i>"I want baby to get prevention from disease and even if I am sick, my child should live"</i> (Breastfeeding women, Keemba)</p> <p>If sick, will decide to test on her own (Keemba men)</p> <p>If asked by doctor, can make her own decision (does not need to consult) (Keemba men)</p> <p>Husband could be considerate and accept (Pregnant women, Keemba); <i>"Husband would encourage wife to take drugs especially if he brought the virus"</i> (Breastfeeding women, Keemba)</p> <p>Want to know status (Pregnant &amp; Breastfeeding women, Chuungu)</p>

<b>Adverse reactions to a pregnant woman finding out she is HIV-positive</b>	<b>Positive outcome of a pregnant woman finding out she is HIV-positive</b>
<p>Consider having an abortion (Keemba men)</p> <p>Depression (Keemba men &amp; women)</p> <p>Suicidal (Keemba men &amp; women)</p> <p>Divorce if she tells husband (Keemba men)</p> <p>Tell no-one (Pregnant women, Keemba)</p> <p>Fear that she will die after delivery &amp; life span shortened (Keemba men &amp; women); <i>“Afraid that this would lead to a bad delivery”</i> (Breastfeeding women, Keemba)</p> <p>Fear that child will die and she will die – <i>“She will think, this child I can’t keep it and I will also die”</i> (Keemba men); <i>“Nothing to do other than fear”</i> (Breastfeeding women, Keemba)</p>	<p>Tell best friends and parents before husband (Keemba men &amp; women)</p> <p>Tell husband (four groups)</p> <p>Eat good food (Pregnant women, Keemba)</p> <p>Inform health workers that HIV-positive (Pregnant women, Keemba); look for help at the hospital eg during delivery, drugs, food (Breastfeeding women, Keemba)</p> <p>Seek advice (Pregnant women, Keemba)</p> <p>Good to know HIV status (Breastfeeding women, Chuungu)</p>

### **Reaction of a pregnant woman to a HIV positive test result**

***"As soon as she delivers, she will die because she has lost blood, the immune system is low and she knows that she has the virus"*** (Breastfeeding women, Chuungu)

Participants predicted that the main reaction would be anxiety that the pregnancy and the delivery would lead to death (see table). They also spoke of depression and contemplations of suicide and abortion. *"Her thoughts would finish her"* said the pregnant women in Keemba. Once more, the focus was on the health of the mother and not the child.

The groups were divided over whether a woman would tell her husband or not. Some said the woman would wait until she was sick, others said that she would disclose her status to her husband and others that she would not. Only one group however said that she would tell no-one. Most felt that the woman would disclose her status to someone – her parents, other relatives, a health worker or her best friend. Other research in Zambia shows that women are far less likely to disclose their status than men (Kelly et al 1994). Turning to a health worker and hospital for advice, help during delivery, drugs and food was mentioned by a number of groups. This is a reflection, in part, of women's confidence in ANC.

### **Community's views on pregnant women with HIV/AIDS and how they would be treated**

***"You feel pity because you know she is sick and she gets pregnant"*** (Breastfeeding women, Keemba)

Two groups claimed to have never known a woman with HIV/AIDS to be pregnant. All the other groups were concerned more for the women than the unborn child. Infact, only two groups even mentioned concern that the unborn child might be sick. Such women would be dealt with compassion and pity and not dealt with any differently from anyone else with the same condition, *"cared for by relatives in the normal way until death"*, and with people *"sharing food and stories"* and praying with her. Becoming pregnant when sick with HIV/AIDS was also mostly regarded with understanding and concern. However, three groups blamed the woman. One said that she would be accused of not attending ANC, another said *"It is the fault of the mother that the baby is not cared for properly (in the womb) as the mother shares the blood with the baby"*, and, another said that some people might comment *"how can she produce when she is sick?"*. People within the same group pointed out, without knowing that she is suffering from HIV/AIDS a woman can easily fall pregnant. One men's group was quick to see the role of the man in the whole scenario – *"If someone is sick and you make her pregnant it is likely killing her...Remember, she is not alone, the man who impregnates her also has the disease"*. The community men's group said emphatically *"It is the parents fault that the child is infected"*.

However, other than feelings of empathy, there were also expressions of *"disappointment"* and *"being much troubled by her"*. A pregnant woman with HIV/AIDS could evidently be ostracised – *"people might not wish to greet her and avoid her...some would jeer and tease her"*, said the group of pregnant women from Keemba, *"This could be frightening for her and make her die early"*. The breastfeeding women in Keemba raised the problem of special diet – *"She would be seen as a problem because she would eat too much, especially meat"*. There is a general feeling

in Zambia that people with AIDS eat too much and crave for good food. It is said that when an AIDS patient is asked to be given nshima with vegetables, they will often say no but if given nshima with chicken or meat they will say "Yes, I will try". There is actually a Tonga song that makes fun of this.

The length of the illnesses and the tiredness of the caregivers was also mentioned – "*Even the parents, as they go out for firewood, will ignore her call for help*". The short temper of such a patient was also brought up. Caregivers scorn their patients saying "Why are you now troubling me, as if I used to enjoy with you".

Being sick and pregnant would be likely to cause abortion or problems in delivery and even cause her death. "*You would be anxious that at delivery when she bleeds, having already lost weight, she might die*" said one Keemba men's group. Breastfeeding was seen as another danger for a sick woman.

### **Preventing pregnancy in HIV positive women**

**"It is not right to conceive because the child will suffer and die although it has not committed any offence" (Breastfeeding women, Keemba)**

It was acknowledged that for a woman to have a child was a strong desire, leaving "*a mark after death*".<sup>46</sup> However, the risk that a woman with HIV/AIDS will die through falling pregnant (during pregnancy or after delivery through sharing the blood or losing blood), and that the child will die, was considered too serious a consequence unless the woman could take pills for a safe delivery.<sup>47</sup> Being pregnant would also mean that the woman was not menstruating and, the breastfeeding women in Keemba explained, "*it is through menstruation that the virus comes out*". It is clear that if a woman knows she is HIV positive and falls pregnant, it makes her fears about her status more intense and immediate. Mogenson writes that a pregnant women is said to have strong blood (ibid 1995:53) so being told that you have HIV is directly opposed to the state a pregnant women should be in. Being HIV-positive, Mogenson claims (ibid), is having weak blood that can receive diseases easily – the concept of weak blood being an old concept within Tonga culture. To be pregnant and to have weak blood is therefore clearly a pitiful state.

Ways of preventing pregnancies were listed by only three groups who mentioned sexual control, the family planning injection, the pill and condoms. One women's group commented that "*condoms are not good because men make holes in them to make you pregnant*". Female condoms were listed by one men's group. Accidental pregnancies were recognised as a possibility.

<sup>46</sup> In many Zambian groups, having a child is prerequisite to being considered an adult. A woman is addressed differently once she has borne a child, often being addressed as the mother of her first born (eg "*Amai Ester*"), and people younger than her should start to use the prefix "*ba*" as a sign of respect. A man or woman who have no offspring are not given a full burial and do not have their name inherited (Bond 1998).

<sup>47</sup> This comment is one of many indications that the Keemba community had absorbed the information given at the various meetings concerning the planned MTCT intervention since it must be a reference to the fact that such interventions are now possible.

### **Knowledge about transmission of HIV to mother and child**

***”Nothing that you can do to stop getting HIV even when you are pregnant because it can be brought by an unfaithful husband” (Breastfeeding women, Keemba)***

The preceding quote shows how women do not often feel able to protect themselves from HIV, even during pregnancy. There were two suggestions to openly discuss with your husband the danger of HIV or to go and get drugs and condoms from the hospital, but mostly the consensus was that *”there is nothing you can do to stop it”*. There were many references to husbands having sex with other women during a pregnancy even though sex during pregnancy is not prohibited in Keemba until the delivery is very close. Actually, most participants said sex was helpful to the pregnancy, *”brewing the pregnancy”*, *”expanding the way for the baby”* and helping the baby grow. One group of pregnant women in Keemba thought that to use condoms during pregnancy would *”spoil the child’s growth and disturb delivery”*. A number of women, who had fall pregnant at school and not had sex during pregnancy yet still delivered safely, said that it was not however necessary to have sex during this period.

Only one woman said that because the cervix was closed in pregnancy, a woman could not get HIV – another contested that the woman could get HIV but maybe the child could not.

***”The blood from the mother and the father feeds the foetus and forms the child. It is this blood that has made the baby infected” (Pregnant women, Chuungu)***

***”The baby will not grow, will be malnourished and look ill” (Men’s group, Keemba)***

Most groups thought that if the parents have HIV, the child will also have HIV. *”The baby gets all the nutrients and the virus from the mother”*, one men’s group explained. The onus was on parents (not the mother) infecting the unborn child. It seems most people in Keemba would support the acronym *”Parent to Child Transmission”* as opposed to *”Mother to Child Transmission”*.

Mogensen’s ethnography throws some insight onto Tonga concepts of blood (1995:52-54). Each *mukowa* (clan) has a different type of blood. A child’s blood is the result of the mixture of the blood of the father and mother. During sexual intercourse blood is exchanged and within a marriage or a steady relationship, starts *”mixing well”*. For conception to take place, the two *mukowa* bloods need to mix well and the strengths of the blood should be compatible – adultery<sup>48</sup> or sicknesses can make one blood to weak for the other and result in miscarriage. A baby is always born with weak blood which strengthens as it grows.

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<sup>48</sup> We were surprised in our research that the belief that adultery can cause difficulties in labour and sickness in the baby was not brought up. Discussions with the moderators during the analysis confirmed that these beliefs do indeed exist, as recorded else where (see Maternal Mortality Study 1998; Bond 1998).

The possible effect of HIV on the child was multifold: "they are sickly before they are born"; premature birth; death from malnutrition/hunger; death within one week/three months/two years; fail to thrive. Transmission through breastfeeding was mentioned by three of the women's groups. The breastfeeding Keemba women said, "*If the mother is sick (with HIV), she should stop breastfeeding because the baby feeds on dirt*". Another group acknowledged the transmission through breastmilk, but said that breastfeeding should continue even if the child is sick but solid foods should be started early. Transmission through razor blades used to cut the cord was also thought to occur by three groups. The MTCT knowledge of one of the pregnant women's groups and one men's group in Keemba was excellent with transmission during pregnancy or during delivery or during breastfeeding cited as ways that the child got infected. Considering how recent the scientific knowledge is about HIV transmission during breastmilk, the influence of the MTCT community meetings on local discourse and knowledge has obviously been quite profound. In the Ndola study, most people thought that mothers passed on HIV to their babies but were unsure of when and how.

Ways in which the baby could be helped were identified as: looking after it in a caring way, providing a nice diet, treating the child at home or the health centre, taking the baby to the homecraft centre or hospital in Monze, giving the child to the grandparents or "wise women" when the mother dies, and, starting solid foods early. One women's group recommended stopping breastfeeding early. There was great poignancy in the some remarks – for example, "*There is no money in the villages to care for such a child. The quality of food is not there – look around for milk but there is no proper life. Just help because the child is a human being so you must help it until it dies. So you give it food and look for milk*" (Keemba man).

## SECTION VIII: BREASTFEEDING

### Length and the significance of breastfeeding

In Keemba, breast feeding ranges between six months to three years but normally last for one year six months. There are perceived benefits of breastfeeding and some of them indicated by the participants were that the babies grew better when breastfed. The women participants all agreed that colostrum is good for a newly born baby - *"The first yellowish milk is very important for the growth of a baby. They better not miss it because it has good nutrients"*. In Keemba, the babies have some protective herbal medicine given to them after birth and are then breastfed but gradually introduced to other foods such as maize meal porridge or *chibwantu* (sweet beer).

The period of breastfeeding was seen as a birth control by some of the participants. Some women were said to breastfeed for as long as three years as this was believed to be vital for child spacing. The women in Keemba see breastfeeding as part of the beauty of being a woman and the pride of childbirth. Childbirth and subsequent breastfeeding as regarded as cementing marital relationships. Child bearing and breastfeeding also mean a lot to the family members. *"The elders, grand-parents and the in-laws say that if your wife is not able to conceive she is not worth it. She should be divorced. She has no honour of being marriage"*.<sup>49</sup> Some women use breastfeeding for abstinence from sex. In polygamous marriages it is easy to persuade the husband to concentrate on other wives whilst breastfeeding. Some husbands saw the advantage of breastfeeding as that of helping the baby to grow normally. Breastfeeding was also seen as a means of controlling the freedom of women. Some participants indicated that breastfeeding women were constrained in their movements. *"Some men do not want to see their wives free of breastfeeding"*.

Sex whilst breastfeeding is not advisable. Whilst some participants said that sex during breastfeeding was taking place, it was the length of the period couples abstained from sex that mattered. The participants noted that the men found it difficult to refrain from sex during breastfeeding. *"The men often want another pregnancy soon after breastfeeding. When you refuse sex on account of breastfeeding they claim they are also breastfeeding. They say you came here to bear children and I paid cattle for that"*. To reinforce this view the participants stated that if women were found with pills they would even be divorced. In anticipation of an unexpected pregnancy most women said they resort to introducing the babies to other foods such as porridge at an early stage so as to condition the babies. It seems that there is no restriction to sex during breastfeeding but precaution would be often taken to protect the baby since the husband's semen or adulterous behaviour can be harmful to the child. The baby can be protected with herbal medicine and by the father's confessions of adultery. Traditionally, old women would decide when sex could resume, presenting the couple with a gift of beads - ideally this would be when the child is weaned. But even by the 1950s, this custom was abandoned with most parents resuming intercourse around six

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<sup>49</sup> According to Colson (1958:149, 154), a woman's right to fertility is more important than a man's right to offspring, and it is more important for women to have children than marry. This meant in cases of male impotency or illness, they were granted a divorce, or if the husband was absent, it was permissible for a woman to have a child with another man.

months after birth and a child only being weaned when the mother was pregnant again (Colson 1958:156). The traditional period of post-partum abstinence was thought to be significant in “allowing” husbands to have sex with other women. In Chiawa, younger couples were far less likely to practice post-partum abstinence partly because they feared it might lead to husbands getting HIV/AIDS during this period (Bond 1998). However, in reality, men and sometimes women do take lovers during pregnancy and breastfeeding. In the group discussions, there was no mention of a disease called *masoto* – a disease that comes about through illicit intercourse and that can adversely affect the health of the child (Bond 1998; Colson 1958).

### **Alternative feeding**

These discussions indicate that alternative feeds are introduced as normal supplement to child nourishment. But there are situations such as maternal death where alternative feeds are introduced as a matter of necessity. Maternal death normally leads to the introduction of other foods early because of fear of starving the baby. A number of alternative liquid and solid foods are given to babies to supplement breast milk. These include maize meal porridge, *chibwantu* (sweet beer), *nshima* mashed in soup or source made from *kapenta*, beans or sometimes beef and cow and goat milk. The other foods include eggs and fruits.

There are different stages at which different mothers stop exclusive breastfeeding and introduce solids. It appears from the discussions, and from the LCMS national survey, that exclusive breastfeeding in Keemba (and Southern Province) is unusual from a very early age. Most participants mentioned that babies could be given other foods, liquid or solid, as early as a few days after birth.

Formula feeds are not popular in Keemba. The participants noted that formula was too expensive. It requires several tins of milk to enable a constant supply until the baby is big enough to rely on other foods. There is also the cost of travel to Monze to buy the formula. The only time when babies have easy supply of formula from the hospital is when a mother dies and even then it is only for a limited period until the child is healthy and a relative comes to take care of the child.

### **Community reaction to not breastfeeding**

Keemba community places a lot of value on breastfeeding. The community as whole, and more especially immediate household members, take a keen interest in a woman who is breastfeeding to ensure that she actually does breastfeed. The community scorns women who do not breastfeed, seeing her as abnormal and accusing her of prostitution. *“Because she does not want to breastfeed, she wants to start having sexual intercourse with other men so that she becomes pregnant again. When you have a baby and you just breastfeed for a few weeks and decide to stop or you do not breastfeed at all people will think that you are abnormal”*. The main concern is often the health of the innocent baby who might die of hunger. This is consistent with findings from the Ndola study where women who do not breastfeed face social stigma and are accused of being engaged in promiscuous behaviour.

The community will, however, sympathise in cases of illness and other conditions such as breast abscesses, the non-production of adequate milk and when the baby is actually refusing to suck due to some illness. Replacing breast milk has to be really justifiable and it very rare to find a woman stopping breastfeeding as a temporary measure for any ailments or problems she might have. Even cow milk may not be easily acceptable as a total replacement. *"People might not think it is a good idea to give cow milk because cows milk is for a calf and even the milk is different. Breast milk is the best"*.

Instances where a woman dies soon after birth leave the baby miserable. The baby will be taken to a close relative of the mother who is breastfeeding to take care of the baby. Sometimes the baby is given to a woman who is not currently breastfeeding. The elderly people, especially the women, decide on whom should take the baby. In the olden days, old women had herbs that they smeared on the breasts to stimulate milk flow. However, the participants observed that this was now rare. What is normal these days is that the immediate family members of the deceased mother would buy powdered milk for the baby and give cow or goat milk. This would be supplemented by light maize meal porridge mixed with groundnuts and other foods. A study 1986 recorded the most common substitutes for breastmilk as infant formula and cow's milk, the goat's milk. The milk was usually given with a feeding bottle (Chibuye et al 1996:23). The same study also said the most common person to look after the baby after a maternal death – or during a serious illness – was the grandmother. In 79% of cases, the person looking after the baby is expected to breastfeed the baby.

There were two successful examples cited of women who had raised children without breastfeeding them in Keemba. One was an old woman in Chuungu who had found a baby thrown down a pit latrine whom she had brought up without breastmilk, using cow and goat milk and other solids. Another was a woman in Keemba who had not been able to breastfeed (she did not produce any milk) and yet successfully raised five children who are all still surviving.

## SECTION IX: LOCAL INITIATIVES FOR CARE AND SUPPORT

Initially participants responded to questions on this theme by saying that *"No response since nothing can be done"* because, they explained, people don't disclose their status and there is no treatment, money or food to improve the life of HIV positives. This is yet another indication of how much of the epidemic feels beyond their control. When pushed for an answer concerning local initiatives for care and support, the groups identified Anti-AIDS in schools, food distribution from the health centre, health education at the health centre, the SDA church (including the Dorcas mothers who visit sick people in their own homes), other Home Based Care and the World Vision that gives seminars and supports orphans. This type of support appears quite limited and inconsistent at present in Keemba. There is no tight run, well resourced Home Based Care project or NGO offering support to households affected by AIDS.

Although the hospital, health centre, witchfinders and traditional healers were identified as giving medicine to people with AIDS, ultimately it falls on the family to take care of such people. *"You keep them in the house because they are part of the family"*, one Keemba man explained. The groups unanimously stated that a sick relative cannot be ignored and that there was nothing else to do except to keep a relative with AIDS at home. *"Families must depend on themselves"*, said the breastfeeding women in Chuungu. *"Normally people with AIDS are looked after nicely"*, said the breastfeeding women's group in Keemba, *"The community can help by giving food"*. The women in Chuungu also mentioned that the neighbours do help, drawing water and bringing sweet beer when the condition is serious. This compassion is a stark comparison to Botswana and South Africa where there are many documented examples of people with AIDS being cast out by their families (Declerque Madala 2000). Even in Ndola, it was reported that there was rarely compassion for people who were HIV-positive outside the family.

However, it was evident from the focus group discussions in Keemba that this compassion is beginning to wane under the weight of cumulative young adult family deaths and poverty. This fatigue has been noted in other settings in Zambia (Bond 2000). Many groups mentioned how parents were angry with having to look after their young chronically sick adult children. The *"sick are a problem"* – they soak up limited resources, demand good, special and expensive food, are short tempered and *"talk too much about their disease"*. The pregnant women's group in Chuungu summarised this fatigue and anger. *"The family complain about the heavy work involved when looking after someone with AIDS. Sometimes they will tell you "Go and work!" or "Put on your jacket and go and get those who you went out with to wash you!"*. Others recalled how when parents are going to the field they will ignore the cries of their sick daughter in the house as they leave. Other research in Zambia has shown how overtime, a household's search for treatment for a chronically sick family members will abate or stop, as their resources, energy and hope dwindle (Bond 1998; Abrahamsen 1993).

An underlying inference in the discussions on this topic was the feeling that the family support exists partly because people don't actually know the HIV status of the chronically ill they care for. The fear was that if the family actually knew that you had tested HIV positive, some support

would be withdrawn and you would be segregated. This is what happens to many TB patients once they are diagnosed with TB – suddenly they are socially segregated and prohibited, given separate utensils and even sleeping rooms and hidden away from visitors (Bond 2000).<sup>50</sup> The question is, therefore, if the family do know that a pregnant woman is HIV positive, will they actually give her less support.

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<sup>50</sup> The irony is that after two weeks on treatment, most TB patients will no longer be infectious. Whereas the period when they remained undiagnosed, they were infectious but unsegregated.

## SECTION X: CONCLUSIONS & IMPLICATIONS OF FINDINGS FOR MTCT INTERVENTION

- ❖ **Facilitating a successful MTCT intervention.** The findings seem to point to the reality that implementing an effective MTCT HIV prevention intervention on its own, separate from overall HIV prevention, care and support efforts, may be unrealistic. The difficulties of making it to the first step (such as testing) are all related to the environment that women live in (the fear of repercussions, the lack of proper care and support, stigma). To have a successful MTCT prevention intervention program, many other aspects of HIV prevention, care and support, stigma within the community need to be worked on simultaneously. This also entails building partnerships with other groups and programmes doing other kinds of HIV prevention, care and support work in order to start changing the overall situation with regards to stigma, care and support. Support issues were emphasised by the study participants and these could be crucial to the programme implementation. Women need to have strong support for them to go through the programme —whether it is from a spouse, in-laws and other family members or the community.
  
- ❖ **Limited capacity and the need to enhance knowledge and capacity to regain control.** At present, in Keemba, the capacity to cope with HIV/AIDS is limited. Faced with poverty, a number of other problems and an epidemic that the Keemba community acknowledges is “*closing homes*”, people feel that the epidemic is beyond their control. There are currently no existing local organisations or structures that are giving consistent support to enable them to shake off the feeling of hopelessness. This is a community that needs appropriate outside organisations to help them cope - for example, the introduction of a peer education for young people. The existing local structures may be useful in the MTCT programme. There has to be deliberate efforts to build both community confidence in the structures such as the NHC, CHW, TBA’s, the health centre, World Vision, Anti-AIDS clubs, traditional leaders (the chief and headmen) and the Church, and to improve the capacity of such structures to manage HIV/AIDS in a sensitive, open and less stigmatising manner.
  
- ❖ **Addressing the inadequacy of existing health facilities.** The inadequacies of the health facilities are highlighted by: breached confidentiality; the limited capacity of health workers in managing both HIV/AIDS and deliveries; shortages of supplies (including needles and syringes, condoms and family planning tablets) and barriers that pregnant women face in accessing health services. Health workers are seen as concealing information relating to HIV status of people, a situation that partly perpetuates stigma and secrecy surrounding HIV/AIDS. The challenge is that if health care workers have difficulties in revealing to sick people that they might have HIV/AIDS, or putting it on a death certificate, how then do they counsel a pregnant woman and still tell healthy pregnant women that they are HIV positive? The community is very sceptical about the ability of resident health workers to maintain confidentiality about HIV status. Health workers involved in MTCT need re-orientation in order to handle these issues more

effectively. With the recent introduction of VCT services, and the involvement of the resident midwife in the post-test club, indications are that perhaps the MTCT training package has had a positive impact.

The association between TB and HIV needs to be explained more clearly and positively – for example, people with HIV are more likely to have TB but can be cured and this can extend life.

The realities of maternal health care delivery and access have implications for the MTCT program. For example, that most women deliver at home (for all the various reasons including having to bring gloves, costs, distances) is essential information that should be taken into account. ANC attendance is very high and women acknowledge that through attending such clinics they are exposed to more HIV/AIDS education than their husbands. However, compliance with taking folic acid tablets is reportedly low, most women deliver at home and post-natal care is neglected. Women could be easily coerced into giving consent for HIV testing in such a clinic setting, especially if they are sick and especially if there are drugs available to help them and their unborn child. Neither at home or at the health centre are women getting adequate care during delivery – the number of TBAs are few and far between, the barriers for accessing health centre deliveries deter many women, the shortages of supplies at the health centre undermine good delivery practice. Their fears about delivery – for example manifested in their desire to have small babies – are understandable and need to be addressed, particularly for those women who know their HIV-positive status and are more frightened of dying during or after delivery due to the loss of their “*weak blood*”.

Perceptions about ante-natal drugs making babies too big serves as a good example of the importance of the messages, their content and how they are disseminated. In order to alley misconceptions arising from AZT/Nevirapine, a carefully thought out information communication strategies will have to be designed to feed directly into the MTCT program implementation. This also stresses the need for on-going research and monitoring of the community to understand how the messages are being understood, interpreted and passed on.

The capacity of the community to absorb health messages is reflected in the good knowledge of HIV transmission and of MTCT, following the meetings discussing the forthcoming intervention. The community also clearly see the role of the health centre in health education. And people are open to trying out different treatment options. All these factors could be successfully built on.

- ❖ **Recognition of household involvement in health decisions.** Both the treatment seeking patterns in response to serious illnesses, health prevention, maternal health and discussions on VCT are characterised by the involvement of household members and the family. A programme such as the MTCT will need to go beyond merely addressing pregnant women and perhaps their spouses to embrace the extended families of the

intended beneficiaries of the interventions. We have seen how the slightest suspicion that a woman is taking family planning tablets can result in conflict. Husbands could be supportive of their wives taking drugs from the health centres. The challenge is how to win their full cooperation, as they are in turn likely to win the cooperation of the "elders". Dealing with these dimensions also raises interesting ethical observations. How does the intervention deal with an individual "personhood" in a situation of "familial self" (De Cremer 1983). Who makes a decision about whether a woman should participate in the programme or not? Who gives informed consent?

- ❖ **Sensitivity to gender differences.** The participants have persistently shown that there are counter-accusations over the role of men and women in the spread of HIV. Whilst the Tonga men are known for their lust for polygamy and having many sexual partners (*mbamambe*), the Tonga women are being accused of being in search of money and gifts, influenced by trading in urban areas and migrant labourers coming to work in Keemba. Young women are obviously a vulnerable group in this community and needed to be targeted in prevention efforts.

The importance of involving men has been emphasised in this study especially owing to the recognition of the role men play in spreading HIV, including to their children through the women. This is something that could be built on to get men more involved. The impressions are that men can test more easily than women, are less likely to be blamed, and probably face less harsh consequences than women if positive. Women are constrained in making a testing decision alone, suggesting that the focus of the VCT should be on men (or couples), rather than women getting approached during antenatal care. During the study, men expressed readiness to participate and take responsibility and this can shape communication messages and perhaps the whole structure of how MTCT program should be delivered. The role of men is important not only in the case of HIV positive women, but also in those who are negative. While it would be ideal to change women's inability to protect themselves, in the short run the importance of involving men so that they are educated and held accountable for the child's safety (from HIV) during pregnancy and breastfeeding should be emphasized as part of the communication messages.

The concerns raised about HIV and pregnancy focus on the health of the woman. This poses an interesting issue, since the most direct benefit of the program is really for the infant. This is about how to balance women's health (emotional as well as physical) and reducing risk of HIV transmission to the baby. This does have implications for how the communication messages will be framed. While there is no direct benefit to the mother's HIV-related health outcome, it could be argued that there is indirect benefit to her health by having a healthy (as opposed to sick) baby to look after---or that somehow knowing HIV status and doing something to protect the baby will reduce worry and therefore improve health. In addition, in the wake of various Protest initiatives in Lusaka that aim to integrate all services for HIV-positive people, women could be offered support beyond delivery.

- ❖ **Application of knowledge and exchange of knowledge.** The contrast between knowing how to prevent HIV versus the actual difficulties of applying that knowledge to real life is equally applicable to the MTCT prevention programme. Condoms are unpopular yet key to MTCT. The programme needs to acknowledge problems with condom use and be realistic about when they can be used and by whom. Condoms need more positive promotion.

While the women and the community might know that the MTCT prevention intervention program is there, actually taking part in it will not be so easy. The disincentives of knowing your HIV status are high - whether alone, or in the context of MTCT. Since VCT is the prerequisite to the rest of the MTCT package, communication strategies will need to educate about VCT in general. The program will need to address the real fears and concerns related to knowing positive status (like thinking they will die faster, denial, stigma, knowing but “not knowing” anomaly, public/private dichotomy).

Key to the understanding and success of HIV prevention messages is to incorporate local discourse into the communication strategy. For example, using theatre to raise the issue of sexual cleansing – which is acknowledged as a significant route of transmission for HIV – and to discuss alternatives. Likewise, discussing the belief in “*strong blood*” and “*weak blood*” and the cleansing power of menstruation could open up discussions on MTCT and living with HIV.

- ❖ **Breastfeeding practice.** Breastfeeding is widely practised and cherished, and a decision to not breastfeed must be an explicit and strong. A woman who did not breastfeed would usually be labelled a prostitute. Supplements are introduced early. To challenge this practice might be easier than to suggest that women do not breastfeed, especially since the cost of alternative feeding is beyond the reach of most households in Keemba.

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