

**WORKING REPORT ON COMMUNITY RESPONSES TO INITIATIVES TO
PREVENT MOTHER-TO-CHILD TRANSMISSION OF HIV IN BOTSWANA**

**Findings from a qualitative study conducted in Bontleng community, Gaborone, Botswana
from November 1999 to May 2000**

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Executive Summary

Botswana is one of the top five countries in the world affected by HIV, with nearly 36% of adults currently infected with HIV. [1] In Botswana in 1998, the median rate of HIV infection among women attending antenatal clinics (ANC) was 43% in urban and 30% in non-urban areas (UNAIDS 2000). Mother to child transmission (MTCT) rates of HIV, a major cause of HIV/AIDS among children under 15 years of age, are estimated to be 40%, resulting in 8,700 babies infected annually. [2]

Clinical trials in several countries have shown that MTCT of HIV can be dramatically reduced through the administration of a short course of Zidovudine (commonly known as AZT) to pregnant women. In response to this burgeoning epidemic the government of Botswana, in collaboration with the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the Harvard AIDS Institute, has initiated an MTCT programme in two communities near Gaborone, to provide mothers with both a short course of AZT and information on alternatives to breastfeeding. However, these projects—in large part due to time constraints—have been conducted with little consultation of or feedback from residents of the targeted communities.

For this reason, in 1999, GlaxoWellcome and UNAIDS jointly funded a formative research study in Botswana on the perspectives, needs, and preferences of women and communities regarding the MTCT of HIV. Carried out by the International Center for Research on Women (ICRW) and Society for Women and AIDS in Africa, Botswana (SWAABO), the main objective of the study was *to obtain information and data that could be used to improve the effectiveness and acceptability of messages and services for MTCT prevention on the community level.* To do so, focus group discussions and in-depth interviews were held with women and diverse residents of one community where the MTCT program was launched in 1999.

Research findings reveal that knowledge about HIV/AIDS, its symptoms, causes, modes of transmission (including MTCT) and prevention, range widely among community members. Lectures at antenatal and well-child clinics were cited as major sources of information about HIV/AIDS and MTCT. The data also show the fear of and stigma against people living with HIV/AIDS (PLWHA) by community members. These patterns in turn deter many residents from being tested for HIV. The decision to be tested for HIV is complex and focus group discussion participants cite the need for adequate counselling and support in order to make this decision. With regard to MTCT specifically, strong cultural norms support breastfeeding and inhibit HIV-positive women from considering other infant feeding choices.

The primary conclusion from the study is that *MTCT prevention programs have an urgent need for the information and perspectives that emerge from community dialogue about HIV/AIDS and MTCT prevention.*

The study yielded several recommendations. In the area of community education, it became clear that efforts should emphasize participant feedback and quality control mechanisms in order to ensure that communities understand the information they receive on HIV, MTCT and related issues. Effort should be made to ensure that service providers understand the relative (rather than absolute)

effectiveness of AZT in preventing HIV transmission, the links between MTCT and breastfeeding, and the potential risks of other infant feeding methods.

In addition, voluntary counselling and testing services should be extended beyond antenatal clinics so that a broad community audience can be reached. Men and elders should be particularly targeted with information on and opportunities to discuss both HIV and MTCT. Support services should also be increased for the families of PLWHA in order to reduce the burden of care and encourage community residents to seek testing and counselling.

Introduction

The major cause of Human Immunodeficiency Virus (HIV) in children under 15 years of age is mother-to-child transmission (MTCT) of HIV during pregnancy, especially late in pregnancy, during labour and delivery and through breastfeeding. Acquired Immunodeficiency Syndrome (AIDS) has caused the deaths of over 3 million children world-wide and another one million are currently infected with HIV. [3] Nine out of ten of all HIV infected infants live in Africa, which accounts for only 10% of the world's population. In urban areas in southern Africa, rates of HIV infection are as high as 20-30% among women attending antenatal clinics, with some clinics reporting rates closer to 60%. In the absence of preventive measures, the risk of an infant of an HIV positive mother being infected ranges from 25 to 35% in developing countries. [4]

Until recently, strategies to prevent infants from becoming infected with HIV included only primary prevention of HIV infection in the mother prior to and during pregnancy and breastfeeding. Other strategies included family planning to prevent pregnancy itself, or pregnancy termination, where legal. In addition, there are specific guidelines for measures during labor and delivery that decrease the likelihood of transmission.

For an increasing number of countries, two more strategies are now available. Recent trials in Thailand, Burkina Faso and Cote D'Ivoire have shown that giving a short course of Zidovudine (AZT) to pregnant women, if the mother does not breastfeed, reduces the risk of MTCT to below 10%, which represents a 50% reduction. More recently, a study in Uganda revealed a similar efficacy giving Nevirapine to the mother at the onset of labor and to the baby 72 hours after birth.

As increasing numbers of pregnant women in Africa are infected with HIV prior to and during pregnancy, prevention of transmission to their infants has become an important component of many national AIDS programmes. UNICEF, in collaboration with UNAIDS, WHO and others have supported pilot projects with the Ministries of Health in eleven countries to provide a short course of AZT or Nevirapine to mothers and alternatives to breastfeeding.

In the context of a raging epidemic that offered few treatment options and in response to the finding that a short course of AZT is effective in reducing MTCT, the pilot projects were forced to move ahead quickly, leaving little time for community consultation. To fill this gap in knowledge about women and communities' perspectives on MTCT, the International Center for Research on Women (ICRW) undertook formative research in collaboration with The Society of Women and AIDS Botswana (SWAABO) in Gaborone, Botswana with funding from GlaxoWellcome and the Joint United Nations Programme on HIV/AIDS (UNAIDS).

It is important that communities have a voice in solving health problems that affect their lives. This is especially true for programmes such as MTCT prevention that include components that have an enormous impact on the lives of women, their partners and their extended families. The benefits of many technologies, in this case drugs and a required blood test, can be overshadowed by conflicting community norms, values and beliefs. With MTCT, the issues are challenging because of the complexity of HIV transmission and the stigma associated with HIV and AIDS. For some pregnant

women, a partner's knowledge, or even a family's knowledge that she is HIV positive can be tragic. Because of the sensitivity of the issue of MTCT and the complexities of cultures and communities, talking to women and others in their communities is a vital step in the process of preventing HIV transmission to infants.

Background

In Botswana, nearly 36% of adults are now infected with HIV, representing more than a tripling of the adult prevalence rate since 1992. [1] In Botswana in 1998, the median rate of HIV infection among women attending antenatal clinics (ANC) was 43% in urban and 30% in non-urban areas. [1] Mother to child transmission (MTCT) of HIV is estimated to be 40%, resulting in 8,700 babies infected annually. [2] Based on data from other countries that showed that a short-term course of an antiretroviral drug (Zidovudine or AZT) and alternative infant feeding can reduce transmission by at least 50%, the government of Botswana decided to implement this preventive regime as a way of reducing MTCT and improving child survival.

Pilot MTCT prevention projects started in the two main cities of Francistown and Gaborone in April 1999. The MTCT prevention strategy involves first training health workers in counselling and obstetric practises, strengthening laboratories and providing supplies to carry out HIV tests and purchasing and distributing AZT and breast milk substitutes. The Government is collaborating with UNICEF and the Harvard AIDS Institute in implementing this programme.

For pregnant women, the project involves voluntary counselling and testing (preferably with the male partner) at a health facility. Women learn about the programme initially through posters, radio messages and health talks at the clinics. Pregnant women are then given more detailed information about the programme and individual confidential counselling from a trained nurse/midwife as part of a routine ante-natal care (ANC) visit. As part of this counselling during the ANC visit, women are offered the option to have an HIV test, which is necessary for participation in the rest of the programme. Women who agree to the HIV test and who are found to be HIV positive are offered oral AZT beginning at 34 weeks of pregnancy and continued through labour. The programme also includes infant feeding counselling and provision of infant formula to HIV positive women who choose not to breastfeed. Infants are given AZT syrup for the four weeks after birth and are carefully monitored. Both mothers and infants receive follow-up care and support from health personnel. [5]

SWAABO has worked widely in community HIV /AIDS prevention work in Botswana over the past ten years. Through this community work, and based on initial anecdotal evidence that indicated the difficulty many women faced in deciding to have the required HIV test necessary for participation in the MTCT prevention programme, SWAABO became concerned about women and communities' needs with respect to information, care and support for MTCT prevention. They saw a need to research women's and communities' concerns about MTCT prevention, before designing community education and mobilisation programmes to support MTCT prevention programmes. With these concerns, SWAABO collaborated with ICRW and initiated a research project in Bontleng, community in Gaborone, Botswana.

Research Purpose and Objective

The goal of this research is to improve the effectiveness of MTCT prevention programmes by providing important data about the perspectives and preferences of women and communities.

To fulfil this goal, the objective of the research was to give voice to the beliefs, perspectives, wishes and needs of women and their communities by documenting the perspectives of women and their communities about mother-to-child transmission of HIV, voluntary counselling and testing (VCT), treatment and breastfeeding options. The studies analysed each of these components in the context of HIV/AIDS in that community and are designed to provide insight into the community context in which MTCT prevention programmes exist, especially in terms of community attitudes about HIV/AIDS. The studies were also designed to provide insights about what women and communities know about MTCT, whether they define MTCT as a problem, and the issues women face when deciding whether to participate in an MTCT prevention programme, especially regarding VCT.

Methods

Focus group discussion (FGD) was the principal method of data collection. In addition, several in-depth interviews were conducted to explore women's experiences with the MTCT prevention programme. Moderators and interviewers were trained to use FGD and in-depth interview guides developed by ICRW in collaboration with the in-country researchers. All guides were pre-tested.

Focus group moderators conducted a total of 11 focus group discussions with 8-12 participants in each group. The groups represented those most affected by MTCT prevention (breastfeeding and pregnant women) and those who play a significant role in shaping community norms and supporting women and men through decisions related to MTCT prevention. Where needed, because of the complexity of the issues, the focus group discussion extended over two sessions. Because of the difficulties of gathering the same group twice, in several cases there were different participants for the first and second round of discussions.

The sample for the FGD included:

- breastfeeding women between the ages of 18 and 30
- breastfeeding women 30 years old or older
- pregnant women between the ages of 18 and 30
- men between the ages of 18 and 30 years old
- men 30 years old or older
- mixed gender group with community elders

Different methods were used for selecting women as compared to men for the focus group discussions. The research was announced and described to women attending ANC and well-child clinics at Bontleng Clinic and volunteers were asked to attend FGD sessions to be held in the evenings at Bontleng community centre. The men were selected by announcing the study in the neighbourhood through community mobilisers and asking for volunteers who were fathers and of the appropriate age. The community elders were gathered by the local councillor (politician) and Village Development Committee chairperson. FGD were held at a time (evenings and weekends) and place convenient for the participants (local gathering places).

In order to learn how women were responding to the MTCT prevention programme, the aim was also to conduct twelve individual in-depth interviews with women who had contact with the MTCT prevention programme and had made different choices about participation in the various parts of the programme. The research team worked with local clinic nurses who were asked to identify women and find out if they would be willing to participate in an interview. Contact information of the women who volunteered to be interviewed was then given to the research co-ordinator.

Because many of the women did not agree to be interviewed, the composition and number of interviews in the final sample differed slightly from the planned one. As was expected, finding women who were willing to be interviewed was extremely difficult, not only because of the mobility of the population (between urban and rural, as well as within the city), but also because of busy

schedules (many of the women are employed), and because of the difficult nature of the topic. None of the women agreed to have their interviews taped, one terminated the interview before it was complete and many women responded to several of the questions with “I don’t know.” Because of the difficulty of finding women to interview, the study site for the in-depth interviews was expanded to include women attending the MTCT prevention services at Princess Marina Hospital.

The following box presents the planned versus actual in-depth interviews:

Planned and Actual Interviews with Pregnant Women: <i>Women were categorised according to their response to offers to participate in MTCT prevention program at antenatal clinic visit:</i>	
<u>Planned Interviews</u>	<u>Actual Interviews</u>
refused HIV testing (2)	refused HIV testing (2)
wanted to consult partner first, never returned (2)	wanted to consult partner first, never returned (1)
accepted HIV test, but never returned for results (2)	accepted HIV test, but never returned for results (2)
tested, got results, HIV negative (2)	tested, got results, HIV negative (1)
tested, took AZT, chose to breastfeed (2)	tested, took AZT, chose to breastfeed (1)
tested, took AZT, chose to formula feed (2)	tested, took AZT, chose to formula feed (3)

In addition, interviews with providers included one semi-structured group interview with Family Welfare Educators and two semi-structured individual interviews with nurse-midwives who provide the counselling for the MTCT prevention programme. Because the focus was on perspectives of women and their communities, only these three interviews with providers were conducted. The recently conducted evaluation of the pilot MTCT programmes [6] provides a much fuller account of provider perspectives on the programme.

Results

This section is divided into two sub-sections: findings on the community context in which women make decisions about MTCT prevention, and community perceptions of and participation in the main components of current and planned MTCT prevention programmes, e.g., voluntary counselling and testing, drug treatment during pregnancy and infant feeding.

The first section includes information based on data gathered regarding perceptions of the scale of HIV/AIDS, knowledge and perceptions about HIV/AIDS, sources of information, community treatment and attitudes about persons living with HIV/AIDS (PLWHA), care and support for PLWHA, and knowledge and perceptions about MTCT and MTCT prevention.

The second section is about issues that are more directly related to the current MTCT prevention programmes. This section includes women and communities' general knowledge about the current MTCT prevention programme in Botswana, as well as their knowledge, perceptions, issues and desires about each of the main components of the MTCT prevention package—HIV voluntary counselling and testing, AZT and infant feeding.

It is important to note that the study was done in only one urban, low-income community in Gaborone and that we recognise that qualitative data from a study in one community cannot be interpreted as representative of the national situation. While the results reflect the views of the study community, the same views are likely to be characteristic of other communities. However, we recognise that on a national scale there are also likely to be important differences. In addition, the study is based on one methodology, which ideally would be complemented by other methods to achieve the benefits of triangulating the data. Despite these limitations, the study was designed to increase understanding of the issues surrounding MTCT prevention for women and their communities and thus offers important insights that can be applied to MTCT prevention programmes in general.

Community Context

While the focus of MTCT prevention programmes is to reduce the vertical transmission of HIV from mother to child, the overall context of HIV/AIDS in the community is an important determinant of the need for the programme and the potential success of the programme in that community. Understanding what communities know about HIV/AIDS and MTCT, where they obtain this information, and how they view, treat and care for PLWHA, as well as what they think about VCT, drugs during pregnancy and infant feeding, helps in understanding the information, education, counselling and support needs related to MTCT prevention programmes.

Awareness of HIV/AIDS in the Community

In general FGD participants and interviewees were aware that there were high levels of AIDS/HIV prevalence in the community - their estimates ranged from 30% to 90% (with the majority in the range 40% to 70%) - but they claimed to have little personal knowledge of people living with

HIV/AIDS. Only a few admitted to know of people with HIV/AIDS; the majority claimed they had “never seen someone sick from HIV or AIDS.”

“Personally I don’t know what people are talking about when they mention this disease AIDS. I have always heard about it, but I can’t actually say that I have seen someone like that. What I have seen is someone who loses a lot of weight and later on has a continuous, running stomach.” (breastfeeding participant)

Most people attributed this to the secrecy surrounding AIDS. As one male FGD participant put it “When people have HIV, it is always a secret. It will just remain a rumour that so and so has HIV, but it will never be verified whether it is true or not. They only mention AIDS when someone is already dead.”

One pregnant FGD member blamed health officials for creating a secretive environment in the way they educated the community about AIDS. She implied that AIDS education had tended to frighten people, rather than helping them come to terms with the disease. She compared public education on AIDS to education on other diseases (e.g. cancer, TB, and diabetes), saying that:

“There is too much secrecy. [AIDS] was not regarded as other illnesses. When it first came, people were secretive. People were not really encouraged to accept their status, like the way cancer patients accept their status... If it was treated like TB, it would not have been a problem. We would not have been afraid to go for the test. I would know it is just like cancer. I would not be so stressed and just accept it.”

Because PLWHA keep their HIV status a secret and their symptoms are often not obvious, people don’t know if they are infected with HIV. There are lots of rumours that individual PLWHAs may be sick from AIDS, but there is no confirmation that this is true. Even if they die, there is no confirmation that AIDS was the underlying cause. When the interviewer probed for more information, one pregnant FGD member said:

“No, if we have to give our views, people are ill and dying, but we don’t know the cause... We don’t know whether people are dying of AIDS or cancer. There is no way we would know.”

Other FGD members underlined the fact that there are no clearly identifiable symptoms that are apparent to everyone in the community. “We can’t identify such people because mostly we look all the same.” (male participant) The symptoms of AIDS may be the symptoms for other diseases. AIDS is therefore perceived as an invisible disease - it is something that people are aware is there, affecting large numbers, but it is something that operates beneath the surface, secretive, hidden. This is what makes it so frightening.

Members of one male FGD complained that, “people don’t admit to AIDS, even at funerals.” One woman said that at a funeral she attended, it was announced that a man had died of ‘four letters’. The male FGD members argued that this secrecy surrounding funerals and the government’s policy of confidentiality was a major obstacle to reality based public education. They maintained that:

“This secrecy can only end if it is publicly announced at funerals that someone has died of AIDS, so that young people can also learn... and friends and relatives can learn.... and maybe change their behaviour.” (male elder)

They argued that if people’s status were made known, *“people [would] not be dying at the rate at which they are dying today.” (male elder)*

Knowledge about HIV and AIDS

The focus group discussions did not provide a detailed assessment of the knowledge base of those interviewed about HIV and AIDS, but they did provide information on the level of awareness in these groups. As expected, there are big differences in understanding within the population studied - some know a lot, others know little and still others are misinformed. While it appears that most people have been exposed to the basic facts on AIDS, there is still a lot of ‘half knowledge’. Even those who appear to know a lot have confused understandings on some issues. There were also a number of commonly held myths, e.g. that condoms contain worms, which are blocking the adoption of the desired safe sex behaviours.

There did not appear to be significant differences between men and women in terms of a general knowledge level, except on certain topics. However, there seem to be a big difference between men and women in terms of belief: the FGD data seems to suggest that most of the resistance to the HIV/AIDS world-view comes from men. The male FGD members were the most forceful in presenting the view that other things (e.g. neglect of tradition and rituals) are responsible for the increased death rate. As one member, who described himself as a traditional doctor, said:

“We have neglected our traditional medicine which used to protect us.... Traditional medicine is the one that is working, but today as young people we have rejected our tradition, that’s why we have all these problems.”

“In our discussions as traditional doctors we have realised it gets transmitted to the baby, if there are no proper rituals for the baby. The baby gets infected if these rituals are not performed at the right time.”

Symptoms

Both male and female FGD members recognised the following symptoms of AIDS - weight loss, chronic diarrhoea, change in colour, weak or loose joints, and susceptibility to flu. One man described the symptoms of AIDS in the following way:

“When it starts they never get healed of flu. They always have diarrhoea. They also complain about aches in their legs, then it is TB. They take a lot of tablets but they continue losing weight. They change colour - they look like a pot, they become so black that even body lotion doesn’t seem to help. They are always vomiting...”

Weight loss and diarrhoea seemed to be the most commonly recognised symptoms of AIDS. One man (a traditional doctor) indicated in a joking way that weight loss is the clearest indicator of AIDS

- *“God may give you the power to help [AIDS sufferers] but in many cases they continue losing weight. As you can see I have lost weight - maybe I have AIDS!”*

In terms of the symptoms for children, female FGD members stated that children with HIV are *“born normal and then just keep getting weak.”* (breastfeeding participant) They added that these children are prone to illnesses and don't live beyond five years.

Causes of HIV Transmission

There were lots of misconceptions about HIV transmission, especially among the male FGD members. Some of the most common misconceptions expressed by the male FGD members included: the spread of HIV from faeces or urine on the open ground by flies or wind, and sharing utensils and dishes.

Some members of male and female FGDs, however, knew the basic routes through which HIV is transmitted - unprotected sex, contact with HIV infected blood if you have a cut or open wound, sharing razor blades and needles, blood transfusions, and mother to child transmission. Several FGD members cited accidents as a situation where HIV could be transmitted - *“If you are involved in an accident with an infected person, you sustain injuries then blood is exchanged!”* (pregnant participant) Members also expressed fears about contracting HIV from PLWHAs through sharing food and toilet facilities. For example one pregnant participant said: *“Some people say they don't want a person to open a box of milk with their teeth because if they are infected or have sores in their mouth they will introduce it into the milk.”* Another woman said you could get infected through *“sitting on a toilet seat immediately over the blood [of an infected person] before it dries when one has a wound on the buttocks.”*(in-dept interview)

Social Causes

FGD members also spoke of the social factors underlying HIV transmission. Both male and female members cited the neglect of traditional culture and the adoption of modern culture as contributory factors - for example:

“We young people don't listen to our parents and that results in teenage pregnancy.” (male participant)

“People know that without condoms, if I have sexual intercourse, I will get pregnant [and] this will prevent them from having sex, because with condoms they don't fear having children. We should go back to our culture. In the past there were no condoms and no problems.” (female elder)

“Government tells us to go to clinics and collect condoms... and this is what has caused this dreadful disease... The condom produces worms and this thing infects us and hence the disease. We have neglected our traditional medicine which used to protect us...” (male participant)

“The machine which was brought to Botswana for abortion by Parliament. I strongly believe is the machine which causes problems, because before this machine

this disease was unheard of. With this machine teenagers get pregnant and go for abortion immediately.” (male participant)

There was also, among the men, a tendency to blame foreigners for the problem:

“The problem is, we are all mixed up. There are people from different areas and countries. We don’t know who brought the virus with him - so he infects others and it goes on and on.”

“Even the Chinese have brought this disease. Even the Zimbabweans - our daughters fall in love with Zimbabweans and they have a terrible disease.”

There was also a tendency, on the part of some male and female FGD members, to blame women for the problem, accusing them of being “promiscuous” and not respecting their husbands:

“Girls change partners like they are changing dresses.” (breastfeeding participant)

“The mothers are to be blamed because sometimes they sleep around during pregnancy and pass the virus to the baby.” (male elder)

“Women get [HIV] because they don’t respect their husbands. They never say I should respect my husband and stop going out with young ones.” (male participant)

However, many female FGD members laid the blame on men for the “promiscuity” underlying HIV transmission. They said that men are not trustworthy - *“there is no man who does not cheat” (breastfeeding participant); “he will start going round, going round the whole of Botswana” (pregnant participant); women stay at home, breastfeeding and child rearing, faithful, men wander around.” (in-depth interview)*

One pregnant woman explained in an insightful way, describing her own experience, how one’s awareness of the risks of HIV infection is clouded by a loving relationship:

“I am pregnant now and may be carrying the HIV virus. I have three children. I don’t use condoms. I just meet a man without protection. We should know that these people are just people. It might take a bit of time for us to show [signs of AIDS] and feel like checking ourselves. Because we have regular monogamous relationships, we become so in love and trusting that thinking of the risk of getting infected becomes far-fetched.”

FGD members, male and female, identified alcohol consumption as a contributory factor underlying multiple sexual partnerships and HIV transmission - *“STD risk increases if you drink and get drunk.”(male participant)*

Prevention or Protection

Many FGD members were able to cite the main forms of prevention advocated by the National AIDS Control Programme¹ - abstinence, use of condoms, being faithful to one partner, and getting tested. As an example one male FGD member gave the following description of these prevention methods:

“There are many ways of protecting oneself. You may stick to one partner - both of you have to be tested for the virus and you should trust yourself and your partner. The other way is to use a condom or you can abstain by just staying away from sex.”

Many FGD members, male and female, questioned the validity of the “stick to one partner” prescription, because we “*don’t know what our partner does in dark corners.*” (male participant)

A number of female focus groups were asked if there was any difference in the safe sex practices adopted by men and women. Those who replied suggested that men rely more on the use of a condom for protection whereas women limit themselves to one partner as their protection. But they also recognised that sticking to one partner is no protection if their partner is not faithful.

Both men and women complained that there was little honest communication between sexual partners about their HIV status or how to practice safe sex - as a result they felt they were forced to practice unprotected sex as a risky gamble, totally dependent on their partners’ honesty -

“Partners don’t talk about sex and protection so partners rely on each other to make sure everything goes well.” (male participant)

“When I meet a woman, she cannot tell me if she has HIV so this virus is going to show signs later when it is already too late to prevent it. If girls were honest, maybe we could [prevent AIDS], but really we can’t because they won’t tell.” (male participant)

“Women put their faith and trust in men. Women trust that men are faithful because men refuse to use condoms.” (in-depth interview)

While many male FGD members mentioned condoms as the main form of protection against HIV, they also indicated certain dissatisfaction in using them. Several men cited the myth of condoms having worms - “*This condom, for some of those who have tested it, you pour water into it and leave it, after some time you find worms in it.*” A number of men said that many people don’t know how to use condoms properly and suggested that youth should be educated on how to use them.

¹ The national AIDS Control Programme’s prevention programme advocates the ABCs of prevention-Abstain, Be Faithful or Condomize.

Sources of information about HIV/AIDS

FGD members cited a number of sources of information about HIV/AIDS, including the radio, clinic, kgotla², newspapers, the schools, parents, personal communication, World AIDS Day messages, and Lovers Plus³ field workers. Radio, clinic talks, and personal communication were mentioned the most frequently. AIDS is often described as the “radio disease” because of the extensive information on AIDS disseminated through the radio. One FGD of pregnant women said they were tired of talks over the radio about AIDS because of the negative message that there is no cure. This view was supported by another woman who said that AIDS education should be positive and avoid scaring people - a negative, frightening approach results in resistance to testing.

Many female FGD members cited the clinic talks given by nurses and Family Welfare Educators⁴ as a major source of information. Women come to the clinic for antenatal care or child care and while at the clinic listen to talks on AIDS given by clinic staff. Some men attend these talks, the women said, but they are usually a small minority and tend to be impatient and not very serious at absorbing this information. One breastfeeding woman said - *“Men say AIDS is just a song on the radio. Even at the clinic they don’t concentrate because they say they are bored.”* Several women mentioned passing the information learned at the clinic to other women, their partners, or other family members.

Female FGD members talked about attempts to get their male partners to discuss these ideas. They said that women were the educators and that men were largely unwilling and uninterested in AIDS education. Women always initiated the discussions with partners and often were discouraged by their partners, who *“don’t care”* or *“don’t listen... because [they think] women want to police them.”*(in-depth interview) The female FGD members said that women were more motivated to talk about this issue because of their strong fears about being at risk.

This finding that men have little to do with or interest in the clinic based AIDS education programmes confirms the findings of other research that men are largely alienated from family planning and other reproductive health programmes.[7] The latter programmes cater largely for

² This is a Tswana word with a double meaning - it means the place where meetings are held and it also means the actual meeting –i.e. Kgotla means meeting place or meeting. The kgotla is a traditional meeting place in the village, usually near the chief’s place - it is usually surrounded by a semi-circular fence of poles. A kgotla meeting is chaired by the chief.

³ Lover’s Plus - is the brand name of a type of condom which was developed by Population Services International, in Botswana with USAID funding and later sold in both Botswana and South Africa. Its name and marketing was developed through a social marketing process.

⁴ Family Welfare Educators: This group of health workers was established as a paraprofessional cadre in the early 70s. The original aim was to identify local women who had the respect of the community and who could organise home visits and community education around family planning and other issues. Originally they were selected by the community and were viewed as community workers. While some of that original community based flavour has not disappeared, many have become absorbed into the clinic structure as people based and working at the clinic. As a result their work with women in the community has dwindled. MOH has identified this as a problem and is currently trying to shift back to a community focus.

women and in effect tend to exclude men. Recently the Ministry of Health have adopted a new policy to promote more gender sensitive programming in reproductive health, including broadening the scope of the Maternal Child Health & Family Planning Programme so that it caters for other target groups, including youth and men.

Views about and Treatment of PLWHA

It is important to acknowledge that many families and individuals in Botswana treat PLWHA compassionately and with dignity. However, it was clear that all the groups perceive that there is a lot of stigma associated with HIV and AIDS in their community. While many FGD members were able to cite the radio message of the National AIDS Control Programme (NACP) - *“a friend with AIDS is still a friend”* - and advocate that they *“should be treated the same way as any other person, sharing everything with them”*, they noted that there was a lot of fear towards and stigmatisation of PLWHA and the overwhelming description of how PLWHA are treated was negative in this study. As summed up by a pregnant respondent: *“A person with AIDS is not treated at all well from what I see.”*

The process of stigmatisation, condemnation, and isolation was described by the women’s focus groups. The stigmatisation starts as soon as someone appears to be exhibiting the main symptoms of AIDS, i.e. loss of body weight or excessive diarrhoea. People begin to gossip about the person behind his/her back and to say that s/he has AIDS. They use diarrhoea as a coded way of describing AIDS:

“When you hear of people talking about diarrhoea, they imply HIV.” “They will be coming not with good intentions but just to laugh at the person. They pretend in the face of the people but when they leave the place, they describe how the house is smelling bad and forget that they were pretending that they were sympathising.” (pregnant participant)

“They say bad things about [a person] to the point where she will even be afraid to mingle with other people.” (female elder)

Once a person’s HIV status is known, the stigmatisation and isolation continues, often in a more overt manner. Put simply: *“If someone has AIDS we don’t want to go near them or even greet them.” (male participant)* And explained in more detail: *“they say this person is not supposed to stay with people or share things like the toilet with them...though I have never seen anyone with HIV, some people say it is dangerous if you share food, let me say, utensils with someone like that. When they are still alive they use their own utensils and you use yours.” (male participant)*

The groups hinted at two explanations for this negative treatment of PLWHA: the lack of accurate knowledge on transmission of HIV that leads to fear of contracting HIV from the PLWHA and the type of person the community assumes contracts HIV. People seem to genuinely fear contact with or helping the PLWHA, as the following quotes illustrate:

“Some don’t even touch them. Some think they will pass on the virus to them even by sitting next to them.” (in-depth interview)

*“All they think about is that if they help... they are going to get infected.”
(breastfeeding participant)*

“Community members may help sick person at the start but once they hear person has AIDS they disappear.” (breastfeeding participant)

“Community members may visit but being scared...they will be saying if the family is scared, what can we do ourselves?” (pregnant participant)

“Some people are scared of AIDS people - they treat them like snakes - when a snake bites, even if you remove its teeth, it will continue to bite.” (male participant)

“We think that when a person has HIV it is easy for them to pass it on to us.” (breastfeeding participant)

In addition to fearing contact with PLWHA, a clear theme emerging from the discussions was that the community equates HIV infection with unsanctioned sexual behaviour. They described this view in terms of community attitudes, rather than their own attitudes. They said that community members regard PLWHA as “careless”, “promiscuous”, “sleeping around”, “fooling around”, and “attracted by the money”.

Many of these negative comments were directed at women who, they said, were “loose women - women who go jamming at night” (male participant) or “me nice” (commercial sex workers). A breastfeeding participant explained that “when they talk about women, they say it is because they were careless, promiscuous, sleeping with any man around. Or they say the woman was attracted by money. So that even when she is infected she will continue with those careless behaviours.” Some of the women’s groups also talked about men in similarly negative terms- “they say the man was promiscuous” (breastfeeding participant) and “they think he picks up women here and there,” (breastfeeding participant) but overall these types of comments were made most often in reference to women.

There was a lot of blame and little sympathy for the situation of female PLWHA - they were simply getting what they deserved. As one breastfeeding woman said - “people would say...that is what you get for bitching around.” Another breastfeeding woman went further and explained that “the other thing is we think that person contracted the virus on purpose.” One pregnant woman noted that there was little recognition in the community that you don’t need to be promiscuous to get AIDS - “they don’t know that AIDS can come to you at home.” Women can remain faithful at home but get infected by her partner who brings it home.

It is clear that there is differentiated treatment of men and women in this stigmatisation. In the case of women it is her own behaviour that has got her into trouble, in the man’s case it is a different story, as one pregnant woman noted:

“If you are a woman and you are HIV positive, people just think you got infected because of unprotected sex. If it is a man, they never think too much of sex.”

According to one man, it is always the woman who is blamed as the source of the problem - *“she came with the problem and gave it to the man.”*

This kind of discrimination results in a serious loss of self-esteem. As one pregnant woman described it - *“When you get AIDS you are ridiculed by society, they laugh at you. You are ill treated, you are no longer related to like before.”* This leads in some cases to suicide: as a male elder explained, *“they prefer to die before people despise them.”*

The stigmatisation and isolation was reported to also extend to the children of an HIV positive woman, who are discriminated against not only by other children, but also by parents and sometimes their own relatives. As some FGD members said- *“other children say, ‘Get out of here, your mother has AIDS,” (pregnant participant) and “the child is teased and rejected by other children who will stop playing with it. They will call him names - ‘Look at this one with AIDS.” (male participant) Another explained- “the mothers will not allow their children to play with the child,” (pregnant participant) while a male participant explained that “some are orphaned. If the child loses both parents, it will suffer even more because relatives won’t treat the child with love like their own.”*

The focus groups were also asked their views about pregnant women with HIV. The women noted that these women are also condemned for their situation - they are viewed as women who *“love to have sex.”(pregnant participant)* A breastfeeding and male participant, in discussing how an HIV positive pregnant woman would be treated in her community said that *“they would laugh at her”* and *“they will hate you, nobody will like you, even those you live with will not like you.”* There was also an element of blaming the woman for her condition (being both pregnant and HIV positive), as described by a breastfeeding participant *“they go around saying that—look she is pregnant and yet it is said that we should use condoms. That is why she has the virus, because she does not protect herself.”* HIV positive women are also pitied, on the assumption that the child will have HIV and that they will both die quickly after the birth.

In response to a question about how PLWHA should be treated, men and women’s focus groups had totally different responses. Male FGD members said that PLWHA should be isolated and not allowed to share utensils with other people. The female FGD members preached equal treatment, treating them like a friend or like any other person:

“They are just people so we should not discriminate against them. They are just like us. If they are your neighbours or they ask for assistance from you, you should not despise or be paranoid about them.” (pregnant participant)

Care and support for PLWHA

Discussion on this topic was not as forthcoming as on some of the other topics and required repeated probing in some cases as many participants responded initially with statements like: *“I have never seen anybody who has that disease (AIDS)”(male participant)* and *“where would we have seen a person with HIV?”(breastfeeding participant)*

Women as caregivers

Once discussion was encouraged, the focus groups described a ‘hierarchy’ of who should care for a sick person, whether the cause is HIV/AIDS or something else. The primary caregiver should be, and usually is, a woman. If the patient is a man, the primary caregiver should be the wife, or girlfriend. In the absence of either of these two women, then his mother would be expected to care for him. For women, the husband or partner is expected to initially seek (but not give) the care. The primary caregiver should be her mother and her extended family. In a manner of explaining the gender division in caregiving, both men and women discussed men’s distance from all issues related to health and in specific, care for ill persons.

Men do not generally go to the clinic, or care for ill persons, as these are ‘women’s issues’ as women are the natural caregivers and deal better with illness. As two men explained about women and care-giving roles:

“I can say they are accommodating or it is because they are people who get involved most when people are ill. We men move backwards, even if it is another man who is ill, men do not assist, they (only) come right at the end (death).”

“When a person is ill, women are the caregivers. Let’s say the patient is a man, you will find that because the woman is not like the man, she will give him care. When it comes to bathing the man, she will do it. But, if a woman is ill it is a taboo (for a man to bathe her). Women are the caregivers.”

In the specific case of a person ill because of suspected HIV/AIDS, the general consensus was that a woman would stick around to care for a husband or boyfriend, but that men would likely disappear once they suspected the woman to have HIV/AIDS. Men taking an active role in caring for anyone ill with HIV/AIDS (whether related or not) was seen as a real exception to a widely accepted norm of women as the caregivers for ill persons.

Role of the family in care and support

The role that the family (beyond a spouse, boyfriend/girlfriend, or mother), would take in caring for a patient with HIV/AIDS was debated by the groups. On the one hand were participants who felt that the family would always care for a PLWHA. The reasons for this care were a mixture of familial obligation, the ‘right’ thing to do, and because of love for the person. Familial obligation to care was explained by two breastfeeding women in this way: *“the person is my family so I can’t desert him,”* and *“as far as I know if a relative is sick you are obliged to care for them.”* A breastfeeding participant in another group indicated that familial obligation may possibly be ‘enforced’ by community pressure on families to care for their own as *“when people come to visit the patient they will laugh at the fact that the patient is not properly taken care of. It is better for people to see that you are taking proper care of the patient.”*

Whether the expression of care being given because it is the ‘right’ thing to do is a fully accepted idea in the community was difficult to ascertain from this data. Many of the responses that talked about how PLWHA should be treated were expressed in words that were either a direct quote, or a slight paraphrasing, of the slogans that are part of the national HIV/AIDS awareness and prevention

programme “*a friend with AIDS is still a friend.*” These discussions also included words like ‘supposed to’ and ‘should’ as opposed to more accepting language, as stated by two participants “*they are supposed to continue loving him as they used to love him*” (male participant) and “*at the clinic we are taught that these people should be treated the same way we treat all people.*” (pregnant participant) A quote from a male participant focuses on the loving aspect of care, but also brings together all three reasons suggested by the groups for why families will care for a PLWHA:

“This person if he has AIDS, he is our son, we give him love so that he would know he is one of us. We also take care of him. We try not to hurt him. We give him accommodation and we are not supposed to discriminate against them.”

On the other side of the debate were participants who thought relatives would not give care to an HIV/AIDS patient, or that care would be given unwillingly. As explained by two male participants:

“Today, when relatives hear that someone has got AIDS, some will help but you will find that most of them distance themselves from that person.”

“These days, relatives don’t help each other like they used to. If you get HIV, no one in the family seems to care about you and they want to distance themselves from you.”

In addition to this sense that the extended family can no longer be counted on (relative to the past), three broadly defined reasons emerged in the discussions that may help explain why the larger family unit may be reluctant to care for a family member ill with HIV/AIDS. The first is the perception that persons with AIDS brought the illness on themselves, the second is the fear of contracting HIV from the patient, and the third relates to the burden of care, both emotional and economic, of caring for a patient when death is the expected outcome.

As described in the discussion about attitudes towards and treatment of PLWHA, the groups described ‘others’ in the community as feeling that PLWHA have brought their illness on themselves because HIV is assumed to be contracted through unsanctioned sexual behaviour. This feeling then translates not only into the general stigma and discrimination that PLWHA experience, but also into how individuals feel about caring for HIV/AIDS patients. The discussions hinted that care of HIV/AIDS patients could possibly be withheld, or given minimally or grudgingly, because of the perception that the PLWHA is responsible for their illness through their own ‘immoral’ behaviour. A breastfeeding participant explained it this way:

“I don’t think they [family members] are interested [in care and support] because sometimes the disease attacks a young person after the parents or elders have tried to talk to him/her [about their sexual behaviour], but to no avail.”

The second reason why care of PLWHA is difficult in this community is the fear that the individuals caring for the patient can easily contract HIV themselves. As one male participant explained about an HIV/AIDS patient “*they are always vomiting and those who are caring for them get infected. It is a big problem.*” When asked to explain how this happens he continued “*I mean just the smell*

can infect you, because their intestines are rotten so the smell can affect you, so that is how you can be infected.” That individuals truly fear infection through caring is echoed by a breastfeeding participant *“even when a person knows that the person is family, they don’t help care for him. All they are thinking about is that if they help that person they are also going to get infected.”*

However, while there is a fear of infection through caring, there was also recognition by some participants that measures can be taken to give care safely. One male participant explained that you might only get HIV through caring for a patient if *“you have not been given protective clothing from the clinic...and if you are not informed...for example with education about how you can protect yourself if you are caring for an AIDS patient.”* Others described the role that home-based care groups play in offering care and support and noted that clinics help recruit and give instruction to volunteers:

“It is usually talked about in the clinics during health talks. The nurse just announces that the community has many people who are sick so those people who can volunteer to help carers should come forth to the clinic so that they can be assisted with how to handle terminally ill patients and also to see whether they are brave to handle terminally ill patients.” (pregnant participant)

The third explanation for why care might be given sparingly is the burden, both emotional and economic, of caring for an HIV/AIDS patient. The reality that death will probably be the end point once a person is so ill they need extensive care leads to feelings of hopelessness and emotional exhaustion, as well as more harsh, but pragmatic, decisions about expenditure of scarce resources on someone who is thought to be dying. Individuals also recognise and fear the burden they might become if they develop AIDS. As a breastfeeding participant stated *“this disease is bad because you start giving everyone problems.”*

One breastfeeding participant described her own experience with care and the sense of hopelessness when caring for a patient who never gets better, even when a clear AIDS diagnosis was never given:

“In the long run even family members lose hope and feel helpless towards the patient.... We would go seek help at the hospital and talk to the nurses who used to visit the patient once a week and they would tell us to come and collect food for the patient. We ended up losing hope and took the patient to the village where we took care of the patient, but we never knew whether it was AIDS or not.”

Another female participant described the physical difficulties of care, the isolation AIDS patients experience, as well as the lack of support by relatives:

“People dehumanise persons living with AIDS. I was once caring for a sick person at home, the relatives never used to come to help, in the end I just ended up caring for the sick person alone. When this sister of mine was sick and had diarrhoea, I used to go to the clinic to get gloves. It is very difficult when someone has diarrhoea and is always vomiting. As a carer you must protect yourself because you run the risk of getting the virus.” (pregnant participant)

That families and individuals do make decisions about care based on what they assume is going to be the final outcome, death, is captured in the following quotes:

“They (relatives) are supposed to care for him, but it will depend on whether (they think) he (will) recover or die. They just consider the reason for providing care.” (male participant)

“I find that relatives are reluctant. We would say, when the riches disappear we see that relatives have very little interest in this person. They start having many other commitments when this person becomes sick...they usually don’t get involved.” (male participant)

Role of community in care and support

In addition to immediate and extended family, we also sought out information on the role of the community in caring for PLWHA. The wider community was not volunteered as a source of support for the direct care and support of PLWHA. When the moderator asked specifically about whether community members will assist families in caring for an AIDS patient, some of the standard responses were *“that cannot happen,” “only two or three, but I really doubt (even those),” “I don’t think so.”* Not only was there a sense that the community would not help, but there was an expression of a cynical view about the motives of community members who did offer help, especially if it was just through visiting the patient. As explained by two female participants:

“They will be coming not with good intentions, but just to laugh at the person” (pregnant participant)

“Some say that a person may come pretending that they are helping with care for the client and sympathising with the client, but deep down shunning not even to touch the patient. At the same time observing and judging how far the illness has gone and even calculating the funeral time.” (breastfeeding participant)

The general consensus was that the community was not a common source of help, though one breastfeeding woman did explain that *“people are not the same. There will be those who would have an interest while other would not.”* Although their role was only mentioned briefly in the FGD, and often after probing, volunteer home base care groups do exist in Botswana, attesting to the fact individuals (mainly women) do help care for PLWHA who are not direct relatives. While the overall tone of the discussions about care and support for PLWHA in these FGD was about the difficulties and fear of it not being forthcoming, it should be noted that many individuals in these communities do give loving care and support to PLWHA.

A few of the women’s groups discussed caring for HIV positive pregnant women in particular and were of the opinion that they would become seriously ill more quickly and therefore be more of a burden to care for.

“With a pregnant person the problem is they will be bed-ridden (more quickly) by the disease whereas someone who is not pregnant may go about trying to seek help. They won’t

be treated the same because the pregnant one is a more serious patient.” (breastfeeding participant)

“Giving care to a pregnant (AIDS) patient will make one run out of patience.” (breastfeeding participant)

Knowledge and perceptions about Mother-to-Child Transmission

FGD members stated that there were large numbers of babies and small children affected by the HIV virus, but that they had little experience of seeing them. Members gave estimates of the percentage of small children affected by HIV, ranging from 40% to 60%. One reason given for the difficulty in identifying small babies with HIV was the lack of clearly identifiable symptoms and their short life span:

“They look fresh (fat) and they die fresh. So we don’t know whether it was HIV or just another disease. The babies don’t usually struggle like adults. They just cough a little and then pass on, so it is very difficult to know whether it was HIV or not.”(breastfeeding participant)

“At the start they look normal and then just keep getting weak.”(breastfeeding participant)

“They don’t live long - they die before their mothers.”(male participant)

The majority of FGD members understood that HIV could be transmitted from mother to child. While some had a clear understanding of the different times when HIV could be transmitted (i.e. during conception, labour, or breastfeeding), many lacked a clear understanding of the range of different times when HIV could be transmitted. They cited one of the three options, but did not seem to be aware of the other options, for example: *“Breast milk has HIV, so the baby gets HIV through breastfeeding or at birth,” (male participant)* and *“babies get HIV through contact with blood while in the womb.” (male participant)*

One concept which was generally not understood was how HIV was not automatically transferred from HIV infected mother to child, given the assumption that mother and child share the same blood and food supply:

“The placenta joins the baby with the mother, so there is no way the baby may not get the virus.” (pregnant participant)

“The baby feeds on the birth supply from the mother during pregnancy - if the mother’s blood has the HIV virus, it means that the baby will get it.” (pregnant participant)

There were also a number of misconceptions about the mother-to-child transmission process. One pregnant woman gave the following explanation:

“Say you are giving birth and the baby has a cut somewhere on the head. When the baby passes it may get scratched by a mother’s bones, so if the mother has those illnesses.... the baby may get infected.”

One man (a traditional doctor) said that HIV is transmitted from the mother to the child if “*there are no proper rituals for the baby...performed at the right time.*”

There was very little awareness of how to prevent HIV transmission from mother to child on the part of male and female focus groups, although women seemed to have more knowledge. Two male focus groups and one female focus group said that nothing could be done to prevent HIV transmission to the child, if the mother was infected. They argued that it was an automatic process (of HIV transmission from mother to child), which could not be prevented.

“The womb is attached to the mother and this womb is blood which comes from the mother to feed the baby. That is why we don’t believe that this so-called treatment [AZT] would be able to separate the baby from the mother’s womb. How will this treatment avoid contact with the infected mother to keep the baby free from infection?” (male participant)

“Don’t know how to prevent [HIV] because if there is the virus, there is no cure, so abstinence is the best. If you are already pregnant and infected, we don’t know how it can be prevented.” (pregnant participant)

Women’s focus groups were asked if a woman could be infected with the HIV virus while pregnant. All agreed that pregnant women were at risk of getting HIV, except if they used a condom. Some said that it was more difficult for them to find other sexual partners when they were pregnant because “*they feel like an old woman,*” but it didn’t stop their partners from having unprotected sex and infecting them. They suggested that women should practice safe sex to protect the unborn child until they give birth.

MTCT Prevention Programme

Knowledge of, and attitudes towards, the MTCT programme

General awareness of the existence of the MTCT programme and how HIV transmission from mother to child is prevented was high among women participants, but low among the male participants (most of whom were already fathers) and both the female and male community elders. Specific knowledge on the various components of the MTCT prevention programme, and the requirements of participation, was weaker, even among women.

Most of the women’s groups had good general knowledge of the programme and explained that they had learned from the nurses at the clinics about “*the medicine that protects the baby in the mother’s womb to prevent HIV transmission or the virus passing to the baby.*” (*breastfeeding participant*) Most women knew that the programme existed at the clinic and had some, though not detailed, knowledge about the specific components and requirements for participation. Being able to get a drug to protect the baby from HIV was the most common response in reply to a question about what

the MTCT prevention programme included. Recognition of the need to have an HIV test was also discussed in most of the women's groups. Infant feeding counselling and the provision of formula feed were less frequently mentioned.

"At the clinic they ask you whether you have an interest in checking for the HIV virus so that if you have the virus in your blood they can give you AZT to prevent transmission from mother to child." (breastfeeding participant)

Men and community elders were much less informed than women about the MTCT programme. Some had heard about the programme on the radio but did not really understand what it was all about and had not bothered to find out more because *'those are women's things.'* Others knew of the existence of AZT and its role in MTCT prevention, but did not know it was available in Botswana *"I understand that there is a drug that can be used to stop HIV transmission, but whether it is being used in Botswana, I do not know."* (male participant) Still others, however, stated that they do not know anything about the programme and some said they had heard something, but didn't really know as the government is still trying to decide which drug to use. Knowledge about the need for an HIV test and infant feeding choices was poor.

In general, community members acknowledged the need to fully explain the programme to people, because *"many people do not understand."* (female elder) When the programme was fully explained to them at the end of the second session of the focus group discussion, men and community elders felt that the programme is good and should be promoted. They felt that even if the woman dies, at least the child lives. Women also felt that the programme was beneficial as it *"saves the child's life – a child is a valuable thing."* (breastfeeding participant) One male participant pointed out that he supported the programme because it was necessary given the level of HIV infection, but he also noted that if HIV infection could be prevented in the first place, then there would be no need for such a programme. *"If we could stop these behaviours [that lead to HIV infection], we can also stop this programme."*

While there was general agreement that saving a child's life was a good thing, there were a few participants who worried about what would happen to the child since the mother was going to die. As one breastfeeding participant explained *"it is a good programme for the baby. But in the process a pregnant woman will be thinking – you know, I am going to die anyway, my baby might live, but if I die what is the point because there will be no mother to raise my baby."* Others, especially men, were concerned about government's efforts at *"curing the baby but not the mother."* They asked: *"why don't we get medication that will cure both the baby and the mother?"*

Upon being asked whether the MTCT programme would encourage women to fall pregnant now that there was a programme to help prevent the child from becoming HIV infected, most community members conceded that although *"it may encourage women who are already HIV positive who see having a child as a way of dealing with the fact that they will die soon leaving no trace,"* (male participant) the programme would not necessarily encourage many women to become pregnant. Even the health care workers stated that *"it is not for Botswana women to carelessly fall pregnant just because MTCT will protect the baby."* The general feeling was that women would maintain the

same pregnancy rates as before MTCT and that most women, if they knew they were HIV positive, would not choose to become pregnant.

An explanation for why an HIV positive women should not, and would not choose to, become pregnant, if she knew she was HIV positive, is the belief expressed by women, men and community elders that pregnancy would hasten the onset of AIDS and death.

“It is not okay! It should only happen by mistake because we hear that if you fall pregnant when you are HIV positive all the diseases which have been hiding within you will now attack you, so it is safe not to fall pregnant if you know you are positive.” (male elder)

“It’s not right because if one has the virus and gets pregnant, the virus will increase in her body. The person may end up dying before her time.” (male participant)

“It is not good because if you give birth when you have the AIDS virus you shorten your life span, but if you were not pregnant you could live longer. Pregnancy destroys the white blood cells further.” (breastfeeding participant)

“I don’t think it is necessary for one to fall pregnant, she shouldn’t, to prevent dying because if she falls pregnant she will die quicker.” (breastfeeding participant)

Voluntary HIV counselling and testing (VCT)

VCT is an essential component of any programme aimed at reducing MTCT of HIV. In order to identify HIV positive pregnant women for enrolment in MTCT prevention programmes, women must first agree to participate in VCT. While VCT offered within an ANC setting differs somewhat from testing in free-standing VCT centres⁵, understanding what women and communities think about VCT in general can give a sense of how women will respond to the offer of testing during an ANC visit. Especially in settings where women, their partners and the community are largely unaware that HIV testing is being offered as part of routine ANC visits. This information can help programmes design appropriate communication and service provision strategies that will facilitate women’s participation in the first step, HIV testing, of the MTCT prevention programme. The questions asked specifically about testing in an ANC setting, and in particular about decision-making on the part of the woman in this context, did not generate much discussion, as the groups did not differentiate greatly between pregnant women and others in relation to VCT.

The focus group discussion (FGD) participants had collectively very little personal experience with VCT⁶. Only one woman volunteered that she had been tested as part of the MTCT prevention

⁵ They differ for the following reasons: women who test positive in the ANC setting are being offered services (AZT and infant formula) to help prevent HIV infection in their child, stand alone VCT centres generally do not offer these services. Individuals who choose to attend stand-alone VCT centres are highly self-selected in the sense that they have made an active decision to seek out testing, while women who are offered VCT as part of a routine ANC visit have not necessarily made an active decision to seek out VCT, and in some cases may be confronted with the idea for the first time during ANC.

⁶ At the time of this study there was only one HIV testing and counselling centre in Botswana, outside of hospital settings-The Botswana Red Cross Society AIDS Information and Voluntary Testing Centre in Gaborone. The idea of

programme and none knew of a person who had voluntarily gone for an HIV test while still healthy. It was clear from the discussions that no culture of VCT existed in this community and that it was unusual to have confirmed knowledge of HIV infection. The participants agreed that one could only suspect infection, but not be sure of it, with the repeated appearance of the signs and symptoms that have become associated with HIV/AIDS.

As several participants in different FGD commented, and as explained by a breastfeeding participant in response to a question about how one can know about HIV status *“we don’t know because we have not been for testing.”* Another breastfeeding woman explained that it would be rare to know that a healthy person was infected with HIV because individuals would never disclose an HIV positive test result. *“I will be afraid to go for a test and if I do test positive I will keep my status a secret. This is why we do not know that so and so has AIDS.”* It should be noted that at the time of the study, outside of hospital settings, individuals seeking out VCT in the Gaborone area had access to only one small VCT centre run by the Red Cross. The reality that access to VCT outside of a hospital setting has been limited is reflected in this comment by a male participant: *“You have to go to the hospitals and see big doctors to tell you whether you have it [HIV] or not.”*

Before discussing issues of disclosure of positive HIV status, the discussions focussed first on the reasons why people might seek out VCT. A varied list of reasons was given for seeking VCT including: wanting to know if frequent illness and symptoms were indeed AIDS, pregnancy, wanting to know HIV status in order to take better care of oneself, own or partner’s sexual behaviour, and the illness or death of a sex partner. The most frequently mentioned reason for seeking a voluntary HIV test was illness. As pointed out by a male and pregnant participant respectively: *“...many people go for a test when they are sick. But when they are fit, like me, it is rare for a person to check,”* and *“they are usually forced by experiencing frequent ailments and thinking a lot about them.”*

Not only is the main reason for seeking VCT visible illness, but there seems to be an underlying assumption that only those who are at great risk of being HIV positive go for VCT. The idea that only those who are at risk would get tested is exemplified in the statement by a breastfeeding participant that *“if you are faithful you don’t need to go for a test.”* In addition, a male participant explained that *“...many people assume that since you have gone for the test you are HIV positive.”*

Benefits of VCT

While all groups were vocal on why VCT is problematic, the sparse discussion on the benefits of VCT was in striking contrast. After a period of silence and continued probing by the moderator in one FGD, a breastfeeding participant volunteered simply that *“it is a good thing”* and that VCT was beneficial because it could help people change their lifestyles and live longer. Another breastfeeding participant said that *“It is important because if my attitude was bad and I find that I have the HIV virus, I would have to change so that I live longer,”* while a male participant

getting tested has not been a major message of HIV/AIDS prevention messages in Botswana to date outside of MTCT prevention. However, there is recently started initiative by BOTUSA (a collaboration between the Botswana Government and The Centers for Disease Control (CDC), USA) to open more VCT centres across the country. They have now opened up two new centres, one in Gaborone and one in Francistown.

explained “*it saves you a lot of worries to go for the test.*” Only two respondents, one male and one female, mentioned the benefits and possibility of receiving a negative test result. The breastfeeding woman exclaimed: “*when you test negative you will be so happy!*” while the male participant stated that testing could be beneficial because a negative test result would motivate an individual to “*prevent and protect yourself from getting it [HIV].*”

Disadvantages of VCT

The reasons for not seeking an HIV test were all related to the perceived consequences of a positive HIV test result and fell broadly into three categories: fear of how the individual would manage emotionally, fear of how a partner would react, and fear related to the stigma and discrimination from the wider family and community. The difficulty and fear that people feel in relation to VCT is summed up by the simple, but clear FGD participant statements: “*it is not easy just to get up and think about an AIDS test,*”(pregnant participant) and “*people are afraid of going for the test.*”(male participant) “*It is scary.*”(breastfeeding participant)

Fear of individual reaction

The FGDs thought that potential negative individual reactions to a positive HIV test could range from general depression to suicide. In their opinion, general depression would occur after VCT because knowledge of a positive HIV status equalled giving up hope since HIV infection means death is coming soon. Statements by male participants that exemplified this sentiment were: “*you have an HIV virus, a killing disease,*” and “*once you have been told, you have to give up hope. We hear that there is no cure for AIDS.*” Discussion about the reaction to a positive test result described the self and society-imposed isolation that would occur after a positive HIV test result. As explained in one of the male focus groups:

“Shock is not something that you can easily accept. It becomes difficult so much so that one starts being lonely...one will start having endless stress, people will start noticing that this person has no quality life.”

“You find that the person you knew before changes and is always in deep thought usually keeping to themselves.”

Others explained that if one was HIV positive it was much better not to know this because of the likelihood that the knowledge would lead to a faster onset of AIDS. One male participant explained this phenomena as follows: “*It may affect that person so much that she will have problems and then the manifestation of the illness will develop much faster.*” Suicide was repeatedly mentioned as a potential reaction to positive HIV results, as described by a male participant “*some people will say that since they are dying, there is no point in prolonging it and so they commit suicide.*” A male community elder offered this explanation for why suicide was a possible response “*it is fear of discrimination that these people commit suicide. They prefer to die before people despise them.*”

Some of the female groups discussed in particular how pregnant women might respond to a positive HIV test result. While the general consensus was that the news would be especially difficult for a pregnant woman because of the implications for her unborn child, the range of possible reactions was from the less specific “*the woman would get scared,*” (breastfeeding participant) and “*she will*

not take it well” (breastfeeding participant) to the more serious “I would kill myself because it would mean that I am also going to infect the baby.” (breastfeeding participant)

In addition, the groups feared a vindictive response to a positive HIV test result. While this came up in relation to both men and women, it was discussed most frequently in reference to men. The FGD groups thought that HIV positive persons would purposefully spread HIV by searching out multiple sex partners. As described by two breastfeeding participants *“he would make it worse by injecting everyone, because he does not want to die alone,”* and *“I think other women may say they don’t want to die alone, so they have sex with men to spread the virus.”*

Fear of partner reaction

Both male and female FGD participants expressed fear about a negative reaction from a partner to news of VCT and positive test results. However, both genders discussed this almost exclusively in the context of how a male partner would react to a woman who disclosed an HIV positive status, or chose to be tested without consulting her partner. While women may get angry with their partner, the general opinion was that she was more likely to stick with her partner, and care for him once he became ill. As explained by one breastfeeding participant *“women would scold the man a few times and then give in because we women are very soft.”*

On the other hand, abandonment of a woman by the male partner was assumed to be a potentially common response and was cited as a reason for not disclosing an HIV positive test result. One breastfeeding participant described how a woman would respond to a positive result *“she would keep quiet because the man might leave when he finds out I am HIV positive. So I would keep quiet so that he helps me with the baby.”* Another breastfeeding woman explained that *“when you tell your man he is going to run away.”* A male community leader explained that if a woman told a husband or partner that she was HIV positive *“the relationship will instantly cease to exist.”* Other potential reactions from a male partner, as expressed by breastfeeding participants ranged from *“he will be so angry!”* to more violent physical responses *“you would even be afraid to tell your partner because he might feel that you infected him with the virus and kill you.”*

An undercurrent in the discussions about VCT in general, and more especially about disclosure of results and women getting tested during ANC, was that the first person to be tested would be blamed for bringing HIV into the relationship. A breastfeeding participant explained that *“If you are positive he will say it is your problem because you are the one who tested.”* A pregnant woman summed it up as *“he will think you brought the disease.”*

Male FGD participants talked about men reacting to women who disclosed that they had either participated in VCT, or were HIV positive, by accusing the woman of being unfaithful, accusing her of questioning his sexual behaviour or blaming her for bringing HIV into the relationship.

“He will be thinking that how can his wife betray him like that and to tell him that she has got HIV. Some men ask in an accusing manner with the questions such as: if you are testing, does that mean I have HIV or do the other men you sleep with have it?”

“Some men would think they are indirectly being accused of cheating. They can also think that she has HIV and that is why she is going for the test.”

“This would anger the man because then he would start asking himself a lot of questions. He might even think that that means his wife is positive and so maybe he is too.”

Women’s FGD participants on the other hand discussed men’s reactions more in terms of men using the fact that the woman was the first to be tested as a way to absolve themselves of responsibility for possibly having infected the woman and for future care of the woman. This discussion was closely linked to women’s fears that men would abandon them if they were HIV positive, using blame and accusation as a reason or excuse to leave.

“He will say that since you went for testing alone, the disease is yours alone.”
(breastfeeding participant)

“He will claim that he is not responsible for infecting you with the virus because you kept it a secret.” *(breastfeeding participant)*

“He would say that she has brought him the disease.” *(breastfeeding participant)*

Others, however, offered more balanced views of how men might react, either to a partner who tells them they are HIV positive, or a woman who accepts testing without first consulting her partner. As one male respondent put it:

“There will be some men who will become upset and assume that since she went for the test that means that she is HIV positive and this is because she has possibly been sleeping around. If he is an understanding husband, though, he can praise his wife for her bravery in going for the test and so this would encourage him to go too, since his pride is at stake.”

Fear of family and community reaction

Beyond concerns about how a partner would react to news of a positive HIV test, all FGDs discussed at length concerns about how an HIV positive person would be treated by the wider family and community. The fear of stigma and discrimination by the community came across as a major deterrent to VCT and of disclosure of either intent to seek an HIV test, or a positive test result. As described in the section on views about and treatment of PLWHA, it is clear that there is a strong perception among participants of significant stigmatisation of PLWHA in this community. That fear of how they might be treated is a deterrent to testing and disclosure of positive results came across clearly in the context of a discussion about who to disclose results to. As explained by two male participants:

“People are afraid to tell others because of the looks they fear that they will get. People are not open about such things.”

“People are afraid to go for the test because there is no courage you can be given to dispel your fear of the test and for example if you have the HIV virus, you can’t even tell your

neighbour about it because in Botswana people, as I think we all know, are not open about such issues.”

Disclosure of HIV test results

The real fear of how you might be treated by the community if HIV positive is reflected in the small number of people that the group could envision disclosing a positive test to. Only mothers came up on a repeatedly consistent basis as the one person to turn to with the news of a positive HIV status. While some participants said they would tell their partners, other participants, especially women, said they would not for fear the partner would leave. Not being able to tell anyone was also a common response to the question. As one male respondent explained *“if a person comes from testing and it is positive, they will probably find it difficult to tell anyone.”*

Not being able to disclose positive results, even to family members, appeared to arise from a distrust of anyone’s capability to keep positive HIV status confidential and the subsequent stigma and discrimination that would follow disclosure. As a breastfeeding participant explained *“it is annoying because you are going to tell your aunt or grandmother only to find out the next day that everyone knows.”* While one or two participants thought that some friends might be trusted, others thought that it would be unlikely that friends would keep status confidential. As explained by a breastfeeding participant *“if I tell a friend, the friend will tell all other people.”*

Both women and men also mentioned concern that partners may not keep HIV status confidential:

“Sometime you tell your man and he would go and tell his family, who would go around telling people that you infected their child with the HIV virus, even though it is him who brought the disease.” (breastfeeding participant)

“The important thing is that her body is still there and she can be angry with you. She may tell everybody that the HIV virus she is carrying means you also have it.” (male participant)

Concerns about health workers keeping results confidential was also raised *“that’s how it starts, gossiping is done by service providers, or people at the lab, who check the blood and give out results.” (pregnant participant)* The one exception to this general lack of trust in people being able to keep confidentiality about HIV status was parents. As explained by a male participant *“your parents will keep your secret, they won’t disclose your status.”*

While the focus group participants thought that disclosure would be difficult and not that common, both men and women voiced the opinion that not only should partners inform each other before going for an HIV test, but that HIV positive individuals should definitely share their results. They felt that partners and spouses had a right to know, because of the risk of sexual transmission, and that parents should be informed since they would probably be the primary care-givers once the person becomes ill. However, the men were much more vocal and adamant about this issue and almost exclusively in the context of women informing men, rather than the other way around. As two men explained *“she should tell her partner, she cannot just go ahead without letting me know,”* and in response to a question on under what circumstances would a woman make a decision to be tested alone *“ [that is] not possible because a woman is strong through a man.”* Women echoed

this sentiment, though not with as much passion *“I think she should tell her partner,”* (breastfeeding participant) and this because *“he would not be pleased”* (pregnant participant) if he was not consulted first.

While the consensus was that women should consult their partners before accepting a test (and should most certainly share the results), there were two minority voices on this issue. A male participant thought it would be acceptable for a woman to seek testing on her own, though under qualified circumstances: *“even if she is your wife, when you are away and she is not feeling okay she can consult doctors and get tested to establish what could be the problem. She has that right, she can tell you when you come back.”* However, this statement did not garner support from the rest of the men in the FGD. A lone pregnant participant stated that *“I don’t think it is important to tell or discuss it with him, it is simple. It is really up to you. Even if I am married I can just leave my husband and go for a test.”*

Suggestions on how to make VCT more accessible

The discussion on VCT ended with an open question on what could be done to encourage VCT and make it easier for women and men to get tested. The suggestions given reflect some of the issues identified in the general discussion. The first suggestion was to provide education and information, not only about the specifics of VCT and what benefits it offers *“they should be informed of the advantages of testing”* (breastfeeding participant), but on HIV/AIDS in general. The groups made statements in reference to all the topics discussed indicating that they thought if the community was better informed they would be more likely to support VCT in general, as well as within the context of MTCT. There were also opinions on the type of education that would be useful: *“education should not be frightening...the way communities are educated scares people and they refrain from testing.”*(pregnant participant)

Others thought that education about VCT needed to emphasise the positive aspects, especially that knowledge of positive HIV status could prolong life: *“we should make them aware that they could grow to be old even though they are HIV positive, because they would live positively after finding out that they are HIV positive.”*(breastfeeding participant) In addition to education, groups specified that both individuals and communities need to be encouraged to participate in VCT. This encouragement would come not only through intensified education campaigns as explained by a male participant *“I think door-to-door education through educators and counsellors can work,”* but also through specific encouragement by medical professionals *“doctors should encourage people to go for the test.”* (breastfeeding participant)

This need for education and information was also linked to treatment of PLWHA, which in turn discourages participation in VCT. One breastfeeding participant explained that the way to make VCT easier was that *“there should be no discrimination at home.”* Several groups talked about the fear people have of PLWHA stemming from their belief that the PLWHA can easily infect them with HIV through casual contact *“they are scared that the person with AIDS may infect them,”* (male participant) or through care *“all they are thinking about is that if they help that person they are also going to get infected.”* (breastfeeding participant)

Another suggestion brought up by the groups was to treat HIV/AIDS more like other diseases. As explained by a pregnant participant *“there is too much secrecy. It is not regarded as other illnesses. When it first came, people were secretive. People were not really encouraged to accept their status, like the way cancer patients accept their status although they become skin and bones, or TB patients. It would not have been a big deal.”* The groups imply that the manner in which HIV/AIDS is dealt with as a secret creates and perpetuates the negative treatment of PLWHA, which in turn discourages individuals from participating in VCT.

Linked to this idea was the suggestion that role models who are open about being positive, and the role VCT has played in improving their lives and keeping them healthy, would be helpful. A breastfeeding participant described an HIV positive woman who was talking openly about her status at the clinic in this way: *“That woman is very important because she explains to people what she does to keep healthy.”* Others explained that if more people were tested openly, it would make it easier to participate in VCT *“seeing someone else going for the HIV test is very encouraging.”* (male participant)

In addition to the call for more education, the issues of the quality of the counselling and availability of support systems were also brought up. In the discussions of the impact of VCT and positive test results, it was recognised that how a person coped with VCT was influenced by the counselling they received. As described by a pregnant participant, how one copes *“really depends on what type of counselling you received before the test.”*

Drug treatment

AZT has been available in Bontleng, as part of the MTCT prevention programme at the Bontleng health centre, since April of 1999. Given that AZT had been available for MTCT prevention in this community for only seven months at the start of the study, we included not only specific questions about AZT, but more general questions about the ease and confidentiality of taking drugs, specifically the antenatal supplements given at ANC clinics during pregnancy.

Most men and elders knew that there was something at the clinic to help prevent MTCT prevention, but fewer knew or were certain that it involved a drug. *“Now, I have heard on the radio that there is a medicine or rather the doctors do something to pregnant women so that the virus cannot be transmitted from mother to child.”* (male elder) On the other hand, most of the women in the Botswana study knew about AZT, and could name it. There was, however, ambiguous knowledge about AZT, how it is administered and how it works. Most women knew that it is given as a tablet, though several thought it was an injection. Two women knew that treatment begins at eight months. Viagra and 4IP were two incorrect names for AZT that came up in men’s groups.

When asked how AZT works, the responses from the women’s groups were general, making it difficult to assess how well women understand the effects of AZT, and that it is not 100% effective in MTCT prevention. For example, one woman said, *“It prevents the virus from passing from mother to her unborn baby.”* (breastfeeding participant)

However, some women did use the terms "reduce" and "decrease," perhaps suggesting they understand the probability of transmission would be diminished. Others, however, put the two types

of terms together, making it unclear: *“It reduces the virus – the child will be born without the virus.”* (breastfeeding participant)

In addition to this, there was some confusion about the effects of AZT on the woman. On the one hand there seemed to be a clear understanding that the treatment was not going to benefit the mother directly *“when we are given talks at the clinic we are taught that it does not mean when a person is HIV positive they will be cured, but they say have found some medicine that will protect babies in the mother’s womb...”*(breastfeeding participant) and some questioning and anger over this fact *“When you are eight months pregnant you are injected to protect the baby, not you.”* (breastfeeding participant)

However, there were a few statements that implied a different perception, or perhaps a hope that the mother would benefit directly in some way. In response to a question to the women’s groups on how they thought men are responding to the MTCT prevention programme, a breastfeeding woman said: *“The men who seem to know about the programme say, ‘Yeah, it is okay. My wife, if they give you the injection for prevention of transmission from mother to child [because] it means that even you yourself will be cured’.”*

In addition, two groups of women believed that once a woman stopped taking the AZT she would become ill, perhaps even die: *“she starts to lose weight and now shows clearly that she has the virus. She becomes actively ill, or even dies.”* (breastfeeding participants) This belief seems to stem from the knowledge that AZT works by ‘decreasing’ the virus in the body and because *“it also makes you strong,”* (pregnant participant) implying that when one stops, *“it means the HIV will get worse because when you stop the AZT it means what will be making it less [is now gone].”* (pregnant participant)

The women’s groups also discussed issues that have implications for compliance related to side effects and whether the drugs can be taken confidentially. Side effects ranged from *“it make them overeat,”* (breastfeeding participant) to *“some put them aside because they make them vomit.”* (breastfeeding participant) Another breastfeeding woman said that *“Some may just take the tablets home and decide not to take them, thinking the tablets have a virus.”* Only one woman thought that she might forget to take the tablets.

The ease with which women can take AZT without others in the household noticing was debated with slightly more women thinking it would be problematic. One woman thought that women would not even take the drugs home for fear of others noticing.

Some women thought that husbands and partners would notice, but that others would not. *“I think the man, yes, can notice. But the relatives, I don’t think so.”* (pregnant participant) Men would notice because of their proximity *“Your man would notice [taking AZT] because you stay with him in the house,”* and as one pregnant woman explained because *“even the supplement tablets that pregnant women bring home, the men usually ask us what they are for.”* Another pregnant woman even said that *“I bring the tablets home he will ask what they do, one by one saying those brown ones, what do they do.”*

However, others thought that it wouldn't be an issue, as illustrated by one breastfeeding woman "*I don't think even the man will notice because men don't take too much notice of anything. He would just assume that you have to take them because you are pregnant.*"

Learning from communities what they know and think about treatment with tablets during pregnancy is directly relevant to MTCT prevention programmes. The difficulties women perceive in taking drugs without others noticing, especially partners, highlights again the influence men have on women's MTCT prevention decisions and the need to fully engage them in MTCT prevention. On the other hand, if AZT can be given in such a way that it seems to be just another routine prenatal drug, then women might not face any questions about it. Lastly, there needs to be on-going monitoring of what the community knows and understands about AZT to inform education and communication messages and respond to incorrect assumptions about how the drug works and what it is doing.

Infant feeding

Given the risk of HIV transmission from an infected mother to her child during breastfeeding, the MTCT prevention programme in Botswana is providing free infant formula to all HIV positive women who enrol in the programme. Understanding the meaning of breastfeeding to women and their communities, the pressures women face to breastfeed, and who is involved in infant feeding decisions is important to designing communication and programme strategies that allow HIV positive women to make a choice between breastfeeding and alternative feeding for their children.

Breastfeeding is nearly universal in Botswana, and lasts on average 19 months (15 months urban and 20 months rural).[8] The Mother and Child Health (MCH) programme in Botswana has been promoting breastfeeding for over three decades as a major child health message. There is even a government policy which enables employed women to take an extra hour of each day at lunchtime to breastfeed, for up to a year after the birth of a child. The change in message about the clear health benefits of breastfeeding for the child (i.e. that breastfeeding can be a conduit for HIV transmission) has been very jarring to everyone's consciousness.

All groups agreed that breastfeeding is the expected and normal behaviour, in addition to being considered tradition. As a male participant explained "*it is tradition, every Motswana woman should breastfeed.*" Not only is it tradition, but "*it [breastfeeding] means she is a real woman.*" (*breastfeeding participant*) That breastfeeding is the norm for not only traditional, but health, as well as practical and economic reasons is well articulated in the views expressed by all groups interviewed. They stated that breast milk has nutrients that not only make the baby strong, but that breast milk protects the baby from diseases. There was also recognition of the dangers and difficulties of bottle feeding relative to breastfeeding, as well as the cost involved and the risk of not having the resources to buy adequate supplies of formula.

"From creation, breast milk is measured, it is never too cold or too hot for the baby. There are no such inconveniences as washing the bottle and the like. Even our grandparents have always disapproved of the bottle because they say bottle milk can go bad and it is not good for the baby, breast milk is best." (*female elder*)

“We have all been breastfed. We are told breast milk has nutrients and it is very clean. The bottles are not properly washed and a baby who is breastfed is stronger than the one who is bottle-fed. Breastfeeding is very necessary.” (male participant)

Reinforcing the breastfeeding norm is also the perception, heard more from male than female groups, that non-breast fed babies are weaker and more prone to illness than breastfed ones.

“A child who is breastfed will be strong because he gets nutrients from the mother. With the bottle-fed child there are no nutrients in the bottle.” (male participant)

“I think when the babies are small [young] the difference is obvious. The breastfed baby is not much prone to illness.” (male participant)

The strength of the norm supporting breastfeeding, as well as the extent of the pressure on women to do so, is reflected in the comments made by all of the groups about how women who don't breastfeed are perceived. Women who don't breastfeed are suspected to be bad mothers who don't love their children and are more concerned about their own needs (appearance and sexual) than the health of the baby. A breastfeeding participant explained that people think a non-breastfeeding woman *“does not care and love the baby.”* One male participant suggested that women who don't breastfeed are more concerned about their appearance than the health of their child. *“The community may think that this mother is full of herself...it may be that they don't want their breasts to sag.”* The most frequent and agreed upon perception of non breastfeeding women, as put by a breastfeeding participant is *“she does not breastfeed so that she can fool around [have sex].”*

This perception is linked to a traditional belief in Botswana that the infant will be harmed if a woman has sex with a man who is not the father of the baby while she is breastfeeding.

“In our culture breastfeeding means to prevent the mother from sleeping around during breastfeeding, if they sleep around they will affect the baby.” (male elder)

“If she doesn't [breastfeed] then people wonder what the problem is. They would wonder whether she has had contacts with a man and is now afraid to breastfeed.” (breastfeeding participant)

The strength of this belief that the baby may be harmed, and that this will keep women faithful to the father of the child, is brought out in this quote from a breastfeeding woman that suggests how breastfeeding is important to a couple's relationship because it assures her partner that she is faithful *“my man knows that I am breastfeeding and there is no way I can have sex with another man apart from him.”*

Despite the strong breastfeeding norm, and negative views about women who don't breastfeed, the groups stated that the community recognises some legitimate reasons for women not to breastfeed. These included breast diseases (cancer, lumps), problems with the breasts, insufficient milk, baby

refuses breast, women have to go back to work, pregnancy⁷ and HIV infection. However, the groups noted that while there are acceptable reasons for not breastfeeding, a woman would need to explain her reasons not only to her spouse, parents and in-laws, but also to other relatives and her community, as *“they would ask questions about why she is not breastfeeding.”* (male participant) If she does not explain, then they will suspect HIV or sex as the reasons. Male focus group participants were more insistent about this point than women *“If I am the father of the baby and the mother is not breastfeeding, the first thing is to question her...she cannot bottle feed for no apparent reason.”*

This need to explain widely a decision not to breastfeed, and the suspicion that HIV infection might be the reason for not breastfeeding, puts HIV positive women who are making decisions about infant feeding in a difficult position. Not breastfeeding appears to be becoming more closely associated with positive HIV status and participation in the MTCT prevention programme, making formula feeding almost the equivalent of a public declaration of positive HIV status.

“We know the failure to breastfeed is associated with the virus. If you have the virus you are not supposed to breastfeed.” (male participant)

“They also think that if she is not breastfeeding she must be in the government MTCT programme. Therefore, she must be HIV positive. That is what people are afraid of so people just say let me breastfeed him so that people may not think I am infected.” (male elder)

The difficult position HIV positive women find themselves in with regards to infant feeding decisions because of the knowledge that HIV can be transmitted through breastfeeding, yet living in a community where breastfeeding is almost universal and a strongly supported norm is summed up simply by a male participant. *“Breastfeeding is a common practice. It is therefore difficult on a woman who is HIV infected.”*

Not surprisingly, given the strong views about the value of breastfeeding and the need for women to explain themselves if they do not breastfeed, the groups expressed the opinion that several people would need to be consulted before a woman could decide to bottle feed. In addition there was some degree of ranking, in order of importance, of who should be consulted. The first person is the child’s father, since he is often the one who *“buys the formula.”* (male participant) The next in importance is the woman’s own mother, who takes care of the woman during her months (2-3) of confinement (*botsetsi*) when she is concerned with making sure the nursing mother adheres to all the cultural rules surrounding this period. The maternal grandmother is also concerned because *“she is the one who is going to look after the baby when she [the mother] is not in.”* (breastfeeding participant) Lastly are the in-laws.

That in many cases it will be difficult for a woman to make a decision to not breastfeed on her own is reflected in the response to a question on how the above mentioned people would react if a

⁷ Pregnancy as a legitimate reason stems from the belief that breast milk from a pregnant mother is harmful to the child and would stunt its growth and development.

woman chooses to only bottle feed. The general opinion was that fathers would be the most insistent and demand an explanation. One male participant said he would take the woman to the hospital for testing so that they would know *“if she has breast problems or another disease”* such as HIV infection. In addition, the fathers would seek the support of the mother-in-law *“if the woman resists”* or *“tells me that the child is hers (and therefore it is her decision).”* The men felt that the woman had to consult the husband, otherwise he would suspect her of unfaithfulness *“she has to inform the husband to say I am not well so I will not be able to breastfeed because if she does not consult you may think she has seen other men or she wants to misbehave.”* However, there was recognition by both men and women that if the father was not married to the mother, his right to be consulted diminished and that of the maternal grandmother increased.

The woman’s own mother would also want to know why the woman is not breastfeeding as they are considered responsible for the child’s nutritional welfare. That the maternal grandmother is an important player in infant feeding decisions is reiterated by this quote from a male participant *“I think that the feeding of the baby is of concern to the older people. The child’s grandmother is the one who is in charge.”* In addition to these immediate family, other relatives and neighbours would also wonder whether the woman has AIDS or problems with her breasts or whether her breast milk is not suitable for her child.

While the overall consensus was that women should (and will) consult the fathers, their mothers and probably the in-laws about a decision not to breast feed, a few women felt that they could make this decision on their own. This was based on the assertion that the children are theirs (women’s) and thus they have the right to decide how they were going to feed them.

The underlying concern about infant feeding in the discussions was the child’s health. In several groups, while members noted that breastfeeding was best they expressed concerns about the transmission of HIV to the baby through breast milk. Some even felt that bottle-feeding was now a better option because *“there is prevention for the child to get HIV even if the mother gets infected in the process.”* (male participant) Another male participant summed up this underlying concern for the child’s health as:

“What the community is keen on is the fitness of the baby. If the child is bottle-fed and they look thin people say bottle-fed babies are sickly. But if it is a breastfed child who is thin people will say the mother does not have enough milk. They would even suggest that the mother could supplement with a bottle so that the child could be fit. So that whether mothers feed with breast or bottle does not matter. What matters is that the child is fit.”

Discussion and Conclusions

Community context is very important for MTCT Prevention Programmes

Participation in the current MTCT prevention programme forces pregnant women to think and decide about three complex, sensitive issues, which are influenced and determined, to varying degrees, by partners, family and community: HIV testing, drug treatment during pregnancy, and alternative infant feeding. The choices pregnant women make about each of these aspects of MTCT prevention have potentially far reaching implications for their own emotional and physical health, the well-being of their children, their relationship to the father of the child, broader familial relationships, and how they will be viewed and treated by their communities.

Pregnant women do not face the decisions presented by MTCT prevention programmes in a social and economic vacuum, but in the context of their lives. Understanding their lives, and hearing what they and their significant others (husbands, partners, family members and communities) have to say about these decisions and the context within which they are made, is critical to designing and implementing effective programmes that offer women a chance for voluntary participation.

The results of this study show the importance of partners and the larger community in women's lives, and in particular with respect to their decisions related to participation in the specific components of the MTCT prevention programme. It is clear from the results of these studies that in order to succeed, MTCT prevention programmes need to make efforts to develop broadly based community support. These programmes need to reach out beyond women attending ANC clinics to the significant others in women's lives with information, education, services and support.

Men and other community members influence women's decisions about participation in MTCT prevention programmes

It is clear from this data that husbands and partners have an important and direct influence on women's decisions to be tested for HIV, as well as some influence on treatment and infant feeding decisions. This influence is most apparent in the discussions surrounding women's decision-making with regards to VCT where all the groups, but men especially, felt that women should not make this decision without first consulting their primary partner. The consequences of doing so could be severe, but in the least would cause distress to the relationship. Men implied that women who chose to get tested without consultation did so because they were unfaithful and therefore were responsible for the HIV infection, if the result was positive. Women expressed fear that a partner would react negatively to a discussion of testing, let alone disclosure of having a test without consultation, or a positive test result.

A finding that emerged from the FGD with direct ramifications for MTCT prevention is the perception in this community that the first person to be tested will be blamed for bringing the infection into the relationship. If VCT is not widely available in the community, and is predominantly available through ANC clinics, women are the ones who will be getting tested, and consequently be blamed for the HIV infection. MTCT prevention programmes need to be aware of

this issue, particularly in a general societal climate that has a tendency to blame women as responsible for the spread of HIV.

In addition to the influence men have on women's decisions about HIV testing, they also have an impact on women's decisions about AZT treatment and infant feeding. Women discussed the possible difficulties of taking AZT without a partner's knowledge, and that the decision to formula feed rather than breastfeed would certainly be questioned by her partner. The groups felt that the father had to be consulted about a decision not to breastfeed, and that there had to be a good reason to explain the need for formula feeding. Unless the woman is going to lie about her reasons, the decision to formula feed forces a disclosure of her positive HIV status to her partner.

In addition to her partner, a woman will have to explain not breastfeeding to a wide circle of people including her parents, in-laws, other relatives and neighbours. Because breastfeeding is so widely practised and the pressure to do so high, women need to justify alternative infant feeding. Again, unless the woman is going to lie, this forces her to publicly disclose her HIV status to a wide group of people. Disclosure of positive HIV status is problematic because of the community context of HIV/AIDS that women live in.

The community context of HIV/AIDS, in particular stigma and discrimination against PLWHA, influences women's decisions about participation in MTCT prevention programmes

This study has shown the importance of the community context of HIV/AIDS to pregnant women's decisions about MTCT prevention. While the primary focus of MTCT prevention programmes is to reduce the vertical transmission of HIV from mother to child, because the overall context of HIV/AIDS in the community has an important influence on women's ability to participate, these programmes need to pay attention to other aspects of the HIV/AIDS situation in these communities.

For example, many of the fears that were expressed in these discussions as barriers to VCT are related to the perceived stigma, isolation and discrimination that PLWHA experience in the community. The stigma, discrimination and isolation faced by PLWHA, as described by participants, is widespread and frightening, acting as a deterrent to persons considering getting tested for HIV. Women making decisions about participation in MTCT prevention programmes, which requires VCT, will be influenced by the community climate of stigma and isolation of PLWHA.

Another community context factor that affects decisions to participate in VCT is the fear expressed that confirmation of positive HIV status might lead to families and communities giving care and support less readily, or even withdrawing it. Potential sources of support and care are an important factor for anyone deciding whether to get an HIV test and how people perceive PLWHA are cared for will have an impact on that decision. Many factors may contribute to this situation including the perceived blame of PLWHA as responsible for their own illness, as well as the harsh economic realities of making decisions about expending limited resources for care of a patient with little hope of getting better. MTCT prevention programmes need to recognise that care and support available for women who test positive, beyond the length of pregnancy and delivery, has an influence on pregnant women's decision to participate in MTCT prevention programmes.

The fear that others will find out about a positive test result if one participates in VCT may be related to the expectation discussed in the focus groups that confidentiality of these results is unlikely. Confidentiality may be problematic either because of fears that health workers will disclose the results, or because the community is so close knit that it would be difficult to keep a positive test result secret. In addition, receiving free infant formula from the clinic was perceived as a clear indication of a woman's positive HIV status. The discussions illustrate how participation in MTCT prevention programmes can potentially force a woman to publicly disclose a positive HIV status, an act which is perceived to have potentially devastating results and few positive benefits.

Listening to communities provides important information for the design of MTCT prevention communication and service delivery strategies

The value of listening to communities is illustrated by these results and the understanding it brings to the importance of the key role men and other significant others, as well as the community context of HIV/AIDS play in women's participation in MTCT prevention programmes. These data also demonstrate the importance of learning about what communities know and understand about the basics of HIV/AIDS transmission and prevention and MTCT of HIV, as well as where they get this information. Dialogue with men, elders and women revealed that the community lacks a clear understanding of HIV transmission and prevention, and knows little about MTCT prevention. This lack of knowledge feeds directly into fears of contracting HIV from casual contact with infected persons, which in turn fuels the stigma and social isolation felt by those assumed to be ill with AIDS and fears of caring for PLWHA. Pregnant women facing a decision to get tested are influenced by the negative community attention experienced by individuals suspected of having HIV/AIDS, which is related to what people know about HIV transmission.

We also learned that women were better informed than men were about HIV/AIDS and MTCT. In discussions about information sources, it became clear that this gender differential in knowledge occurs because the main source of detailed knowledge on HIV/AIDS and MTCT is health workers at the health centre. Women attending well child and antenatal clinics receive health information, while men and elders rarely access the health facilities and are consequently less informed. Yet, men and elders play a large role in women's lives and influence decisions like HIV testing and infant feeding. The participants recognised this gap in who has access to information of this nature, and the distance that men have from all issues of health care and caring for ill persons. Men and elders indicated that they are receptive to learning, but feel like they are currently excluded because of where the information is shared. Women, on the other hand, had doubts about whether men really want to learn.

This study also provides information on general, as well as specific, knowledge about the actual MTCT programme being implemented at government clinics. Again, women are better informed than men and elders about the general MTCT prevention programme. Specific knowledge about the three main components was not high, even among women. In addition, participants were sceptical that an MTCT prevention programme could really work because of a lack of knowledge about basic anatomy, physiology and pregnancy. Participants expressed the belief that mother and baby would always have the same HIV status as not only is a baby made from the mother and father, but is fed in-utero by the mother and shares her blood. It is clear that the community, and even women, are unclear about many issues related to the MTCT prevention programme, including perceptions about

MTCT of HIV, the effects of AZT and infant feeding options, that need to be addressed by ongoing communication and education strategies.

Given the influence of men and elders on women's participation in MTCT prevention programmes, this knowledge of their lack of information on HIV/AIDS in general, and MTCT prevention in particular, is key to designing communication, education and mobilisation strategies that work to create a supportive environment, which allows women to take full advantage of the benefits the MTCT prevention programme has to offer.

Focus group discussions: both a research and community education tool

In the process of conducting the focus group discussions, it became clear that for many of the participants this was the first occasion for them to seriously engage with HIV/AIDS and MTCT prevention issues in a meaningful way. This suggests that they have been outside the HIV/AIDS debate and have been given no opportunity to become full participants, but instead are passive recipients of HIV/AIDS education which has tended to rely more on messages, one-way communication, and generalised slogans than a process of participatory, learner-centred discussion. This type of communication process that does not allow for information and questions to go in both directions, gives people no opportunity to digest and assimilate the message, let alone discuss with others how these messages might be applied in their own day-to-day behaviour. For example, negotiating condom use with a husband is not a simple, straightforward process like making oral rehydration solution. It is a very complex process and one which women have little control over. Simply giving women the message without creating the space for them to absorb, ask questions and discuss implications and how they might go about doing this, does not prepare them to deal adequately with this process.

The focus group discussion format not only serves as a research tool and a mechanism for giving information, but also offers the opportunity, and creates a space, which allows community members to talk about these difficult issues openly and in ways that help them deal with their full implications for their own behaviour.

Recommendations

MTCT programmes present complex challenges and opportunities. They have the potential to save the lives of many children and, more generally, to break barriers about HIV in communities, leading to overall positive outcomes for HIV prevention and care programmes. They also can range from being ineffective in that women do not utilise the components of the programme, to bringing rejection, stigma and hardship on women, families and children.

The challenge to MTCT programmes is to lay the groundwork for broad community support. In most communities, women do not make large decisions such as whether or not to seek MTCT services alone, and often they do not have major influence over them. They are integral parts of nuclear and extended family systems that have defined roles and expectations for them, and decisions are made by others within this context. In particular, many women are dependent on partners for economic support, and the partners have much to say about decisions related to pregnancy, breastfeeding and certainly HIV testing. Programmes that are going to be successful are those that are designed in a way that takes these factors into account.

The first step is listening to what the community has to say not only about the specifics of MTCT prevention, but about the context within which women make decisions about MTCT prevention. This type of data can contribute to the utilisation and effectiveness of MTCT prevention programmes by providing valuable insights for the design of communication strategies, as well as the design and provision of the services. The following recommendations emerge from the data gathered in this study.

MTCT Prevention Education Strategies

It is recommended that MTCT Prevention Education strategies:

- *Educate the community about the basics of the anatomy and physiology of pregnancy so they can better understand how MTCT occurs.*

Current misconceptions about pregnancy and HIV transmission are a barrier to participation in MTCT programmes because there are those who doubt that it is possible that an HIV negative baby could be born to an HIV positive mother. Removing misconceptions about pregnancy and HIV transmission during pregnancy can help facilitate the participation of the community in the MTCT programme by promoting an understanding of how it is possible to prevent the transmission of HIV from a positive mother to her infant.

- *Use strategies that reach men and elders in the community with information and opportunities for discussions about HIV, especially MTCT.*

Many men and elders are not currently being reached with this information. They are key decisions makers and have influence in the family and in the community about issues such as counselling and

testing and infant feeding. It is critical to help men learn about MTCT in order to engage them as partners in preventing MTCT of HIV. Reaching men requires that educational sessions, materials and messages are available beyond the walls of antenatal clinics. One possible clinic based site is the primary or outpatient clinic waiting room where health talks could include information about MTCT of HIV. Community outreach is also a strategy to reach men.

- *Prepare providers so that they understand well the link between HIV and breastfeeding, and the risks associated with other infant feeding options and can competently and compassionately counsel women about them.*

Recent research findings and recommendations regarding breastfeeding by HIV positive mothers are complex and confusing. It is important to give health providers good information and the opportunity to clarify values, attitudes and questions. Providers' understanding and attitudes about infant feeding affect their ability to assist mothers in making informed choices. Above all, HIV positive mothers need emotional support from providers for whatever decision they make. It is also important that there be understanding in the community that the programme does not attempt to coerce women to make a given choice, but rather aims to assist women in that choice.

- *Increase correct knowledge about HIV transmission and safe ways to care for AIDS patients to reduce the fear and isolation of PLWHA.*

Education about HIV/AIDS and how to care for AIDS patients is critical because misconceptions about how one can get infected (casual contact, caring for someone with HIV, debris in the air) increases the fear of contracting HIV from PLWHA and leads directly to their physical and social isolation. Individuals then fear testing, and a positive result, in large part because they think their families and communities will respond negatively.

- *Use education strategies that are participatory and create opportunity and space for open discussion and feedback about HIV/AIDS and MTCT. Focus group discussion serves as both a research and education tool.*

In the process of conducting the FGD for this study, it became clear that for many of the participants, this was their first opportunity to seriously discuss these issues in an open manner. Because of the complexities of MTCT of HIV and the difficult decisions that participation in the MTCT prevention programme requires, if HIV/AIDS and MTCT prevention are to be successful, programmes should use an education process that is participatory and allows for learner-centred discussion. Focus group discussions are an example of these and have the advantage that they can be used as both a research tool to learn how to design communication strategies, as well as a tool for carrying out education that is participatory and creates a space that is relatively 'safe' for discussion of these difficult issues.

Counselling and Testing Services

The recommendations for counselling and testing services are that:

- *Where possible, offer counselling and testing services outside of antenatal clinics that include individual, couple and family counselling services.*

While MTCT prevention programmes are encouraging couples to be tested together, the location of testing in ANC clinics makes it more difficult for men to test anonymously as men do not generally attend ANC clinics. The importance of involving men in VCT is highlighted by the fear expressed in both countries that the first person to be tested will be blamed for bringing the infection into a relationship. If VCT is located only in ANC clinics, men will be less likely to participate and the women who decide to get tested without their partners and are HIV positive are more likely to be blamed for the infection. If VCT is more widely available in the community, making it easier for men to get tested, this will facilitate women being able to get tested for HIV within ANC.

- *Ensure that community members can receive counselling and testing from health workers who are not known to them.*

Many health providers experience role conflict when they serve their own community. This becomes evident especially when they are required to perform functions such as giving bad news or maintaining confidentiality. Providers' difficulty in sharing HIV and AIDS diagnoses with patients as well as violations of confidentiality about test results within the community were frequently mentioned by FGD participants as barriers to participation in VCT. Programmes could find a way to successfully motivate and train community members who are also health providers to give sensitive, competent counselling, education and support in MTCT programmes. Alternatively, programmes could find providers who are not connected closely to the community that they serve to provide the VCT component of MTCT prevention services.

- *Promote the benefits of VCT widely to create a 'culture' of testing and make it more common and acceptable in the community.*

It was clear from the discussions that VCT is not widely accepted, or available, in these communities. If women are to be supported and facilitated to participate in MTCT prevention programmes that require VCT, these programmes need to work on encouraging VCT for the whole community so that participation in VCT is common and acceptable.

Community Support

It is recommended that community support for MTCT be encouraged and that communities:

- *Address and reduce stigma and discrimination against PLWHA, making it psychologically safer for women to participate in VCT.*

Women faced with a decision about VCT will be influenced by how they perceive their families and community will treat them if it becomes known that they participated in VCT, and especially if they are HIV positive. MTCT prevention programmes need to recognise the influence that general community attitudes towards PLWHA have on women's ability to participate in these programmes and work towards improving community support and acceptance of VCT and PLWHA.

- *Increase the willingness of families to provide adequate care to PLWHA by providing sources of help for them to care for a relative with AIDS.*

Family attitudes about caring for PLWHA are influenced by both the hopelessness felt about the inevitability of death and the heavy burden of care. Families' knowledge that HIV is the cause of illness is perceived to decrease their investment in the provision of care. This attitude undermines confidence by PLWHA that they will be adequately cared for when they become ill, increasing resistance to knowing and having others know that one is HIV positive. Providing support to families caring for PLWHA might alleviate part of this dilemma for families and PLWHA.

- *Create mechanisms to receive on-going feedback from the community to monitor how they are understanding communications messages and how they are perceiving the components of the MTCT prevention programme to ensure that problems with and misconceptions about the programme are dealt with quickly.*

In addition to using community input in the design of programmes, it is valuable to continue to periodically engage community members as well as programme participants in discussions once the programme is set up. Reactions to the way VCT is organised, for example, might result in improvements in the counselling approach used or could reinforce the success of what is in place.

In conclusion, the information gleaned from focus group discussions and interviews is rich and the lessons are many. The communities that participated are replete with opinions, beliefs and traditions about the many variables that influence mother to child transmission of HIV and its prevention. With active listening it is possible to gain insights into how to design and deliver interventions that are utilised and more effective in saving thousands of infant lives in the developing world. In the process of preventing MTCT, there are added benefits to communities such as increasing knowledge about HIV/AIDS and MTCT, decreasing stigma and discrimination against PLWHA, making VCT more accessible, and increasing care and support for PLWHA. However, the goal of protecting infants, with all the added community benefits, can only be fully realised if communities understand and support women when they try to prevent the transmission of HIV to their infants.

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