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Prevention of Mother-to-Child Transmission (PMTCT) in South Africa: Analysis of Calls to the National AIDS Helpline

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HIV-positive women can transmit HIV to infants during pregnancy, childbirth or breastfeeding. It is estimated that 90% of HIV infections amongst children occur as a result of vertical transmission. Interventions for prevention of mother-to-child transmission (PMTCT) include voluntary testing to learn one's HIV status, antiretroviral treatment to prevent HIV transmission, specific delivery practices, and safe infant feeding. In South Africa, the antiretroviral drug Nevirapine has been available to pregnant women and their newborn infants through the public sector since 2002. The challenges involved in implementing a nationwide PMTCT programme – including training health care workers and raising awareness about PMTCT interventions – are considerable. This report draws upon findings from focus group sessions with counsellors at the South African National AIDS Helpline to highlight the informational needs about PMTCT reflected in calls to the Helpline. The research findings point to some awareness of the risks of MTCT and the availability of Nevirapine to prevent transmission, but continuing information needs about many aspects of PMTCT. On the basis of these findings, the paper makes recommendations for enhancing PMTCT-related communications.

Strategies to respond to the global HIV epidemic include preventing new infections and providing care and support to infected individuals. Among prevention efforts, reducing HIV transmission from mothers to children is seen as a high priority. In 2002, 800,000 children were estimated to be newly infected with HIV and 610,000 were estimated to have died (UNAIDS/WHO 2002). Over 90% of the new infections were estimated to be as a result of mother-to-child transmission (UNICEF 2002b).

It is estimated that 3.2 million children under the age of 15 were living with HIV in 2002 (UNAIDS/WHO 2002). Ninety percent of HIV-positive children live in sub-Saharan Africa (UNICEF 2002b), where the epidemic is undermining child survival rates and may lead to a doubling of child mortality rates in some countries by 2010 (WHO 2002).

Prevention of mother-to-child transmission (PMTCT) was identified as one of five priority areas for response at the United Nations Special Session on HIV/AIDS in 2001. Heads of state committed their governments to reducing the proportion of infected infants 20% by 2005 and 50% by 2010 (WHO 2002). A three-pronged approach is advocated for reducing transmission: primary prevention of HIV infection among young women; prevention of unintended pregnancies among HIV-positive women; and prevention of vertical transmission from HIV-positive women to their infants (UNICEF 2002b).

HIV-positive women can infect their infants during pregnancy, childbirth, or breastfeeding. Without preventative interventions, 15-45% of infants born to HIV-positive mothers are likely to contract HIV. The risk of transmission depends, in part, on whether the child is breastfed and for what duration (WHO 2002; UNICEF 2002a).

Key PMTCT interventions include access to VCT to learn one's HIV status, ARV treatment to prevent HIV transmission, safe delivery practices (including Caesarean section), and counselling and provision of safe infant feeding. In developed countries, where such

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practices have become a standard part of antenatal care, MTCT rates have been reduced to less than 2% (UN 2001; WHO 2002).

HIV testing of pregnant women

VCT is the entry point for PMTCT programmes: pregnant women cannot take steps to prevent HIV transmission if they do not know their own status. Rates of VCT uptake in antenatal settings vary within and between countries. Barriers to uptake include fear of learning one's status; fear of disclosing a possible positive status to husbands/partners; fear of stigma or discrimination; sense of fatalism about the usefulness of knowing one's status; and the perception of being at low risk for HIV (Maman *et al* 2001; Pool *et al* 2001; Campbell & Bernhardt 2003).

In many countries, antenatal HIV screening is available on an 'opt-in' basis as part of antenatal care, meaning that women are offered the option of an HIV test and must give informed consent for the test to be done. As the epidemic has spread, in an effort to increase VCT, some experts have called for HIV screening to be offered to pregnant women on an 'opt-out' basis, meaning that an HIV test would be routine unless a woman actively refused to be tested (De Cock *et al* 2003).

'Opt-out' HIV testing for pregnant women has been adopted as policy in some countries. In 1999 the US Centers for Disease Control revised earlier recommendations for HIV screening of pregnant women to endorse HIV testing as a routine part of antenatal care. While preserving a woman's right to refuse testing, the CDC recommends simplifying testing processes and making the consent process more flexible to remove barriers to testing (CDC 2001). The introduction of 'opt-out' testing regimes in parts of Canada, the United States and the United Kingdom have led to an uptake in testing (Jayaraman *et al* 2003; De Cock *et al* 2003; Simpson *et al* 1999). In October 2003, the government of Botswana announced that 'opt-out' HIV testing would be introduced at all government clinics, including antenatal clinics, beginning in 2004 (IRIN 2003).

Antiretroviral treatment to prevent HIV transmission

In 1994 a clinical trial in the United States demonstrated that a three-part, long course treatment regimen using the antiretroviral drug Zidovudine was effective in preventing the vertical transmission of HIV (Mofenson 2003). Subsequent studies have found that short-course regimens, such as multiple-dose Zidovudine/Lamivudine, and single-dose Nevirapine regimens, are equally effective and safe for PMTCT (Mofenson 2003; Moodley *et al* 2003).

For many years ARV treatment was prohibitively expensive for widespread use in most developing countries. However as the costs have fallen and treatment regimens have been simplified, ARV treatment has become a more realistic option in resource-poor settings (WHO 2002). The World Health Organization (2004) recommends that:

- HIV-positive women who need ARV treatment for their own health should take it during pregnancy as it will improve the mother's health and reduce the risk of HIV transmission to the infant;
- HIV-positive pregnant women who do not yet need ARV treatment for their own health should be offered ARV prophylaxis to prevent transmission to their child; and
- The selection of ARV regimen should be done at the national level, taking into account issues of efficacy, safety, drug resistance, feasibility and acceptability within the given context.

Breastfeeding

HIV transmission can occur as long as a mother continues to breastfeed her child. The longer the child is breastfed, the greater the risk of HIV transmission (WHO 2002). Risk of transmission may also be higher for infants of newly infected mothers, whose initial viral load is high (WHO 2003).

The issue of HIV and infant feeding is complex. In involves weighing up the potential risk of HIV infection against risks of other illnesses and malnutrition. The relative risks to breastfeeding or not breastfeeding in terms of MTCT also differ depending on the local context, including factors such as the availability of clean water, access to affordable formula, and the cultural acceptability of breastfeeding.

The benefits of breastfeeding are well-documented. They include complete nutrition for infants during the first months of life, protection against certain illnesses and infections, and birth spacing (UNICEF 2002a). The general WHO recommendation is that infants should be breastfed exclusively for the first six months of life for optimal growth, development and health. Analysis has shown that children who are not breastfed are at a heightened risk for malnutrition and life-threatening disease during the first year of life, when compared to children who receive at least some breastfeeding (WHO 2003).

In light of the risks of HIV transmission, WHO recommends that, in those settings where replacement feeding is 'acceptable, feasible, affordable, sustainable, and safe,' HIV-positive mothers should avoid breastfeeding altogether. However, in contexts where women cannot afford formula, or where the water supply is not safe, WHO recommends that infants be exclusively breastfed for the first months of life and that breastfeeding be discontinued as soon as is feasible (WHO 2003). HIV-positive women should be counselled about the risks and benefits of various feeding options, taking into account local conditions (UNICEF 2003a).

Other precautions that can be taken to minimise transmission when breastfeeding include preventing and treating breast problems, preventing new HIV infections while breastfeeding, and treating sores or thrush in the infant's mouth as early as possible (UNICEF 2002a).

Challenges to PMTCT

A number of economic, social and political barriers exist to the uptake and expansion of PMTCT services, particularly in developing countries:

- ❑ Limited access to, and acceptability of, VCT in some countries may block the uptake of PMTCT (WHO 2002; Wilfert 2002; Mofenson 2003);
- ❑ The antenatal care infrastructure in some developing countries is not widespread or developed enough to provide an effective platform for delivering PMTCT services (WHO 2002; Mofenson 2003);
- ❑ Limited capacity of some health care systems and their employees to administer PMTCT services (including ARV treatment), to effectively instruct and counsel clients on related issues, and to monitor and ensure quality control;
- ❑ ARVs continue to be prohibitively expensive in some countries;
- ❑ Logistical challenges to the administration of ARV treatment, particularly in places with high proportions of home births and the rapid discharge of new mothers from hospitals (Wilfert 2002); and
- ❑ Stigma, fear of learning one's HIV status, and fear of disclosing one's status may dissuade some pregnant women from accessing PMTCT (ICRW 2002).

Prevention of Mother-to-Child Transmission in South Africa

In 2002 South Africa had an overall HIV prevalence rate of 11.4%, and an antenatal prevalence of 26.5% (Shisana *et al* 2002; DOH 2003). Women in South Africa are at greater risk for HIV infection than men. Among 15-49 year olds, prevalence among women is higher than among men – 17.7% vs 12.8% respectively. HIV prevalence is higher among women than men among several age groupings, including 15-19 year olds (7% vs 4%), 20-24 year olds (17% vs 8%), and 25-29 year olds (32% vs 22%) (Shisana *et al* 2002).

The highest antenatal HIV prevalence (34.5%) was found among women aged 25-29. Extrapolating the survey data to the general population, the Department of Health has estimated that 2.95 million women (aged 15-49) were HIV-positive in 2002 and that 91,271 babies became infected with HIV through mother-to-child transmission (DOH 2003).

Following a politically contested process over use of ARVs for PMTCT through the public health system, the provision of Nevirapine to pregnant women and their newborn infants became part of national PMTCT policy in South Africa in late 2002. The key events in this process included:

- ❑ October 1999 – South African government ordered the Medicines Control Council (MCC) to review the safety and possible toxicity of AZT for PMTCT and prohibited its use in South Africa pending outcome of the review;
- ❑ Early 2000 – MCC declared that the benefits of AZT outweighed the risks for PMTCT. However AZT was not adopted by government for use in PMTCT;
- ❑ 1999-2000 – Evidence of the effectiveness of single-dose Nevirapine in preventing MTCT emerged in international studies, and in the South African Intra-partum Nevirapine Trial (SAINT);
- ❑ July 2000 – government declined an offer of a five-year free supply of Nevirapine from manufacturer Boehringer Ingelheim;
- ❑ August 2000 – government announced that Nevirapine would be tested for two years at 18 pilot sites across the country to determine the operational feasibility of a national PMTCT roll-out. Nevirapine was not to be made available in the public sector outside designated sites, but could be accessed privately via medical aid schemes;
- ❑ April 2001 – Nevirapine was registered for use with MCC for PMTCT;
- ❑ August 2001 – the Treatment Action Campaign (TAC) filed a constitutional claim against the government, asking courts to order that Nevirapine be made available to all pregnant women through the public health sector where medically indicated;
- ❑ December 2001 – the High Court ordered the government to make Nevirapine available to pregnant women who give birth in the public health sector and to their babies, and to plan a comprehensive programme for reducing MTCT nationally. The government appealed the ruling;
- ❑ July 2002 – the Constitutional Court upheld the December 2001 ruling and ordered the government to remove restrictions that prevented Nevirapine from being available for PMTCT at non-pilot sites, to permit and facilitate the use of Nevirapine for PMTCT, to make provision for training health care workers in Nevirapine provision, and to extend testing and counselling facilities as necessary to expedite the use of Nevirapine (Heywood 2003).

The current Department of Health guidelines advise that all pregnant women receive individual counselling on HIV, risks of HIV transmission from mother to child, HIV testing, implications of positive and negative results, and give informed consent for testing. Pregnant women who test HIV-positive are to be given information on PMTCT interventions, including the availability of Nevirapine, instructions on breastfeeding, information about partner testing, and referrals to support services (DOH 2002).

Pregnant women who elect to use Nevirapine are given a Nevirapine tablet, at or after 28 weeks of gestation, in order to self-administer at the onset of labour. Babies of HIV-positive mothers are to receive a single dose of Nevirapine between 24 and 72 hours after delivery. If the Nevirapine was taken by the mother within two hours of labour, the baby is to be given an extra dose of Nevirapine immediately following delivery. At the point of labour, midwives, nurses and doctors are to enquire and ensure that HIV-positive women have taken the Nevirapine tablet as instructed (HST 2002).

Guidelines on the management of HIV-positive pregnant women in public sector health facilities state that elective caesarean section deliveries should be

discussed with pregnant women in three instances: if they have previously delivered via caesarean section, if there is a gross fetopelvic disproportion, or if there are other contra-indications to vaginal delivery (DOH 2000). Otherwise, the guidelines for labour management of HIV-positive women advise that labour and delivery be as natural as possible and avoid the artificial rupture of membranes, episiotomy, invasive monitoring and other procedures. Health care workers are to observe aseptic techniques during labour, including the use of chlorhexidine solutions for vaginal examinations (DOH 2000).

The Department of Health's Directorate of Nutrition endorses five different options for infant feeding by HIV-positive mothers: exclusive breastfeeding for the first six months; heat treating expressed breast milk; exclusive breastfeeding for a shorter period; identifying an HIV-negative wet nurse; and exclusive formula feeding for six months. It is recommended that the choice of feeding be affordable (continuously for six months), feasible, acceptable and sustainable (DOH 2004).

Key Issues Surrounding PMTCT in South Africa

In 2002, Health Systems Trust published interim findings on the national PMTCT pilot programme. The review was intended to highlight operational issues around PMTCT rollout, rather than the effectiveness of interventions in preventing transmission.

The study found that, across the 18 pilot sites, an average of 51% of women agreed to be tested for HIV as part of antenatal care. Between and within provinces, however, the rates varied from 17% to 90% (HST 2002). Three factors that influenced the VCT uptake rate were the availability and accessibility of counselling and testing facilities (infrastructure, availability of trained counsellors); the levels and quality of encouragement and counselling (morale, attitudes and knowledge of counsellors); and community factors (e.g. level of denial and stigma within a community; community mobilisation) (HST 2002).

The report also highlighted challenges to PMTCT roll-out in South Africa, noting that many of them are systemic in nature, rather than related directly to PMTCT as such. These include:

- Human resources need to be improved in terms of both quality and quantity (minimum staffing levels, involvement of lay counsellors, management training, staff development etc.);
- Health system management infrastructure needs to be strengthened at sub-district level in order to integrate PMTCT services into other health programming; and
- Physical infrastructure and lack of privacy at some sites is an obstacle to providing effective counselling and testing.

Other possible challenges to PMTCT cited include:

- Obstacles to accessing PMTCT treatment for some women living in rural areas for whom distance to clinics and transport are problematic;
- Low levels of 'treatment literacy' among pregnant women who must self-administer Nevirapine;
- Challenges to pediatric administration of Nevirapine due to the large number of home births and/or new mothers who are discharged from the hospital within 24 hours of delivery; and
- Poor patient record keeping which undermines the consistency of care (HST 2002).

Findings from the Helpline

Methods

The Communicating AIDS Needs Project (CAN) focuses on individual and community-level responses to HIV/AIDS with a view to understanding communication and resource needs at both levels. The project includes a number of in-depth research activities in selected South African communities, as well as reviews of service provision and communications systems. One component of the project is research and analysis of calls to the national AIDS Helpline.

The AIDS Helpline was established by the South African Department of Health in 1992, in partnership with Life Line. The Helpline service was consolidated into a centralised call centre in Johannesburg in 2000. It is staffed by full-time, trained counsellors and can handle up to 24 incoming calls at a time. Calls are monitored through data capture forms, and also through automated electronic call counting. It provides callers with basic information, counselling, and referral to services in all 11 South African languages and is available 24 hours a day, seven days a week.

The Helpline has received close to seven million calls since May 2001; approximately seven percent of these are 'genuine calls' (currently defined as calls that are more than one minute in duration) where information, referral and counselling is provided. A quantitative analysis of calls to the Helpline between July 2000 and December 2003 found that slightly more than half of genuine calls to the Helpline are for information, but the proportion of counselling calls has been rising over time. Seventy-five percent of callers are under 30. A growing proportion of callers to the Helpline are disclosing their HIV status (Katz 2004).

During the latter half of 2003, a series of focus group discussions was conducted with AIDS Helpline counsellors with a view to assessing call trends and exploring key issues raised by callers. The focus groups were conducted with five to six counsellors at a time and followed standardised protocols. Most counsellors had worked at the AIDS Helpline for two or more years, and were thus able to reflect on a large body of calls to the line. All counsellors had completed relevant counselling training courses and received ongoing supervision, training and debriefing.

The duration of the focus group sessions ranged from one and a half to two hours. Sessions were mostly conducted in English, although allowance was made for the use of other languages as the need arose. Facilitators

prepared discussion guides prior to each session and discussions were tape-recorded, translated where applicable, and transcribed. All transcriptions were checked for accuracy.

Focus group transcripts were read a number of times by a senior researcher to allow for an understanding of the material and to develop a strategy for coding. The data was then coded and categorised electronically by two researchers using HyperRESEARCH OSX 2.6.

Strengths and limitations

The focus group discussions with Helpline counsellors were conducted as a counterpart to a quantitative analysis of data on calls to the Helpline, the results of which have been published separately (Katz 2004). The qualitative research was intended to highlight key issues and gaps in understanding about HIV/AIDS on the basis of actual cases and examples recounted by Helpline counsellors.

It is important to underscore that the findings of this research are not uniformly generalisable. Whilst calls to the AIDS Helpline are made by callers countrywide, callers are primarily individuals inclined towards information seeking. The issues raised in this report emerged from subjective recall of participating counsellors.

The strength of the approach is that it provides a relatively simple means through which to assess concerns and misunderstandings in relation to HIV/AIDS, drawing on national level perspectives. The calls allow for analysis of gaps in understanding, which in turn provide useful reflection on potentials for communication campaigns and local and/or service-level communication support. Novel perspectives also emerge through the capacity to develop an understanding of the experience of HIV/AIDS within individual contexts. It is also acknowledged that the AIDS Helpline service plays a valuable role in reducing misunderstanding, and also providing a mechanism to address individual level concerns and contexts – communication processes that are only matched by face-to-face counselling.

Findings

Analysis of the focus group data revealed that PMTCT-related calls to the Helpline generally fell into six main themes, with related sub-themes:

- ❑ Requests for information
  - Modes of transmission from mother to child
  - Can an HIV-positive woman have a baby?
  - Nevirapine
- ❑ HIV-positive women and child-bearing
  - HIV-positive women wanting children
  - Pressure to have children
  - HIV-positive women having children, but not disclosing status to partners
- ❑ PMTCT and HIV testing
  - Fear of testing
  - Fear of disclosure
  - Is the HIV test mandatory?
- ❑ PMTCT experiences
  - Treatment by health care workers
  - Incorrect administration of Nevirapine
- ❑ Breastfeeding
  - Lack of information
  - Mistrust of advice from health care workers
  - Hiding HIV-positive status
  - Role of husband or male partner
- ❑ HIV status of the child

Requests for information

Modes of HIV transmission from mother to child

Counsellors reported receiving calls from people wanting to understand how HIV transmission occurs between mothers and children. Questions included how to determine the HIV status of an unborn child, whether breast milk can contain HIV, and whether a child can contract HIV from the mother through the placenta or umbilical cord.

> *People will ask about PMTCT… the ways of transmission. How do we [verify] the negative status or the positive status of a child inside the mother's womb? One caller was asking, 'Can a child get infected while still inside her mother's womb?' And they will try to explore how and you have to explain. The basic thing becomes transmission – how does transmission work, how does transmission occur with a pregnant mother, which areas possess dangers?*[1]

> *Another question on PMTCT that people would like to know is if it is true that there is a quantity of HIV in breast milk… They want to know how the child can be protected. The other thing is the question around the placenta and if the baby feeds via the umbilical cord, what passes through? How do we ensure that HIV doesn't pass through?*[2]

Infants can be infected with HIV during pregnancy, delivery and breastfeeding. Calls to the Helpline indicate that some callers have low levels of knowledge about these transmission routes from pregnant women to their children.

Can an HIV-positive woman have a baby?

Counsellors reported receiving calls from HIV-positive women and men needing information about whether an HIV-positive woman can have a child. These calls sometimes come from people who have just learned their status and are trying to understand the implications of a positive status on their ability to have children in the future:

> *Sometimes you find callers who have just found out that they are HIV-positive and… wish to have a family one day. Such callers will ask, 'Is an HIV-positive person able to have a baby?' And you find that underneath that question, they simply want to ask about the process of mother-to-child-*

transmission and prevention. That's where, as a counsellor, you get a chance to unpack the process and educate them so that they will be able at the end of day to make their own informed choices. It's not really confined to people who are already expecting a child and learn that they are HIV-positive.[3]

In other cases, the calls come from HIV-positive women who wish to have a child and need to know if it is possible to do so safely, without infecting the baby:

Mostly they call because they have a problem. It's either they are pregnant, or they are infected [and] they want to have a baby. They want to know if is it possible to have a baby if you are HIV-positive. How do you prevent transmission of infection?[4]

Nevirapine

Counsellors reported receiving calls with requests for information about Nevirapine – how it works, its effectiveness and its safety. Some callers also raised questions about the necessity of taking Nevirapine to prevent vertical transmission.

The other question that arises with [regard to] PMTCT is around Nevirapine – does it work? Does it help to stop the baby from being infected? (Second counsellor interrupts): Is it a hundred percent? (First counsellor continues): Ya, the accuracy.[5]

[Nevirapine's] risky. They understand it's risky, so they want to know how accurate is it. To be sure if you take this there won't be any transmission.[6]

I once had a caller – she said she had a friend. The friend didn't take any Nevirapine and the baby's fine. So now, she thinks she doesn't have to take Nevirapine [either]. But I think they are taking their chances for the baby to be infected. She doesn't have to only look at what happens to the friend – think of yourself as a person that might be able to infect a baby.[7]

Calls to the Helpline suggest that Nevirapine is commonly associated with the prevention of HIV transmission to children, but that there is confusion about what Nevirapine actually is and how it works:

People know that there is a thing that stops the baby from being infected with HIV…. They know that Nevirapine's main purpose is to stop transmission from mother to child. Men will call in and wonder why they are prescribed Nevirapine, why the doctor has prescribed Nevirapine. Because they believe that Nevirapine's main purpose is for PMTCT.... Part of [a man's] regimen is Nevirapine, and he starts asking himself, 'But no, this has something to do with a womb. I don't have a womb.'[8]

Counsellors described receiving some calls from pregnant women with technical questions about the self-administration of Nevirapine tablets:

Last call that I had was a woman who was nine months pregnant. She was given Nevirapine and they told her that she must wait for those pains. When you know that these are labour pains then you take your medicine. The problem was that almost every day she is experiencing pains. She didn't know if these are the pains – labour pains – or just ordinary pains. [She asked] 'So what if I drink this medication and then the next thing it happens that these are not labour pains? What do I need to do? Do I have to go back to the hospital? Will they give me another Nevirapine?' [I said] that she needed to consult with those people who gave her the Nevirapine. [The pregnant women] need to be educated as to if this happens, this is what you need to do – that you need to have a contact person to call if the woman doesn't do it the way she was supposed to. So I referred her back the place where she got it.[9]

Another HIV-positive woman called needing to clarify information she had received at a clinic when she had tried to access Nevirapine during a second pregnancy:

I had a call last night. The lady was pregnant and HIV-positive. And she had a baby. For the first pregnancy they gave her Nevirapine. Then she fell pregnant again, once the baby was still young. She called the Helpline and wanted to know whether… well, she went to the clinic, and they said they can't give her Nevirapine for the second time. You only get Nevirapine once.

Second counsellor: There is a logic in it: resistance. The logic is about resistance – that you can develop drug resistance.

Third counsellor interrupts: She has had it before.

Second counsellor continues: And this is part of the information that people should get before they get Nevirapine. They should know about that. Logically, you've got one chance to have a child if you are HIV-positive. The second one – it's sheer luck. [10]

HIV-positive women and child-bearing

HIV-positive women wanting children

Counsellors described calls from women who know their HIV-positive status and wish to have a child:

There are HIV-positive women who call and tell you, 'I need to have a baby. I don't have a child. I really need to have one. Tell me the dangers of getting pregnant when you are HIV-positive.'[11]

Pressure to have children

While in some cases, the desire to have a child seems to be related to the woman's own needs, in other cases HIV-positive women feel pressured by extended family members to bear children to fulfil traditional expectations of motherhood.

Some have a deep-seated feeling of being a mother, of nursing a child. They miss that. But most of them are doing it to save their marriages. Because if you don't bear a child, especially within our African custom, for the husband, the name of that family will not increase.[12]

There was once a man who was having a problem with a girlfriend. They wanted to have a baby, but they can't [because of their positive status]. But now the younger brother has had a child – that day it was the child's birthday. So it came as a hit to them – no, we cannot have a baby. The family is asking questions, 'How come the younger one is having a baby and it's even his first birthday? What about you? Can't you make babies with your woman? Why did you marry her?' Now they were pressurised to end up disclosing. The lady was afraid, because she felt like afterwards they were not going to like her as they used to.[13]

HIV-positive women having children without disclosing status to partner

Counsellors related several examples of calls from HIV-positive women who knew their HIV status and were having children (or intended to have children), despite the fact that they had not disclosed their status to their husbands or partners. In some cases the women were aware of risks of transmission to the child and were taking precautions to prevent infection:

This woman had a worry about how to disclose to her husband about her status. She discovered [that she was HIV-positive] during pregnancy and her baby now is two months. She used Nevirapine to protect the child and she does not breastfeed at all – she had a lot of information around HIV/AIDS. The other problem is that they don't use condoms, because she doesn't know how to introduce the condom into the whole thing since the husband doesn't have any clue about it. So that was her problem. We discussed everything and she said at the moment she is not ready to disclose, but she wants to tell her husband about her status.[14]

The only problem is that [the caller was] not ready to tell her husband [about her status]. But she can safely hide this tablet [Nevirapine] until such time as she experiences the pains. And in actual fact, she's given it before giving birth, but when you experience labour pains you take this, and with a child it's the same – they get it directly from the hospital. So it's easier for them to decide to take it [without the husband knowing].[15]

Counsellors related other examples, however, where the callers were aware of transmission risks, but did not take precautions to prevent MTCT as this was not sufficiently prioritised.

In most cases when those woman call about disclosure, they don't want to disclose. They say that they will keep getting pregnant so that when they get HIV children they are going to die, and maybe the husband will realize that if my babies are dying every now and then, it means there is something. Or you can find… a young lady – she was getting married or lobola (dowry) was being paid. The mother in-law wants her son to have a child, but it's difficult because they are going to find out that the lady is HIV. And then it's hard for the lady to disclose to her boyfriend or the mother-in-law. She knows the information: if I have sex without using a condom with my husband, I'm going to infect my husband and then there are chances for the baby to be infected. You find that it's hard for them, even if you try to explain. [They say] 'I had to get married' or 'Already the Lobola has been paid – I'm supposed to have a baby.'[16]

A counsellor described one call from a woman who intended to hide her status from her partner and to have children with him, aware that Nevirapine could be used to prevent the children from becoming infected with HIV:

There was a caller who said, 'Look, I'm not going to disclose. I'm in love with this man and that's it.' She was in love with this foreign guy and the guy was doing everything for her. And the woman was also educated and everything, but she felt that, 'Look, I'm not going to disclose, because the man is going to marry me and he expects children.' And I said, 'Okay, so what are your intentions?' 'My intentions are to give him what he wants.' And I said, 'But can you see what you are doing?…What if the guy becomes HIV-positive and the kids?' And she said, 'It doesn't matter. We'll see what life comes with.' And it hurts, because you see at the end of the day that there are a lot of lives that are going to be affected… and we don't have a guarantee that these kids are going to be HIV negative or positive…. I said, 'Do you see what you are doing?' She said, 'No, there is Nevirapine. The kids will survive [apart from] me and the father.'[17]

PMTCT and HIV testing

Fear of testing

Counsellors described calls from women who had been afraid to test for HIV during antenatal care and who gave birth to HIV-positive babies. They suggested that pregnant women need more information about the advantages of testing and PMTCT interventions in terms of protecting their child's health:

Maybe more emphasis should be put on educating pregnant women about HIV, because the problem starts there. Now most of the women don't want to take an HIV test – they don't see the reason why.

The most important thing is to save the baby, and if they are not tested [the babies may] die. There's [not enough] information on the importance of testing: they are focusing on themselves more than on the kid. Now they give birth without being tested and they are not going to be given Nevirapine because they were not tested. Then they find the baby gets sick after birth and there's nothing that can help them… More emphasis should be put there on educating pregnant women [about] the importance of testing. They should look at the advantages to saving the baby.[18]

Fear of disclosure

Women who learn that they are HIV-positive during antenatal care sometimes fear disclosing their status to their husbands, partners and families. Counsellors gave examples of such calls:

> *It happens a lot. A woman will call and say, 'I'm from the doctor and I've done an HIV test. And I learned I am HIV-positive. How am I going to tell my husband that I am HIV-positive?'*[19]

> *There [was a woman] who was afraid of disclosing to her husband, because her friend had told her husband. Now the husband left. And her friend said to her, 'I told my husband that I am positive.' And she's positive and is afraid of disclosing to her husband, fearing that the husband will leave.*[20]

> *It's not a wife, it's a girlfriend. She has a baby and she's HIV-positive. Before the boyfriend knew that she's HIV-positive, he wanted to marry her. After finding out that the lady is HIV-positive and is bearing a child, he decided that he wanted to end the relationship. Because he found out that she's HIV-positive and the baby may be HIV-positive. And their relationship just ended.*[21]

Is an HIV test a mandatory part of antenatal care?

Counsellors described conversations with callers who wanted to know if HIV tests were a mandatory part of antenatal care. Other callers expressed confusion about whether they were tested for HIV or not as part of routine antenatal checks.

> *Most of them want to know if it's a must for them to do an HIV test when they are pregnant. So you can see that they don't want know their status. You tell them, no – it's not a must, because you will be asked at the clinic to give consent. If you don't give consent, there is no test that will be performed on you later. They only treat you for full blood count, syphilis, or something, but excluding HIV.*[22]

> *[There are callers who say] 'I was pregnant and they did not give me a test' and so on and so on. And you have to explain, 'You must give your permission.' 'But they took my blood!' Then you explain, 'No, it was for syphilis…'*[23]

PMCTC experiences

Treatment by health care workers

Counsellors expressed that some callers feel that they are treated poorly by health care workers when seeking antenatal care. This led to situations where pregnant women do not return for follow-up visits or feel unable to ask questions of health care workers.

> *The other thing is because of the negative attitude to pregnant women… it ends up becoming difficult for patients to go back [to the clinic]. It's very difficult.*
>
> *Facilitator: Can you talk more about that? What are they worried about?*
>
> *Because you find that other health care workers, like nurses, will shout…*
>
> *Second counsellor interrupts: They are bickering.*
>
> *Counsellor continues: They shout. They start blaming you. They say, 'If you did not do that, this wouldn't have happened' – all of those things. And it becomes difficult, especially for teenagers, to go back. Because they cannot even ask any questions to them.*[24]

> *I believe it's tradition – there is a tradition we grew up with that health care workers are not good in terms of social relations with patients. And because of that, obviously a person when she gets there already had a fear, a phobia towards you as a health care worker. And she will just take everything that you say without questioning anything. And she will just go and say, I want to talk to the AIDS Helpline guys. Because much of the things you ask yourself, 'But why didn't this person didn't ask this questions there? Because she should have asked these questions there.'*[25]

Incorrect administration of Nevirapine

A counsellor described an example of a woman who did not receive Nevirapine in time while in the labour ward, despite asking the nurses for the tablet:

> *One woman called and said when she felt labour pains, she was admitted to the hospital. But the sisters there told her no, she's still far – she's not yet ready to deliver the child, so they cannot give her the treatment at that time. She was crying that immediately after the sister left, she went into labour and by the time this sister came back with the medication – it was about fifteen minutes or so – she was already in labour, so it was too late. It was difficult to find the real reasons why they should have said that, because in antenatal clinics women have been educated about their labour*

pains. Immediately when you see the symptoms of the labour, you need to take the medication… and preferably the pill must remain with you if you are highly due… So I believe there is still a problem, because there are a lot of women who are calling and they don't feel that they receive good care and treatment in terms of mother to child.[26]

Breastfeeding

Lack of information

Counsellors indicated receiving many calls from new mothers with questions about infant feeding procedures and the risk of HIV transmission via breastmilk. These calls reveal confusion about the changing recommendations and contradictory information on offer about infant feeding. They also suggest that some women are discharged from the hospital following delivery without fully understanding feeding instructions given to them by health care workers.

> *They don't ask the nurses when they tell them the instructions, 'Do not give the baby water when you breastfeed.' And then they ask us, 'Why must I not give the baby some water?' So we had to explain.*[27]

> *The general thing about PMTCT is that people don't know the [details] – especially the feeding issues or the water issue. [This is what] people want to talk about – should I breastfeed or should I not? Some say I should breastfeed for four months, others say I should not at all.*[28]

> *The information around PMTCT never came out clearly – it comes as a result of continuous research over the long run. And people are being told that now you can breastfeed up to a certain period of time without interference, without mixing with any other things–- water, formula, milk, and so forth. And now people are surprised to receive this new information.*[29]

Mistrust of advice from health care workers

Some women call the Helpline to verify information about breastfeeding given to them in hospitals and clinics. Counsellors describe that callers sometimes mistrust the advice and instructions given to them by health care workers.

> *There is a lot of issue around whether mothers should breastfeed the child exclusively for three months and then after that go to another type of feeding. Or whether HIV-positive mothers don't breastfeed at all or do the mixture.*

> *Second counsellor: Especially among mothers there is a lack of trust in health workers. The health workers are explaining to them what to do – [for example] not to breastfeed at all, but they want to confirm from us whether is it OK to breastfeed or what.*[30]

> *I had a caller three weeks ago. The guy is HIV-positive, the wife is HIV-positive. The wife had a child through a caesarean. Then both of them went for counselling since they are both HIV and they were told that they must not breastfeed the child, because the risks are so high for the child to get infected. But they wanted to prove that – is it going to happen? The child started to develop symptoms and then the guy, when he called, was asking, 'How long is the thrush going to last?' And then I was like, 'But when you started calling me you said you and your wife went for counselling and they told you that your wife shouldn't breastfeed your child because the child might not be infected.' They must wait for certain period or, if she breastfeeds the child, she must only breastfeed the child not giving other things because if the child has the virus, the virus will start to be more active. Then he said, 'Yes, they told us, but we were not sure about that.'*[31]

Hiding HIV-positive status

Counsellors described calls from women who had not disclosed their HIV-positive status and were trying to hide their status at home by breastfeeding their infants at least part of the time to avoid suspicion from family members. This practice of mixed feeding increases the risk of HIV transmission to the infant.

> *You find that especially teenagers – even though they know exactly that they are infected – continue breastfeeding their child. They are afraid that if they stop breastfeeding the child their parents will ask, 'Why don't they breastfeed the child?' Therefore it's a very difficult thing, because they don't want to disclose their status – they are not yet ready. So the baby is at jeopardy of getting infected.*[32]

> *[There was another] woman. After giving birth – she tested positive – she was given options of how to feed the baby – either to give only formula, or breast milk. So she would give everything, because she never told the husband that she tested positive. So if she would give, say, the breast milk only, the husband would ask, 'What happened, why not this and this?'*[33]

> *Most mothers have problems when it comes to disclosure… especially when it comes to breastfeeding, because the person didn't disclose at first. So when it comes to breastfeeding, people who are married end up asking them questions – why the mother is not breastfeeding the child, and all that stuff. They end up lying, because the person will end up telling the family two things and too scary things. Someone will come out and say, 'They said at the clinic I've got breast cancer, so I can't breastfeed the child.' By the time the mother is developing the symptoms of HIV and they [the family] are starting to find out that there is something wrong with this woman, then maybe the woman discloses and says,*

'I'm HIV.' Now they are starting to deal with HIV and cancer, because she started by lying.[34]

Role of husband or male partner

Calls to the Helpline reveal the extent to which husbands and male partners play an active role in making decisions about things such as infant feeding. In the following example, the husband resents the fact that health care workers were advising his wife on feeding practices without his involvement:

> *I had an interesting call yesterday. The lady is HIV-positive and she's within the hospital. She gave birth – she was given Nevirapine – and was told by the nurses that she shouldn't breastfeed the baby at all. What did she do? She breastfed the baby within the hospital. And she was angry – why did the nurses say that she couldn't breastfeed? She told her husband, 'The nurses are saying that I shouldn't breastfeed because I'm HIV-positive.' Her husband was also angry: 'Why do these people have to take decisions without me?' … I tried to calm her down and say this is what happens within the hospital, [talked] about mother-to-child-transmission, tried to explain the procedures that happen in the hospital – you cannot do this, you can do this. And she was still insisting that, 'I need to breastfeed my baby. The baby is hungry. The baby needs to eat.' She was given this formula at the hospital. She described that the formula milk is forming the white stuff in the baby's mouth and the baby's lips are cracking and all that. I also tried to explain, 'If you breastfeed the baby and those cracks [are there], you might be able to infect the baby with the virus. But the mere fact that the baby got the syrup and also gave you Nevirapine, you know, they are trying in a way to protect for the baby not to be infected. Now by doing that you may be able to infect the baby with the virus.'*
>
> *Facilitator: So did she understand that there was a risk through the breastfeeding?*
>
> *Ya, she understood. I gave her that, but she was not sure of what the husband is going to say. He knew that she was positive. The [problem] is why can they take positions? That was the thing…. I tried to empower her around issues of women – that she has a decision to make as a mother. Not that your husband must take decisions for you. For the sake of the baby, take decisions for yourself… But the problem is that she didn't talk to her husband. The husband is only angry that they've taken the decision that she should stop breastfeeding.*[35]

HIV status of the child

Counsellors described receiving calls from women who had not been tested for HIV while pregnant and who, following the child's birth, were concerned that the child might be HIV-positive.

In some of these calls, mothers would ask about symptoms in an effort to determine whether the child might be HIV-positive:

> *Facilitator: Do you ever get calls from women who chose not to test when they were pregnant, they've given birth to a child, and now they're worried that the child may be positive?*
>
> *Often… They want to know the symptoms. What are the symptoms if the child is HIV? When to test the child?*
>
> *(Second counsellor): They will tell you, 'The child is not growing normally, it's not playing. What must I do?'*
>
> *(Third counsellor): Sometimes when the child is only two weeks old!*[36]

In other cases, mothers concerned about their child's status want to know how and when they can take their child for an HIV test:

> *A mother would ask, 'When should I take my child for testing?'*
>
> *Facilitator: You mean, how old must the child be?*
>
> *Yes, how old. We have to explain around the issue – that from 18 months you can try and go.*[37]
>
> *A woman will ask whether she should stop breastfeeding. When you go on probing and asking, 'Were you tested?' 'No, I was not, but I suspect the baby might have HIV.' And now it's going to be difficult for the health workers to help that kind of a person, because she was never tested and the baby would wait for a certain time to be tested, to find out if it is HIV-positive or not.*[38]

Counsellors also describe calls from HIV-positive women who worry that their child might be HIV-positive, even though they took precautions during pregnancy and birth to prevent vertical transmission.

> *Others don't believe that Nevirapine really does work, or can work. Take, for instance, a known HIV-positive mother who went through the PMTCT programme. And somewhere down the line, depending on the health status of the child, she will always be opposing this idea that her child is HIV-negative. Even if the child can be proven to be HIV-negative. Even when they are 3 or 4 or 5, she will still oppose this, but only because she is HIV-positive. And looking at the baby, the child's [speech] is not so good, or it's very tired. Then she will always have her doubts around that.*[39]

Discussion

Focus groups discussions with Helpline counsellors helped to identify some of the information gaps that seem to exist in South Africa about mother-to-child transmission of HIV. The main findings of the research

include:

- ❑ There appears to be a lack of understanding about the various modes of HIV transmission between mothers and babies;
- ❑ Although awareness of Nevirapine as the leading PMTCT intervention exists, knowledge about how Nevirapine works and technical aspects of its use (related to self-administration, development of possible drug resistance, etc.) may be limited;
- ❑ HIV-positive people, both men and women, who wish to have children do not always know if this is possible or how it can be done safely;
- ❑ There may be a lack of clarity around the fact that HIV testing in antenatal care settings in South Africa is elective (requiring a woman's consent), rather than routine;
- ❑ There seems to be uncertainty around infant feeding guidelines for HIV-positive women, with callers expressing confusion about seemingly contradictory recommendations; and
- ❑ Testing of infants and children for HIV is an area that appears to be poorly understood by callers.

PMTCT-related calls to the Helpline were clustered into several main areas: requests for information; HIV-positive women and child-bearing; PMTCT and HIV tests; experiences with PMTCT; breastfeeding; and the HIV status of children.

Counsellors described receiving calls from individuals requesting basic information about various aspects of mother-to-child transmission. Questions about the modes of HIV transmission between mothers and children were frequent. This suggests that there is a need for further information on the ways in which HIV can be transmitted vertically. Calls to the Helpline indicate that a key message that needs to be conveyed around MTCT is that transmission can take place during pregnancy, during the process of giving birth, and following birth. It is essential that these various modes of transmission are understood, as HIV infection can occur at any stage. For example, taking precautions such as Nevirapine at the time of delivery will not protect an infant from infection if he/she is later breastfed by an HIV-positive mother.

Counsellors reported receiving calls from HIV-positive women – and some from husbands or partners of HIV-positive women – wanting to know if it is possible for an HIV-positive woman to have a child. Given the advanced stage of the epidemic in South Africa, it is not surprising that this question is being raised with greater frequency. Women who have recently learned that they are HIV-positive may want to understand the implications of their status for their ability to have children in the future. In other cases, there are women who have known their HIV-positive status for some time and who wish to have a child – but don't know how this can be done safely. Helpline counsellors are able to explore a caller's individual context in order to advise them on possible options.

Calls about Nevirapine are also received at the Helpline. Questions range from basic inquiries about how Nevirapine works and its effectiveness in preventing transmission, to technical questions about self-administration of the tablets and whether Nevirapine can be taken during more than one pregnancy. As PMTCT programmes are scaled up across the country and more women have access to them, it is possible that the Helpline will see an increase in calls about Nevirapine.

A second area of calls about PMTCT relates to child-bearing by HIV-positive women. Counsellors reported calls from HIV-positive women who either wanted to become pregnant, or felt pressured to bear children – generally by family members or in-laws. In some cases, the women had not disclosed their HIV-positive status to their husbands, partners and/or families, and were therefore facing dilemmas about the potential risks of HIV transmission. Some callers who had not yet disclosed to their husbands secretly took Nevirapine to prevent vertical transmission; other seemed not to know about the possibility of taking Nevirapine or were deliberately eschewing it. It was apparent, however, in calls related to breastfeeding, that there are significant challenges to 'hiding' one's HIV-positive status while simultaneously trying to minimise risk of transmission to one's child. Some of the scenarios recounted to Helpline counsellors and described in this report underscore both the challenges – and the necessity – of HIV disclosure to partners and families.

A third area of calls relating to PMTCT was about HIV testing as part of antenatal care. Some callers expressed a reluctance to test, while others described a fear of disclosing their positive status to others. There appeared to be confusion about whether HIV testing is a routine part of antenatal care in South Africa (i.e. an 'opt-out' policy), or an elective one ('opt-in'). Counsellors expressed the view that callers generally believe that HIV testing is automatic for pregnant women (it is not – women must give consent for testing). This leads to misunderstandings on the part of some women who assume they have been tested for HIV, when in fact they have not. Such calls suggest that communication campaigns need to address more clearly both the importance of HIV testing when pregnant and the procedures for doing so. Women should know that they must give informed consent to be tested and understand the benefits to learning their status.

Counsellors described receiving some calls from women about their experiences in accessing PMTCT. Although some callers expressed that they had received poor treatment from health care workers, including Nevirapine being administered incorrectly, such experiences cannot be generalised. It is also important to note that counsellors did not recall instances of female callers reporting that they had been unable to access antenatal care or PMTCT programmes. Discussions with counsellors suggest that further investigation into women's experiences with PMTCT is required.

Breastfeeding and HIV was another major theme that emerged from the analysis of calls to the Helpline.

There appears to be considerable confusion about recommended infant feeding practices. Counsellors reported calls from HIV-positive women who needed information about the risk of HIV transmission via breastfeeding, who did not understand the instructions given to them in the hospital, or who mistrusted the advice given to them by health care workers.

As noted earlier, breastfeeding and HIV is a complicated issue and it is not surprising that calls to the Helpline reflect confusion on the part of callers. Decisions about whether or not to breastfeed should be informed by a woman's specific circumstances – and in particular, her access to safe water and suitable formula. Generic recommendations are therefore difficult to make. The Department of Health endorses five different approaches to infant feeding by HIV-positive mothers, including exclusive breastfeeding, two forms of modified breastfeeding (heating expressed milk and shortening the length of exclusive breastfeeding), using a wet nurse, and exclusive formula feeding (DOH 2004).

Studies on breastfeeding practices in South Africa have found low levels of exclusive breastfeeding, attributing this in part to 'mixed feeding' being the socially and culturally accepted mode of infant feeding (Bland *et al* 2002). Calls to the Helpline echo this finding. Some women expressed concern that exclusive breastfeeding would trigger suspicion on the part of husbands or family members and had chosen mixed feeding as a way to conceal that they were HIV-positive. As mixed feeding carries a higher risk of HIV transmission than exclusive breastfeeding, women choosing this approach are putting their infants at heightened risk of infection. Calls related to breastfeeding suggest that there are significant information needs on this subject that should be incorporated into communication campaigns.

A final set of PMTCT-related calls to the Helpline relates to the HIV status of infants and children. Counsellors reported calls from women who were, for various reasons, concerned that their child could be HIV-positive and who wanted to know when the child could be tested or how to 'diagnose' HIV according to symptoms. Some women had not been tested during pregnancy and were worried that they might have infected their child through MTCT. Still other women appeared not to trust the effectiveness of Nevirapine therapy and suspected that the child might become HIV-positive even though tests results were negative. Such calls suggest that there is insufficient information and low levels of understanding about testing children and infants for HIV.

Recommendations

It appears from the focus group discussions that a number of information gaps exist amongst callers in relation to PMTCT. Many of these gaps can readily be addressed through communication campaigns as well as local-level communication and practices linked to PMTCT programmes.

On the basis of the research findings, the following recommendations are made:

- ❑ Communications about PMTCT should incorporate information on the following issues:
    - Potential modes of HIV transmission between mothers and babies;
    - The importance of testing for HIV when pregnant, or when intending to become pregnant;
    - HIV testing is not a mandatory part of antenatal care – it requires informed consent;
    - The safety and effectiveness of Nevirapine;
    - Infant feeding recommendations for HIV-positive mothers; and
    - Testing an infant or child for HIV.
- ❑ There appears to be a lack of information geared towards HIV-positive women or couples who wish to have children. Specific issues include: whether an HIV-positive woman can have a child, how this can be done safely, whether Nevirapine can be taken during more than one pregnancy, and if an HIV-negative woman can safely have a child with an HIV-positive man.

Given that the present research has limitations in terms of scope and generalisability, further research into PMTCT implementation and take-up is recommended. The above findings provide insight into possible areas of investigation including: experiences of women accessing PMTCT programmes; Nevirapine self-administration; infant feeding practices of HIV-positive women; and unmet training needs for service providers involved in PMTCT implementation.

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Footnotes

1 8854 MTCT FG 2 June.txt
2 25225 MTCT FG 2 June.txt
3 5788 CAN HL FGD 5 Sept.txt
4 7070 MTCT FG 2 June.txt
5 10914 MTCT FG 2 June.txt
6 11228 MTCT FG 2 June.txt
7 11742 MTCT FG 2 June.txt
8 5994 MTCT FG 2 June.txt
9 633 MTCT FG 2 June.txt
10 7739 MTCT FG 2 June.txt
11 418 MTCT FG 2 June.txt
12 23269 MTCT FG 2 June.txt
13 24556 MTCT FG 2 June.txt
14 1602 CAN HL FGD 30 Sept.txt
15 22555 MTCT FG 2 June.txt
16 23249 CAN HL FGD 30 Sept.txt
17 33122 CAN HL FGD 4 Nov.txt
18 13902 CAN HL FGD 3 Oct.txt
19 19935 MTCT FG 2 June.txt
20 21775 MTCT FG 2 June.txt
21 25930 MTCT FG 2 June.txt
22 18352 MTCT FG 2 June.txt
23 14791 MTCT FG 2 June.txt
24 15759 MTCT FG 2 June.txt
25 16518 MTCT FG 2 June.txt
26 4427 CAN HL FGD 5 Sept.txt
27 12169 MTCT FG 2 June.txt
28 4716 MTCT FG 2 June.txt
29 13181 MTCT FG 2 June.txt
30 25392 CAN HL FGD 5 Sept.txt
31 5487 CAN HL FGD 7 Oct.txt
32 15951 CAN HL FGD 3 Oct.txt
33 1646 MTCT FG 2 June.txt
34 1478 CAN HL FGD 7 Oct.txt
35 2161 MTCT FG 2 June.txt
36 26365 MTCT FG 2 June.txt
37 28082 MTCT FG 2 June.txt
38 15523 CAN HL FGD 3 Oct.txt
39 28486 MTCT FG 2 June.txt