

# The perceptions of pregnant women, attending antenatal clinics, on the prevention of mother-to-child transmission of HIV programme

<sup>a</sup>Akeke VA, MBBS, MPH, MMed

<sup>b</sup>Oguntibeju OO, DTech, FACBS, FIBMS, CSci

<sup>c</sup>Govender S, MBChB, DCH DA, FCFP

<sup>a</sup>Elizabeth Ross District Hospital, Qwa-Qwa, Free State, <sup>b</sup>Department of Biomedical Sciences, Faculty of Health and Wellness Sciences, Cape Peninsula University of Technology, Bellville, and <sup>c</sup>Department of Family Medicine and Primary Care, Faculty of Health Science, Stellenbosch University, Tygerberg

Correspondence to: Prof OO Oguntibeju, e-mail: oguntibeju@cput.ac.za or bejufemi@yahoo.co.uk

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## Abstract

**Background:** The prevalence of human immunodeficiency virus (HIV) infection among women of reproductive age and children below the age of 15 years continues to increase, especially in the countries hardest hit by the acquired immunodeficiency syndrome (AIDS) epidemic.

**Method:** A qualitative method was used to determine perceptions. It involved four focus group discussions among antenatal clinic attendees in the 27 primary healthcare clinics in Qwa-Qwa, Free State province, South Africa.

**Results:** Participants indicated good knowledge about the prevention of mother-to-child transmission of HIV (PMTCT) programme. Participants expressed fears that included stopping the treatment after delivery, the family neglecting the baby if the mother died, stigma, discrimination and domestic violence. The majority of the participants were happy with their relationship with the clinic staff. More than half of the participants expected negative reactions from family members if they followed the programme advice, because of the negative attitudes of their male partners and the elders' resistance to change, owing to their cultural beliefs. Participants agreed that the programme provided adequate knowledge about HIV, modes of mother-to-child transmission of HIV, and how to prevent it.

**Conclusion:** The high level of knowledge among the participants could be attributed to the counselling and health talk sessions offered by clinic staff.

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## Introduction

The prevalence of human immunodeficiency virus (HIV) infection among children below the age of 15 years continues to increase, especially in the countries hardest hit by the acquired immunodeficiency syndrome (AIDS) epidemic. The majority of infected children acquire the infection through mother-to-child transmission (MTCT).<sup>1</sup> Consequently, the prevention of HIV infection in infants and young children is an important aspect of the fight against HIV infection. Although HIV infection among infants is a worldwide problem, it is worst in sub-Saharan Africa, where almost 90% of all HIV-infected children live. The rate of MTCT varies from 15% to 30%, in the absence of any intervention and without breastfeeding.<sup>2</sup> It is estimated that a further 5-20% will become infected with HIV through breastfeeding.<sup>3</sup> Antiretroviral (ARV) regimens have reduced transmission rates to about 10%.<sup>4</sup> The regimen widely used in developing countries is single-dose nevirapine (NVP) given to the mother and baby.<sup>4,5</sup>

South Africa is one of the countries with the highest rates of HIV infection; in antenatal clinics in some provinces (e.g. in the Free State province) seropositive rates are as high as 30%. In 2005, it was established that in the absence of the prevention of a mother-to-child transmission of HIV (PMTCT) programme, about 50 000 infected babies were born in South Africa.<sup>6</sup> Extrapolations of the 2005 annual antenatal HIV seropositive survey results estimated that there were 235 000 HIV-infected children younger than 15 years in South Africa.<sup>6</sup> However, community-based surveys have generally identified higher childhood seroprevalence rates; the 2002 Human Sciences Research Council study showed that 5.6% of children aged two to 14 years were HIV positive.<sup>7</sup>

Following a High Court ruling initiated by the Treatment Action Campaign in 2002, the South African Government decided to roll out the use of NVP for the prevention of MTCT. Initially, 18 pilot sites were set up (two pilot sites in each province), and this was later scaled up to be implemented in all public health institutions.

Although the dual therapy, which comprises the addition of zidovudine (AZT) to NVP, was approved by the Free State province in May 2008, the implementation at primary healthcare facilities only commenced in December of that year. According to this new guideline, the AZT is started at 28 weeks of pregnancy, in addition to the single-dose peripartum NVP given to mother and baby. Prior to December 2008, only single-dose NVP was provided.<sup>8</sup>

MTCT of HIV can occur during pregnancy, labour and delivery, or breastfeeding. For effective prevention of MTCT, a four-pronged strategy is required.<sup>8-10</sup> This involves primary prevention of HIV among women and their partners, avoidance of unwanted pregnancies among HIV-positive women, prevention of HIV transmission from HIV-positive mothers to their babies during pregnancy, labour, delivery and breastfeeding, and provision of treatment, care and support to HIV-positive women, their children and families.

Interventions for the prevention of MTCT during pregnancy, labour, delivery and breastfeeding include the use of ARV drugs, replacement feeding from birth, elective Caesarean sections and minimising the practice of invasive obstetric procedures like episiotomy, artificial rupture of membranes, and foetal scalp monitoring in HIV-infected women.<sup>9, 10, 11</sup>

This study was conducted among the primary healthcare clinics in Qwa-Qwa, Free State, South Africa, a rural area in the eastern part of the province. The population is a predominantly Sesotho-speaking black community of about 300 000 people.

The main objectives of the study were to explore the perceptions of local women regarding the PMTCT programme and to evaluate the strength of these perceptions.

## Method

### Study design

A qualitative methodology was used, involving a number of focus group discussions.

### Study population

The target population for this study was the pregnant women attending antenatal clinics in Qwa-Qwa. The community is served by one regional (or level 2) hospital and one district (or level 1) hospital. There are 28 primary healthcare clinics that refer patients to the district hospital. The pregnant women attending these clinics for their antenatal care (except those attending the clinic in the small town of Kestel nearby, about 30 km from Qwa-Qwa) were interviewed during the study period. The 27 clinics were grouped into four clusters according to the catchment areas. A focus

group discussion was held in each of these clusters. Each focus group comprised eight to 11 women, where at least one woman represented each clinic. A total of 39 pregnant women participated in the study.

The inclusion criteria were as follows:

- All women interviewed were 18 years old and above, irrespective of the number of antenatal visits recorded or the gestation of their pregnancies.
- They were attending antenatal care in the designated clinics at the time of the study.
- The women received pre- and post-test HIV counselling.
- Those who tested negative or positive for HIV and those who refused testing were all included in the study.
- Women of all races and backgrounds were included in the study.

The only women excluded were those who refused to participate or did not sign the consent form.

### Data collection

The data were collected from four focus group discussions that explored the perceptions of the participants regarding the PMTCT programme. The focus group discussions were guided with open-ended questions. The thematic framework used for data analysis included the familiarisation stage, indexing of the data, grouping of the data, and interpretation of the thematically charted qualitative data.

### Recruitment

The nursing sisters in the clinics assisted in the recruitment of the participants. At the outset, the nursing sisters were informed about the project. They, in turn, informed the antenatal clinic patients in the patient waiting areas, during consultation, and during the pre-test HIV counselling sessions with the aid of a patient information leaflet, which had been translated into Sesotho by a bilingual expert (Sesotho and English). Interested patients were then recruited by the nurses in each of the designated clinics, who then submitted the lists of those who had agreed to participate in the study.

### Procedure

Four focus group discussions were held. Clinics with accommodation facilities were selected as the venues for discussion in each of the cluster areas, and the participants in the respective cluster areas met in that clinic on a particular date (and at a particular time) for the discussion.

Consent forms were signed by all participants at the beginning of the discussion sessions. During the discussions, the participants were encouraged to feel free to express themselves and be open in their discussions concerning their experiences, ideas and beliefs regarding the PMTCT programme. An interpreter was recruited to translate from Sesotho to English and from English to Sesotho.

The sessions lasted one-and-a-half to two hours. Discussions were recorded with a cassette tape recorder and field notes were taken. English language transcripts of the discussions were made directly from the audio tapes and were cross-checked for correctness before being analysed.

### Data analysis

Analysis of data was carried out by the authors. A four-stage approach was used.<sup>12</sup>

The first stage was the familiarisation stage, during which the investigators familiarised themselves with the data. The second stage involved the indexing of the data. Key themes were identified and an index was then created, so as to make it easier to code each data segment. Codes were developed according to the numbers of data segments, so as to clearly identify the data segments. The third stage involved the grouping of the data. Data segments from different interviews that shared the same thematic elements were grouped together on a chart or sheet of paper. The fourth and final stage involved the interpretation of the thematically charted qualitative data. The data were now analysed to explore themes and make interpretations.

### Ethical considerations

All ethical standards pertaining to human research were carefully considered in this study. Competent medical personnel were involved in this study. The nonmedical personnel that were used during the interviews and data collection (i.e. fieldworkers) were trained to enable them to perform their duties effectively.

The potential risks were that some participants might become emotionally distressed during the focus group discussions, hence arrangements were made that a psychologist would be available to attend to such participants should this occur. Fortunately no such incident occurred. The confidentiality of all respondents was maintained. No names were recorded as part of the personal data collection. The right to privacy was protected by the use of codes instead of names during the focus group discussions. The participants were told not to introduce themselves before responding to the questions asked. This helped to reduce stigmatisation during the focus group discussions.

Participation in the study was voluntary and no negative action was taken against those who refused to participate. The respondents were informed that they had the right to withdraw their participation at any stage of the study.

The Head of the Department of Health in the Free State gave written permission for participants to be interviewed. The nature of the study was thoroughly explained to the participants and each signed the consent form prior to participation. All participants were legally and mentally capable of giving consent. The commencement of the study was subject to the approval of the Research Ethics Committee of Stellenbosch University.

## Results

### Participants' profiles

All participants were aged 18-40 years. The profiles of the different categories of participants were as follows: single, first pregnancy, HIV-positive, unemployed; single, first pregnancy, HIV-negative, unemployed; married, first pregnancy, HIV-positive; married, first pregnancy, HIV-negative; married, more than one pregnancy, HIV-positive; married, more than one pregnancy, HIV-negative; single, more than one pregnancy, HIV-positive; single, more than one pregnancy, HIV-negative; single, first pregnancy, HIV-positive, employed; single, more than one pregnancy, HIV-positive, and employed.

### Major themes of findings

The focus group participants expressed similar viewpoints, which made it possible for thematic generalisations to be made.

*Knowledge of how the virus is transmitted from mother to baby:* Most of the participants knew how HIV is passed from the mother to the child. Some also said it could be transmitted to the baby while in the uterus, during labour, while breastfeeding and even during mixed feeding after delivery.

*Role of clinic staff in preventing HIV transmission:* The focus group participants showed a high level of knowledge regarding the role of health workers in the PMTCT. Some participants said that health workers encouraged pregnant women to attend antenatal clinics and to undergo voluntary counselling and testing (VCT) as a way of preventing the transmission. Most of the participants said that the clinic staff educated them on how to feed the baby, care for the baby and themselves, and the use of condoms. Almost half of the participants said that the clinic staff played a role in preventing MTCT by providing advice on the use of ARV therapy.

*Perceptions on concerns related to or disadvantages of the programme:* More than half of the focus group participants mentioned resistance to ARV drugs as one of their concerns about the programme. Participants were also concerned about stopping the treatment after delivery, the high number of orphans, depression and suicide, as well as the family neglecting the baby if the mother died.

Participants were worried about what would become of their children when they eventually died from the disease. Some participants felt that the programme might lead to a high number of orphans if the mothers did not continue with the treatment after delivery. Some participants had experienced problems in the family because of their status. Almost half of the participants felt that participating in the programme could lead to stigma, persecution and violence.

*Perceptions on readiness to undergo the HIV test:* The fear of testing HIV positive was the major concern among those who said it was not easy to undergo the test. The responses of the participants were influenced by their experiences.

*Perceptions on the ease of taking ARVs:* At the time of this study, the government had just introduced the dual therapy, by adding AZT to NVP. Prior to December 2008, only NVP was used. However, most clinics were yet to receive stocks of AZT, and hence most of the participants who were on the programme received perinatal single doses of NVP, usually taken during labour. There were two participants who were on highly active ARV therapy (HAART), which comprised a three-drug regimen, prior to becoming pregnant, and one participant who was on dual therapy. The responses from those who were on NVP but were yet to take the medication were influenced by what they had heard from others who had taken the medication or the clinic sisters, rather than offering their personal experience.

*Perceptions on the relationship between participants and the clinic staff:* The majority of the participants were happy with their relationship with the clinic staff.

*Expected reactions from family if the programme advice were followed:* More than half of the focus group participants expected negative reactions from their family members if they followed the programme advice. Some of these responses were influenced by cultural and traditional values. The negative attitude of the male partners was an example of this. However, some participants believed that, if the family members were counselled and educated about HIV, then they would be more supportive.

*Perceptions on the advantages of the programme:* The participants agreed that the programme has many advantages. This response was based on what they had experienced personally. Most of the participants regarded

the knowledge gained by participating in the programme as one of the advantages. Most felt that the programme prevents the transmission of HIV from mothers to their babies and some felt that, after participating in the programme, they were less fearful of undergoing the HIV test. All the participants were excited to be part of the programme.

## Discussion

### Knowledge about the programme

Participants in each of the focus group discussion sessions demonstrated a high level of knowledge of the PMTCT programme. This could be as a result of the information received during the pre- and post-test counselling session, and the health talk session offered by the clinic staff.

This finding compared favourably with findings of other studies.<sup>1-7</sup> Most women learnt about the PMTCT programme from the clinic counsellors.<sup>11</sup> Our finding is also similar to that of a study carried out in Uganda, namely that 16% knew about PMTCT as a mode of HIV transmission but, after counselling, this percentage increased to 70%.<sup>13</sup> In yet another study, only 16% of women were aware that medication obtainable from the hospital could prevent MTCT at baseline, compared to 34% at follow-up.<sup>14</sup>

### Perceptions of the concerns about the programme

The focus group participants expressed several concerns regarding the programme, including developing resistance to ARVs, the fear of stopping ARVs after birth, and the idea of saving the baby's life when the parents were going to die (which may lead to high number of orphans). Studies carried out in Kenya have shown that women participating in PMTCT programmes often complain about the hopelessness of saving the babies when the parents are actually hoping to die, as well as some taboos that hinder the implementation of the PMTCT programme.<sup>15</sup>

The problems of stigma, discrimination, persecution, domestic violence, and even divorce as a result of their HIV status, as well as cultural beliefs and traditional values that impede the implementation of the PMTCT programme, were other concerns voiced by the participants. In Mombassa (Kenya), 90 (31%) of 290 HIV-positive women who were included in an intervention study to reduce MTCT informed their partners of their results. In three cases the women were kicked out by their partners, and in three cases the women reported violence. In other words, six (6.6%) of the 90 HIV-infected women who were expecting a supportive attitude actually experienced violence instead. In the same study, 16% of the respondents reported finding HIV testing useless and were depressed, mainly because HIV has no cure.<sup>16</sup>

The working mothers among the participants were not happy about the inadequate maternity leave granted by their employers, as this could impede their full participation in the PMTCT programme. A study conducted in Tanzania revealed that while health workers did a wonderful job of convincing women of the advantages of exclusive breastfeeding, the women were left to their own devices when it came to solving the practical problems of breastfeeding while simultaneously holding down a full-time job. It was found that the women had to deal with conditions such as no on-site child care, lack of an expressing or a breastfeeding room, and short maternity leave at most workplaces.<sup>17</sup>

Another concern raised by some of the focus group participants was the issue of depression and suicide attempts. Some participants believed that some women could become depressed or commit suicide if they found out that they were HIV positive. In a multi-country study conducted between 2001 and 2003 to examine community understanding and experience of HIV stigma in one rural and one urban site in Tanzania, data showed that family and community stigma impedes people's ability to discuss safer sex with partners, use of condoms, disclosure of HIV status, use of PMCTC and VCT services, treatment of opportunistic infections, and provision of care. Furthermore, the quality of life is compromised, as people living with HIV and AIDS often act on the external stigma they experience, leading to self-isolation, self-deprecation, giving up of life aspirations, internalising guilt and blame, and sometimes even contemplating suicide.<sup>17,18</sup>

#### **Perception of readiness to undergo HIV testing**

Regarding the readiness to undergo HIV testing, more than half of the participants perceived it negatively, largely because of the fear of the consequences of an HIV-positive result. This fear has been reported as one of the barriers to participation in PMTCT programmes.<sup>19-21</sup>

Furthermore, in another study conducted in Mombassa (Kenya), 16.7% of HIV-infected women did not see the advantage in knowing their HIV status, mainly because they would then possibly be worried about being sick or dying (68%), and because AIDS could not be cured anyway (35.3%).<sup>15</sup>

However, most women who said it was not easy to undergo the HIV test agreed that it became easier after they had undergone HIV pretest counselling. Likewise, in a study that was carried out in northern Nigeria in 2000, to examine the predictors of readiness for HIV testing among young people, knowledge about HIV prevention, knowledge about a source for VCT, discussion about condom use for HIV prevention, and perceived risks were found to be strong predictors for readiness to undergo HIV testing.<sup>22</sup>

#### **Perceptions of the ease of taking antiretroviral drugs**

Most of the participants were yet to take ARV medications, except for two participants who were already on HAART. The responses from those already on HAART were influenced by personal experiences and knowledge gained during the drug-readiness classes, while the responses from those who were not on HAART were influenced by what they had heard about the ARVs, rather than personal experiences.

Most of the participants perceived that taking ARVs was not going to be easy, especially when considering the possible resistance that might manifest when they needed the medication in future when their CD4+ T-cell count fell. Some said they would like to continue the medication after delivery. Disclosure was another important issue mentioned by the participants that would make it easier for them to take their medication. They indicated that if no one was helping or supporting the patient, as a result of non-disclosure, the patient could more easily forget to take the medication. Potential side-effects of the medication were also mentioned as an issue. Some of these factors that the participants perceived to have the potential to hinder the ease of taking the ARV medication during PMTCT have also been reported in other studies.<sup>23</sup>

In a cross-sectional study carried out to determine important factors that affect ARV drug adherence among male and female adult HIV/AIDS patients attending a teaching and referral hospital in Kenya, the most common reasons for missing the prescribed dosing time were being away from home (68.8%), being too busy (58.9%), forgetting (49.0%), having too much medication to take (32.6%), and the stigma attached to ARVs (28.9%).<sup>24</sup>

#### **Perceptions of the relationship between participants and the clinic staff**

Some of the participants in this study reported having a good relationship with their clinic staff. The clinic staff was said to be very open, as the patients were free to ask any questions and the staff did not discriminate. However, some other participants reported negative experiences with the clinic staff: one mentioned that the clinic sisters were abusive and hostile because of the patient's HIV status.

A study found that women were satisfied with the services they received from the PMTCT programme, and they believed that healthcare staff offered them not only medical care, but also social and emotional support. In fact, the author concluded that the healthcare system is a vital point of support for pregnant women with HIV.<sup>25</sup>

### Expected reactions from family if the programme advice was followed

Negative reactions were what most of the participants expected from their families if they followed the programme recommendations. The negative reactions expected were influenced by negative cultural beliefs and traditional values, stigma, discrimination, and persecution, as well as the negative attitudes of their male partners and extended family members. Very few participants expected love and support from their family members. MTCT programme users from different backgrounds anticipated negative reactions from their family members if they followed the programme advice.

Lack of male partner support, and family and community stigma have been found to be barriers to participation in PMTCT programmes in Tanzania and Uganda.<sup>18, 20</sup>

A study carried out in rural southern India revealed that if a woman were to breastfeed her baby, negative attitudes expected from the partner would include the following: 84% thinking that the mother is harming the baby, 78% thinking she is not a good mother, 74% thinking she is HIV-positive and 66% thinking that she has been unfaithful.<sup>26</sup> In this study, although 85% of the women interviewed expressed their willingness to be tested, most of them were concerned about confidentiality and disclosing HIV seropositive status because of fear of negative reactions from their husbands, parents and the community.

According to a study carried out in Tanzania, a woman is most likely to receive greater support from her partner and family members when VCT is discussed and agreed upon by the couple before the woman is tested, and that men are threatened and hence are more likely to react negatively to disclosure, even if the result is negative, when negotiation of attendance of a PMTCT programme had not been discussed.<sup>27</sup>

In yet another study carried out in rural Tanzania, HIV-seropositive women whose partners attended HIV (VCT) were three times more likely to use NVP prophylaxis, four times more likely to avoid breast feeding, and six times more likely to adhere to the infant feeding method selected than those whose partners did not attend.<sup>28</sup>

### Perceptions of the advantages of the programme

The advantages mentioned by the participants included gaining knowledge by participating in the programme, preventing MTCT, reducing or allaying fear associated with undergoing HIV testing, making one aware of one's HIV status, and the fact that the programme has the potential to change the culture and behaviour of the community for the better.

Similar responses are described in other studies. For example, a study in Uganda demonstrated that participation in (PMTCT) services improves knowledge of MTCT, as well as appropriate intervention strategies among the maternal and child health attendees.<sup>13</sup>

Furthermore, in a study carried out in Blantyre (Malawi), in 2004, the majority of 126 women attending antenatal clinics identified HIV testing of pregnant women as a potential benefit, and necessary for the prevention and potential control of HIV/AIDS. Knowing one's HIV status instead of being ignorant was the benefit most frequently mentioned by the women.<sup>29</sup> Other benefits mentioned by the study participants included future family planning as an incentive to reduce the number of sexual partners, and knowing the cause of the problem in the case of a child failing to thrive (rather than blaming witchcraft). Others said the programme actually prevented or reduced MTCT.

### Perceptions of participation in the programme

It was observed that all the participants responded positively about what it felt like to be part of the programme. Their reasons for being very happy about the programme included knowing their HIV status, gaining new knowledge about how to care for self and baby, and also because the programme gives hope to those who are HIV positive.

### Limitations

The inability to conduct focus group discussions in each of the 27 clinics constitutes a limitation of this study.

### Conclusion

The participants demonstrated a high level of knowledge regarding the PMTCT programme. Most of them knew how the virus is transmitted from the mother to the child and how this transmission can be prevented. This high level of knowledge among the participants could be attributed to the counselling and health talks sessions offered by clinic staff.

There is no doubt that the knowledge gained through the involvement in the PMTCT programme has the potential to change misconceptions about HIV transmission and positively influenced the cultural beliefs and traditional values that mitigate the implementation of the PMTCT programme, especially if the family and members of the community are involved in the programme.

### Recommendations and policy implications

In order for PMTCT interventions to be successful, the following recommendations are made:

- The general public should be educated about HIV/AIDS, PMTCT and the prevention of HIV transmission. The spouses of the pregnant women and other family would benefit from specific counselling, which could ameliorate family stigma towards HIV-infected mothers.
- There is a need for interventions that will help to empower women to negotiate sex and safe sex, and increase their ability to negotiate condom and contraceptive use, as well as increasing their ability to access effective PMTCT programmes and maternal and child health, and reproductive health services.
- There is need for a formal ongoing process by which objective measures are periodically utilised to monitor and evaluate the quality of PMTCT programme services (clinical and administrative) provided to patients enrolled in the programme.
- There is need for a programme of ongoing, quality professional development for the healthcare workers involved in the programme. This will promote capacity building and more effective implementation of the programme.

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