



**SOCIAL MOBILISATION AND COMMUNICATION  
TO PREVENT MOTHER-TO-CHILD  
TRANSMISSION OF HIV**

2010







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## *Developed by*

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## *Acronyms and abbreviations*

AIDS	acquired immune deficiency syndrome
ANC	antenatal care
ARVs	antiretroviral drugs
AZT	zidovudine
CBO	community-based organisation
CMT	Community Media Trust
DoH	Department of Health [South Africa]
FGD	focus group discussion
HCT	HIV counselling and testing
JHHESA	Johns Hopkins Health and Education in South Africa
m2m	mothers-to-mothers programme
MTCT	mother-to-child transmission of HIV
NGO	non-governmental organisation
NVP	nevirapine
PCR	polymerase chain reaction [HIV test]
PHDP	positive health, dignity and prevention
PLHIV	people living with HIV or AIDS
PMTCT	prevention of mother-to-child transmission of HIV
SANAC	South African National AIDS Council
UNICEF	United Nations Children's Fund
USAID	United States Agency for International Development
WHO	World Health Organization

## Executive Summary

This study was conducted to support the development of a national campaign entitled ‘Social Mobilisation and Communication Strategy for the Prevention of Mother-to-Child Transmission of HIV.’ The aim of study was to provide an evidence base for informing the development of communication and social mobilisation strategies to support increased PMTCT uptake and efficacy. The research consisted of two key activities: 1) a literature review to identify the main challenges and opportunities for PMTCT uptake, with a specific focus on communication approaches; and 2) fieldwork at five sites in South Africa: Maluti-a-Phofung in the Free State Province, Moretele in the North West Province, Senqu in the Eastern Cape Province, and Maphumulo and kwa-Nongoma in KwaZulu-Natal Province. These five pilot sites, identified as some of the worst-performing districts in terms of incidence of MTCT and uptake of PMTCT, were selected from a list of 18 priority districts named for intervention by the Department of Health (DoH).

This report begins by contextualising of the need to scale up efforts aimed at the prevention of mother-to-child transmission of HIV (PMTCT) by giving an overview of the situation in South Africa. It then provides an overview of a literature review which proposed a social ecological model for communication of PMTCT intervention programmes. The results section focuses on challenges and opportunities for communication of PMTCT services to various stakeholders, such as women, male partners, health workers and the affected communities.

Fieldwork was conducted at five sites across four provinces in South Africa, from September to October 2009. A total of 27 focus groups and 25 individual interviews were conducted. The research participants included women aged 18 to 50; HIV-positive women, including women who had utilised PMTCT services or were considering using PMTCT services; men aged 18 to 50; healthcare workers; reproductive health practitioners, including service providers involved in PMTCT services, infant nutrition advisors and traditional birth attendants; women community elders, including grandmothers and mothers-in-law; and NGO representatives.

The summary lists key topics that were investigated in the study, including factors that are inhibiting the uptake of PMTCT services in the five sites.

## Public knowledge about PMTCT

Knowledge about PMTCT issues varied among the various groups of participants. Healthcare workers, women of child-bearing age and HIV-positive women were more knowledgeable about PMTCT as compared to men of reproductive age and elderly men and women. Clinics and other health facilities were reported as the main sources of PMTCT information.

## HCT as an entry point

The overall perception about HIV counselling and testing for HIV (HCT) was that most people are afraid to test for HIV infection mainly due to fear of the disease and premature death that may be facilitated by stress of testing positive. As a result both men and women underutilise HCT services in their areas. Most people only test for HIV infection when they are critically ill or are pregnant. It was reported in all study sites that the only time that most women get to know about their HIV status is through the antenatal care (ANC) clinics.

## The health system and clinics as an entry point for PMTCT

The evidence points out that PMTCT information dissemination often happens in waiting rooms at clinics and this is problematic in that clients spend limited time there and there is a lack of privacy and confidentiality. When communicating their HIV-positive status and enrolment into the PMTCT programme to their husbands or significant others, women tend to adopt the discourses of ‘the clinic’ and repeat what the clinic has said to them as opposed to asserting their own decisions.

## Other sites as entry points for PMTCT

Apart from working with women of reproductive age visiting clinics, there was isolated evidence of PMTCT campaigns that are delivered through health services aimed at communities (for example, the DoH endeavours to educate elderly women about PMTCT, with a view to building support for daughters choosing not to breastfeed).





### *Lack of HIV-status disclosure as an obstacle*

Lack of HIV-status disclosure among HIV-positive women to their significant others – including male partners, parents and in-laws – was reported as a source of conflict about infant-feeding options in particular. The participants reported that infant-feeding choices are often taken as an indicator of a woman's HIV status, or are interpreted as a sign of being an 'irresponsible' mother. Lack of disclosure was also associated with poor adherence to the infant-feeding option that a woman had chosen.

### *Infant-feeding practices as an obstacle*

It was reported that unavailability of infant formula at three sites led to mixed-feeding practises. Mothers who opted for exclusive formula-feeding sometimes resorted to mixed-feeding practices due to the unavailability or insufficient supply of formula at their health facility. Infant-feeding is generally the domain of mothers, and choosing not to breastfeed has not been a problem in the past when the reasons for not breastfeeding were openly known – for example, if a mother has insufficient milk. Women participants mentioned that nowadays the choice not to breastfeed is often directly linked by people in the community to the mother's HIV status.

### *Engagement of men*

The majority of male participants reported that they wanted to do more in order to support their female partners. The men who participated in the research generally held strong opinions about wanting their role to be acknowledged as active, from the time of a partner's early pregnancy to post-delivery, and for fathers to be perceived as more than 'distant providers' of material things for their pregnant partners.

The recommendations from this study emphasise a need for an ecological model to be implemented in order to improve communication of PMTCT services. Specific recommendations are made at each of four levels: individual; social network; community; and societal/systemic. The six areas covered are: prevention of PMTCT through prevention of HIV infection in women of childbearing age; family

planning as a PMTCT intervention; enrolment in PMTCT programmes; support for people in PMTCT programmes; infant nutrition protocol support; and involvement of men.

## 1 Background to the Study

### 1.1 The need to scale-up prevention of mother-to-child transmission of HIV

In 108 low- and middle-income countries all together, it has been estimated that about 1.5 million women living with HIV gave birth in 2006.<sup>1</sup> In South Africa in 2007, approximately 707 948 pregnant women were tested for HIV, and about 290 000 pregnant women living with HIV needed antiretroviral drugs (ARVs) for PMTCT.<sup>2</sup> Furthermore, it was estimated that close to 200 000 children (aged 0–4 years) in South Africa in 2007 were infected with HIV.<sup>3</sup> Annually, as a result of mother-to-child transmission of HIV (MTCT), at least 75 000 children in South Africa die before their fifth birthday.<sup>4</sup> While there are a number of health-related challenges that contribute to these deaths, it is argued that HIV-related illnesses account for a large proportion, while the most common route of HIV infection for children under age 5 years is through vertical transmission or MTCT.<sup>5</sup>

Well over 90% of new HIV infections among infants and young children may occur through MTCT. Without any interventions, between 20% and 45% of infants may become infected with HIV through MTCT, with an approximated infection risk of 5–10% during pregnancy, 10–20% during labour and delivery, and 5–20% through breastfeeding.<sup>6</sup>

However, it is estimated that the overall risk of vertical transmission can be reduced to less than 2% if a package of evidence-based interventions are made available and used by HIV-positive pregnant women and mothers. The package of interventions is based on the United Nations' four-element strategy for PMTCT. The first three of these strategies are focused on prevention of new HIV infections, while the fourth strategy focuses on ongoing care and treatment for HIV-positive mothers and HIV-exposed infants and young children. The four-prong approach highlights the protracted nature of successful PMTCT and thus the

need for commitment to a long-term, comprehensive and integrated response. The four-elements are:

- Primary prevention of HIV infections among men and women of child-bearing age.
- Prevention of unintended pregnancies among both HIV-positive and HIV-negative females of child-bearing age.
- Implementation of PMTCT protocols for women pre- and post-childbirth.
- Provision of appropriate treatment, care and support for women living with HIV and their children and families.

The success of PMTCT programmes rests on expanding access to PMTCT services and ensuring that these services are known, perceived as important, and made accessible.<sup>7</sup> Success also rests on providing adequate information to the general population and relevant service providers, and on providing adequate and on-going support to HIV-positive mothers once they have given birth. The potential for interventions to reduce the risk of vertical transmission to less than 2% underscores the importance of a PMTCT communication strategy that reaches all relevant stakeholders.

In South Africa, the PMTCT programme available to HIV-positive pregnant women is available through about 3 000 primary healthcare facilities across the country, offering a comprehensive package to reduce MTCT.<sup>8</sup> Although there is evidence pointing to the acceptability, feasibility and cost-effectiveness of PMTCT programmes in low- and middle-income countries,<sup>9</sup> in the South African context there is a need for good-quality and routinely offered healthcare services to increase the uptake of PMTCT services.

The success of a PMTCT programme lies with pregnant women opting to be tested for HIV. The proportions of women attending antenatal care (ANC) clinics who chose to test for HIV in 2007 across the country's 52 districts ranged from 44% to 100%, while in 23 districts less than 50% of the pregnant women attending opted to be tested.<sup>10</sup> Also, an evaluation of the country's PMTCT programme pilot sites found that 85% of pregnant women who tested actually re-

1 UNICEF (2009)

2 WHO, UNAIDS & UNICEF (2008)

3 WHO, UNAIDS & UNICEF (2008)

4 Bradshaw et al. (2008)

5 Centers for Disease Control and Prevention (2007)

6 WHO & UNICEF (2007)

7 WHO & UNICEF (2007)

8 Department of Health (2008b)

9 WHO (2006)

10 Barron et al. (2007)



ceived their HIV-test result, and only 55% of HIV-positive women received nevirapine (NVP) prophylaxis.<sup>11</sup>

Despite the availability of the PMTCT programme in South Africa, evidence suggests that numerous factors influence women's participation in the programme, thus resulting in many missed opportunities for PMTCT. Studies done in the Eastern Cape Province have shown that while the Department of Health (DoH) has made services freely available, factors such as socio-economic conditions, poor roads and telecommunication, and an underdeveloped transportation system remain obstacles to women accessing the PMTCT services.<sup>12,13</sup>

The poor functioning of the healthcare system, shortages of staff, healthcare workers' often poor attitudes and

poor interactions with clients, inadequate counselling and information, lack of integration of family planning and HIV-prevention/PMTCT services, poor referral links, lack of communication within the healthcare system, and non-provision of nevirapine, all indicate that there are many missed opportunities for PMTCT.<sup>14,15,16,17</sup>

In 2007 it was estimated that 707 948 pregnant women in South Africa were tested for HIV, and about 290 000 pregnant women living with HIV needed ARVs for the sake of PMTCT.<sup>18</sup> Despite problems with the PMTCT programme, the intervention has reported certain successes.

11 Doherty et al. (2003)

12 Skinner et al. (2005)

13 Peltzer et al. (2007)

14 Frizelle et al. (2009)

15 Nkonki et al. (2007)

16 Rispel et al. (2009)

17 Painter et al. (2004)

18 Frizelle et al. (2009)

In 2007, an ongoing study conducted at Site B clinic in Khayelitsha (Cape Town) showed the prevalence of vertical transmission of HIV to be 3.5% among ANC attendees. The underlying factors for the success in Khayelitsha included 10 years of aggressive PMTCT intervention, which led to an HIV-testing acceptance rate close to 100%.<sup>19</sup> There was also an active promotion of exclusive formula-feeding with the provision of infant formula for the first six months (depending on the mother's choice not to breastfeed), and the introduction of an aggressive drug regimen (i.e., AZT [zidovudine] antenatally from 28 weeks, plus single-dose nevirapine for the mother and AZT for seven days post-natally for the baby, while meanwhile nationally only single-dose nevirapine was implemented to reduce vertical transmission).<sup>20</sup> The study at Site B provided evidence that PMTCT programmes in resource-constrained settings can reach all women who need the services and can in turn reduce MTCT to levels below the target of 5% as set out in the DoH's *HIV and AIDS and STIs Strategic Plan for South Africa, 2007–2011*.

The revised policy and guidelines by the DoH – from monotherapy to dual therapy – only came in 2008, due to pressure by PMTCT activists who had been advocating for amendments to the National Strategic Plan (NSP) policy and guidelines which did not incorporate the most recent scientific discoveries regarding PMTCT.<sup>21</sup> The 2008 guidelines recommended that HIV-positive mothers and pregnant women with a CD4 cell count above 200 be placed on antiretroviral therapy (ART), and that pregnant women with a CD4 cell count below 200 receive a once-off course of dual-therapy for PMTCT.<sup>22</sup> However, all HIV-positive pregnant women will now have access to ARVs if they have a CD4 cell count of 350, or if they have HIV-related symptoms, regardless of their CD4 count.<sup>23</sup> This change will improve the lives of HIV-positive pregnant women and their babies through the provision of early access to ART.

19 Booth (2008)

20 Médecins Sans Frontières et al. (2008)

21 Frizelle et al. (2009)

22 Department of Health (2008a)

23 Jacob Zuma [World AIDS Day] (2009)

## 1.2 Background to the study

The current research was conducted in support of a national campaign entitled 'Social Mobilisation and Communication Strategy for the Prevention of Mother-to-Child Transmission.'

The campaign intends to achieve the following targets as set out in the NSP:

- Increase the rate of HIV testing among pregnant women attending public health facilities to 95% by 2011;
- Increase the uptake of PMTCT services at public health facilities to 90% by 2011;
- Increase the number of infants who are tested for HIV (using a PCR test) by age six months to 95% by 2011;
- Increase the proportion of HIV-exposed infants who receive exclusive feeding;
- Increase correct and consistent condom use among men and women;
- Reduce the average number of sexual partners among men and women of child-bearing age;
- Reduce the incidence of HIV infections among men and women.

USAID, Johns Hopkins Health and Education in South Africa (JHHESA), and Community Media Trust (CMT) were approached by the South African National AIDS Council (SANAC) to support the development and implementation of a national PMTCT social mobilisation and communication strategy. It was intended that this would in the first instance be a limited intervention aimed at establishing an approach that could then be rolled-out at the national level. The Centre for AIDS Development, Research and Evaluation (CADRE) was commissioned by UNICEF to undertake research to inform the development of the campaign.

## 1.3 Research objectives

- To identify challenges and opportunities regarding PMTCT uptake at public health facilities in South Africa, as documented in the literature, and which could be addressed through a national social mobilisation and communication campaign.



- To provide the evidence-base for informing the development of communication and social mobilisation strategies in support of PMTCT at the community level.
- To provide guidance for the development of better-tailored communication campaigns aimed at improving PMTCT uptake and effectiveness.

### 1.4 The research process

The study was divided into two stages: 1) a literature review to address the first objective, above; 2) qualitative research to address the second and third objectives, above.

A literature review was conducted in June 2009 and focused on the following areas: stakeholders' knowledge of and attitudes to PMTCT; socio-behavioural factors that facilitate or are obstacles to access and uptake of PMTCT services; the identification of existing strategies and models for PMTCT communication and social mobilisation at the community level; evidence of the effectiveness of existing communication practices related to the uptake of PMTCT; and social mobilisation and communication needs mentioned in current South African guidelines and in other national and international PMTCT programme reports. The literature review also aimed to distil a set of recommendations for developing communication campaigns to optimise PMTCT uptake in South Africa.

The literature review document was examined by UNICEF, South Africa's DoH and JHHESA, and comments were integrated following the review. It was published as a self-standing document entitled: *Strengthening PMTCT through Communication: A Review of the Literature* (available online through: <[www.cadre.org.za](http://www.cadre.org.za)>).

Next, qualitative research was conducted in five priority sub-districts in four provinces in South Africa, as identified during a National Department of Health mapping of PMTCT. The sub-districts had relatively high levels of HIV prevalence combined with particularly low levels of HIV testing and PMTCT uptake by mothers. The study sites were: 1) Senqu in uKhahlamba (Eastern Cape), 2) Maphumulo in iLembe (KwaZulu-Natal), 3) Maluti-a-Phofung in Thabo Mofutsanyana (Free State), 4) Moretele in Bojanala (North West), and 5) Nongoma (KwaZulu-Natal).<sup>24</sup>

As a precursor to the formal research some informal discussions were held with women (either pregnant or not pregnant, HIV-positive or HIV-negative) to get a sense of the issues that existed in relation to their experience of pregnancy in general and PMTCT in particular; this was done to further inform the development of the research instruments. Key findings from the informal discussions include:

- A demand for information related to sex during pregnancy and post-pregnancy;
- A need for emotional support of women living with HIV who are pregnant or already mothers, and requests for materials/resources to boost their coping;
- A cultural and social importance attached to the concept of motherhood;
- A need for information about PMTCT-related issues and services to be targeted to a wider audience than pregnant mothers – but to include their partners, in-laws and other community/family members;
- A need to involve men as partners in PMTCT;
- Clear communication messages around infant-feeding choices.

<sup>24</sup> The DoH has designated 18 districts nationally to be prioritised in the PMTCT Acceleration Plan. The districts were selected on the basis of

deprivation index ranking, ranking on key health-delivery indicators, and on the basis of HIV prevalence in the annual antenatal HIV seroprevalence survey. Within the 18 districts, five sub-districts for the pilot project were selected, representing a range of provinces and community and cultural settings, through which to research PMTCT-related communication strategies and community mobilisation possibilities.



## 2 Communication Theory Underlying the Study

The theoretical framework underlying the research is the social ecology model of communication for social and behavioural change. This model acknowledges that change at one level may be influenced or facilitated by that at another level.<sup>25</sup> The diagram below shows the different domains of communication that need to be activated in bringing about social change. This model provided the main categories for understanding social communication and social mobilisation in both the literature review and the research study.

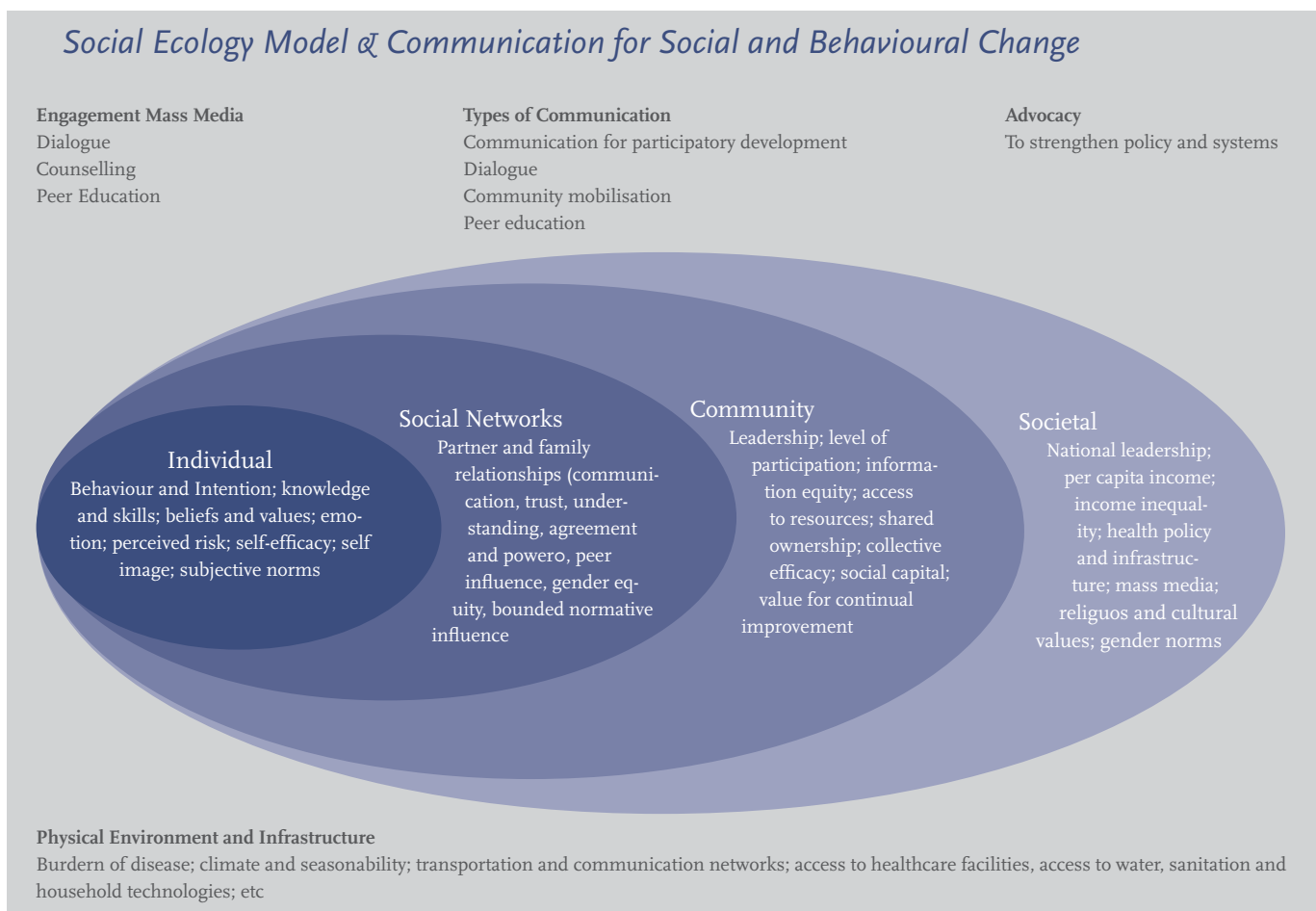
In keeping with a social ecology model of communication, findings from the literature review were considered in relation to four levels: societal, community, social networks, and individual. The findings pointed to many programme

elements that have been successful in increasing the uptake and effectiveness of PMTCT services. The literature review also revealed the complexities and challenges of PMTCT interventions – which are by nature protracted efforts – and the importance of a comprehensive and integrated response at work through different levels of communication.

Thus, it is not sufficient to communicate about PMTCT issues only at the individual level – that is, with pregnant women; there is also a need to influence the various stakeholders at other levels through which the women interact in order to facilitate changes in behaviour. This calls for deeper investigation into national policies on PMTCT, attitudes and practices in local cultures, the socio-economic and cultural contexts, as well as the roles played by women’s families and male partners.

Up to now, despite the presence of PMTCT services in communities, PMTCT interventions have largely paid lip-service to the roles played by broader societal structures

25 Frizelle et al. (2009)





that influence the decisions made by pregnant women. For example, the influential roles of male partners, mothers-in-law and neighbours have been noted,<sup>26</sup> yet little or no intervention work has been carried out to deeply understand their involvement in a woman's pregnancy, their concerns or level of knowledge about PMTCT, and especially what role they can play in communicating PMTCT messages and supporting an HIV-positive pregnant woman or mother. Most examinations of PMTCT interventions have relied mainly on accounts related by pregnant women, without having directly engaged other actors. Yet for successful communication of PMTCT messages, these other actors are crucial and need to be directly engaged.

Other important actors identified by the social ecology model are policymakers and health programme implementers. There is a need to ensure that PMTCT-related policies are relevant to the situation in which they are being implemented and that the intervention gains community acceptance and ownership. Policies that are imposed from the top may clash with local knowledge or be culturally insensitive, and therefore rejected by some people. For example, the literature review indicated that in certain cultures it is culturally inappropriate to disclose pregnancy until the pregnancy shows; some cultures prefer breastfeeding; and in certain cultures women have no autonomy over infant-feeding options.<sup>27</sup> In this context, PMTCT communication should be directed at all key stakeholders, rather than focusing only on pregnant women as single, autonomous units.

Finally, a communication strategy should take into account the fact that women who want to use PMTCT services are faced with numerous barriers, some individualistic and others relational, social or structural in nature. These include lack of transportation to a clinic and lack of detailed information from healthcare providers about PMTCT. According to HIV-positive women, healthcare providers are sometimes judgemental or tend to persuade pregnant HIV-positive women to choose one infant-feeding option over another.<sup>28</sup> HIV-positive women also face the challenge of disclosing their HIV status to their partners, sometimes with fears of violence or being accused of having infected their partners.<sup>29</sup> At an individual level, some women may be scared to test for HIV or may feel embarrassed or

ashamed if they test HIV-positive, leading to reluctance to use PMTCT services.

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26 Peltzer et al. (2007)

27 Thairu et al. (2005)

28 Frizelle et al. (2009)

29 Long (2009)

### 3 Research Questions

In keeping with the objectives of the study, the following research questions were pursued at each of the study sites:

- What understandings of PMTCT processes exist at a community level (e.g., in relation to HIV testing, antiretroviral treatment and infant-feeding)?
- How are understandings of PMTCT processes shaped by cultural practices, religious beliefs, socio-economic realities, gender perspectives and health communication efforts? Particularly in the areas of: i) HIV/AIDS prevention and management; ii) childbirth; and iii) infant-feeding practices?
- What are the best communication channels and modes of influence to pursue in addressing PMTCT?
- What are the key communication channels, and who are the main opinion leaders that should be engaged in developing PMTCT-related communication and social mobilisation campaigns in each community, considering the possibilities through the following levels: i) individual behaviour; ii) interpersonal communication; iii) community/social networks; and iv) institutional structures.

### 4 Research Design and Methods

The study employed a qualitative research design to determine the perspectives of various stakeholders involved in PMTCT, through fieldwork at five sites in South Africa.

#### 4.1 Overview

A total of 27 focus group discussions (FGDs) and 25 key informant interviews were conducted; these were aimed at understanding the socio-economic, cultural and service-delivery environments related to PMTCT at each of the five sites.

The focus groups and interviews were conducted in English and local languages (isiXhosa, isiZulu, Sesotho and Setswana) as appropriate. The research commenced with a meeting with the sub-district health manager at each site. The health managers received communication from the National Department of Health telling them about the study and including the appropriate authority and request for them to assist in the research. Thus, the health managers were briefed about the study and its expectations regarding their participation as well as the participation of other target categories (e.g., women aged 18–50 years, men aged 18–50 years, healthcare workers, HIV-positive women, community elders).

#### 4.2 Description of the sites

##### 4.2.1 Maluti-a-Phofung

Maluti-a-Phofung is one of six local municipalities in Thabo Mofutsanyana, one of five district municipalities ('districts') of the Free State Province. Although it is a rural area in the eastern part of the province, it has a fair access to basic infrastructure. Maluti-a-Phofung has a population of about 360 800, the largest of the local municipalities within Thabo Mofutsanyana, with about 50% of district's population.<sup>30</sup> HIV prevalence in Maluti-a-Phofung is about 35%<sup>31</sup> among antenatal women and about 33%<sup>32</sup> in the Thabo Mofutsanyana District Municipality.

30 Statistics South Africa (2001)

31 Maluti-a-Phofung Local Municipality (2009)

32 Department of Health (2008b)





#### 4.2.2 Moretele

Moretele local municipality is located in Bojanala Platinum District in the north-eastern part of the North West Province. Moretele is one of six local municipalities in the district and has a population of approximately 182 500.<sup>33</sup> Unemployment, poverty, inadequate health services and the inaccessibility of services remain the key challenges in most parts of Moretele. HIV prevalence is estimated at 28.7% in Bojanala Platinum District Municipality and 33.6% among antenatal women.<sup>34</sup>

#### 4.2.3 Senqu

Senqu is one of five local municipalities in Ukhahlamba District, one of seven district municipalities in the Eastern

Cape Province.<sup>35</sup> Senqu has a population of approximately 135 000 or almost 40% of the district's population.<sup>36</sup> HIV and AIDS is a significant challenge facing the people of Senqu, with high rates of child mortality.<sup>37</sup> HIV prevalence among antenatal women is estimated at 21.9%, a decrease from 29.4% for the year 2007 in Ukhahlamba.<sup>38</sup>

#### 4.2.4 Maphumulo

Maphumulo is one of four local municipalities within the iLembe District located on the east coast of KwaZulu-Natal Province. Ilembe is one of 11 district municipalities ('districts') in the province and is home to approximately 560

<sup>33</sup> Bojanala Platinum District Municipality (2009)

<sup>34</sup> Department of Health (2006)

<sup>35</sup> Statistics South Africa (2001)

<sup>36</sup> Statistics South Africa (2001)

<sup>37</sup> Senqu Local Municipality (2005)

<sup>38</sup> Department of Health (2008b)

500 people.<sup>39</sup> The official DoH HIV/AIDS statistics indicate 14.4% HIV prevalence in iLembe; however health officials there suggest that the epidemic is more wide spread than official reports indicate.<sup>40</sup> HIV prevalence among antenatal women in iLembe District is estimated at 35.8%.<sup>41</sup>

#### 4.2.5 Nongoma

Nongoma local municipality is one of five in the Zululand District Municipality, which is part of a larger historical area known as Zululand, an area of KwaZulu-Natal Province. It is a predominantly rural municipality, with poor access to electricity and telephone networks and poor roads; it is a very traditional part of Zululand and home to the royal palaces of the Zulu nation. Nongoma has a population of approximately 199 000, or about 25% of the district's population.<sup>42</sup> HIV and AIDS is an obvious challenge facing the population as Zululand District Municipality has an estimated HIV prevalence of 36.1% among women attending antenatal clinics.<sup>43</sup>

#### 4.3 Key informant interviews

Key informants were selected after consultation with the sub-district health officials who were familiar with their area and who had an understanding of leadership and community structures in the area.

The following areas of expertise were covered in choosing the key informants: 1) government department efforts to promote the PMTCT programme; 2) leadership and coordination of PMTCT services; 3) civil society efforts to promote HIV prevention in general, as well as through PMTCT, HIV testing, and counselling and support; and 4) community leadership. It was expected that the district health officials would be able to make appropriate referrals to cover all of these areas. They were asked to refer the researchers to both government and civil society experts and leaders.

The key informant interviews focused on the following topics: current and past PMTCT programmes, including leadership, coordination and outreach efforts; the focus of

the PMTCT intervention, including whether family planning has been promoted as an approach to PMTCT; problems with existing PMTCT efforts and the perceived reasons for poor performance; local opportunities and community attitudes regarding HIV testing; existing HIV-related counselling and support initiatives; and the socio-economic, cultural, religious and gender issues that may impact on PMTCT uptake.

#### 4.4 Focus group discussions

Focus group discussions (FGDs) were used to elicit the perspectives of the participants in each community on key issues relating to PMTCT-service delivery and uptake. The types of focus groups and the issues they explored are described below. FGDs are an effective medium for understanding points of consensus and difference in communities, and towards this end efforts were made to recruit members within each focus group using the principle of maximum variation. This meant having men and women and people of different ages and marital and parenthood statuses within each group.

##### 4.4.1 Selection and recruitment of the participants

An over-recruitment strategy was used whereby 14 participants were invited to participate in each group; it was likely that this would yield the optimal 8 to 12 individuals per group, as recommended in the literature.<sup>44</sup> Contact persons at each research site were identified and made responsible for contacting FGD participants and securing venues for the discussions. The recruiters were reimbursed for their time and any costs incurred (such as transportation).

The five types of focus groups brought together at each study site were:

*Women of child-bearing age (18 to 50 years)* – including women who did not have children, single mothers, mothers in ongoing relationships with the fathers of their children, and mothers with children of child-bearing age. It was important to include those who had been exposed to PMTCT communication by virtue of having given birth at facilities where PMTCT was promoted, and also people who

39 Statistics South Africa (2001)

40 iLembe District Investment Brochure (2008)

41 iLembe District Investment Brochure (2008)

42 Zululand District Municipality (no year)

43 Department of Health (2008b)

44 Patton (1987)



had never been pregnant or had never participated in the PMTCT programme, in order to understand their exposure to PMTCT as well.

*HIV-positive women* – including women who had utilised PMTCT services – were engaged to understand how PMTCT was being promoted and the elements of success of the programme in their area in addition to the flaws in PMTCT-related social mobilisation and communication.

*Men aged 18 to 50 years* – including single and married men, and men with and without children. By and large, men have not been involved in PMTCT interventions and it is important to consider their roles in supporting or hindering women who engage PMTCT services and practices, which includes the extent of men's support for their female partners undergoing HIV testing.

*Healthcare workers, reproductive health practitioners, health providers* involved in PMTCT services.

*Elderly women* who potentially have a role to play in pregnant women's lives.

#### 4.4.2 Focus group discussion procedures

FGD guides were developed for the five categories of groups. Three days of fieldwork were planned for each site. However, the researchers needed to return to some of the sites for a second round of data collection to fill in missing information. The research team also realised a need to have FGDs with older women as they were reported as being influential in pregnancy-related decisions and childrearing.

Once the focus group participants had gathered, a preliminary discussion was held to ensure that all participants understood the purpose of the research and the contents of the focus group participant information sheet. The FGDs each lasted for up to two hours.

#### 4.4.3 Data management

The audio data were transcribed and translated. In cases where the transcription was done by someone other than a facilitator, the facilitator checked the accuracy of the transcription prior to the data analysis. In cases where the participants had used deep vernacular to express themselves, the facilitators communicated with the translator/transcriber to ensure a mutual understanding of the thoughts expressed. The transcribers were chosen on the basis of their competence in the language of the participants.

#### 4.4.4 Data analysis and report-writing

After completing each FGD, the facilitator and co-facilitator teams wrote a brief summary of the key themes that had emerged from each FGD. This was followed by a one-day workshop where the researchers met to share the main findings and to reflect on the fieldwork processes and study limitations. Afterwards, the transcripts were distributed to the researchers allowing them to familiarise themselves with the data and to identify dominant themes and codes emerging within each category of focus group participants.

A second workshop was held wherein each researcher presented his/her findings and these were compared to the findings of the other researchers, resulting in the development of certain generic themes to inform the analysis and write-up. Notes from the key informant interviews and transcriptions of the FGDs were managed and analysed using NVivo8 software. This facilitated coding, annotation and extraction of data, and the construction of thematic and interpretive accounts. It also allowed construction and visualisation of complex relations between elements of the data. The data was analysed with a view to identifying PMTCT communication interventions most likely to yield a high impact and to facilitate diffusion of PMTCT information to where it is most needed and most likely to have the intended effects.

#### 4.5 Ethical considerations

Ethical approval was received from the research ethics committee at Rhodes University (Grahamstown, Eastern Cape Province). The KwaZulu-Natal Provincial Department of Health granted permission for the study to be conducted in KwaZulu-Natal. The researchers adhered to rigorous ethical requirements for conducting research on sensitive topics. The participants were given a detailed informed-consent document that outlined ethical issues relevant to the study; they were allowed time to read the informed-consent document, and the facilitator explained its contents using the language(s) the participants were most comfortable with. All participants in the study signed an informed consent form.

#### 4.6 Study limitations

The general tendency of health officials to defend the local healthcare system worked against exploring the realities, challenges, and failures of the PMTCT programme. The health officials tended to report successes, positive outcomes, and compliance with government guidelines rather than discuss the problems or challenges that may lead to low PMTCT uptake at their sites. In addition, strong oversight by DoH personnel during the research, and their involvement in recruitment of the respondents, is likely to have limited the critical perspectives of the health services by the users. Attempts were made to compensate for this by conducting additional FGDs and interviews which were more representative of a broader community.

The women living with HIV who participated in the study were mostly members of support groups; this must be borne in mind as women who are not support-group members, and/or have little or no psychosocial support otherwise, would be likely to report different experiences and perceptions regarding PMTCT. However, this limitation was partly compensated for by participants who did report on their broader social circumstances and not only on their personal situations or life histories.

A DoH and JHHESA initiative prior to the research fieldwork involved PMTCT community dialogues in some of the areas covered in the study. This likely led to a more positive overall picture of community engagement than would otherwise have prevailed, since some communication activities were spurred by the JHHESA dialogue process; for example, some healthcare workers had started door-to-door visits to educate people about health services, including PMTCT. To a limited extent this may have created the general impression that there are greater levels of community activation around PMTCT than is the case. On the positive side this provided insight into understanding community level HIV prevention opportunities, and we have factored in the effects of the JHHESA interventions in drawing conclusions about the situation on the ground.

## 5 Findings

The findings are divided into three sections. The first section focuses on the participants' general knowledge of

PMTCT and the entry points to PMTCT. This is followed by a discussion of the obstacles to PMTCT uptake. The last section deals with the involvement and engagement of men in PMTCT. The discussion is enriched with quotes from the participants to illustrate certain points.

### 5.1 PMTCT knowledge and access

This section focuses on knowledge of and access to PMTCT information. We begin by looking at the general levels of PMTCT knowledge among the groups of participants, and move on to consider the sources of PMTCT information ('entry points' to PMTCT), the barriers to successful PMTCT communication and uptake, and how these barriers can be overcome.

#### 5.1.1 General knowledge about PMTCT

Knowledge about PMTCT and related issues varied among the groups of participants, with men and elderly women appearing to be the least-informed groups. Among the five categories of focus groups, women aged 18–50 and HIV-positive women who belonged to a support group based at a health facility were relatively knowledgeable about PMTCT, while men aged 18–50 and elderly women were the least knowledgeable about PMTCT. Health workers demonstrated extensive knowledge about PMTCT during the FGDs.

These different levels of knowledge among the FGD participants merit further description. For example, knowledge about PMTCT services among women aged 18–50 can be best described as basic. These participants said they had heard about PMTCT services from various sources (e.g., media, health centres), but were imprecise about what they knew when probed about their knowledge. The following quote illustrates this point:

We know that there is such a programme but we do not know the procedure. What I know is that when you are pregnant you are not supposed to test later than seven months. It would be too late. But I do not know other details. Maybe they only give such information to those who are on the programme already. I do not know how it works; I only know that it helps the child not to get infected. (FGD, women aged 18–50, Moretele)





In one focus group with women aged 18–50 several participants reported a complete lack of knowledge about PMTCT. When a facilitator asked, ‘What is your understanding of PMTCT; do you know anything about it?’ a few participants answered ‘No’ or ‘I don’t understand.’ Although isolated cases, these responses show that participants in the same category of FGD did not share an approximately equal knowledge or lack of knowledge about PMTCT issues; instead, notable differences in levels of general knowledge existed within and between groups, and these will be reflected in the quotes included throughout this report.

Women who were HIV-positive and using PMTCT services were fairly knowledgeable about PMTCT processes. These women were able to describe what steps a pregnant woman needs to take to protect her child from contracting HIV – from doing an HIV test, undergoing counselling, how to use nevirapine, and how to take care of the child after the birth:

We know that when you have been diagnosed and you know your HIV status you should disclose to your partner or a family member. When you know your HIV status you have to use a condom so as to protect the baby; when you are due to deliver the baby you have to take nevirapine. You take nevirapine when you are in labour. When you are due to deliver you get nevirapine. (FGD, HIV-positive women, Nongoma)

To me a person has to know about her HIV status, and if you are positive you must start using condoms when having sex with your partner. Then there is treatment that you get and you must use it as explained to you in the clinic; then at seven months you get a tablet, then when you are in labour it is when you can take that tablet, and when you have a baby, it also gets syrup. (FGD, HIV-positive women, Senqu)

When a mother is HIV-positive she is not supposed to breastfeed; there is formula milk given to mothers to feed the baby and there are bottles given to the mothers and they are forbidden from using teats. There are measurements that the mother should follow when using formula milk and not say, ‘My child eats a lot.’ You should stick to those measurements no matter your baby’s weight. (FGD, HIV-positive women, Senqu)

Among the men interviewed at all the sites (different sub-districts), knowledge about PMTCT issues was generally limited. In particular, the male participants in at least four sites expressed scepticism about the whole process of PMTCT-service provision for women and babies, saying it

was unclear (how it is done) and unrealistic. One issue that the men grappled to understand was how a child who is born of an HIV-positive parent can end up HIV-negative. They felt that such a child should automatically be HIV-positive because it ‘carries the parents’ blood’:

I am confused as to how the baby can be born HIV-negative from an HIV-positive mother; I really want to understand that...how can an HIV-positive mother give birth to an HIV-negative baby? No, I want to understand this...I’m not denying that, but how does it happen...the mother’s blood is the baby’s blood. The HIV is in the blood.... The blood is the same. (FGD with men, iLembe)

When the child is not yet born the mother is the one who can infect her. The mother can be HIV-positive but the child can still be negative. This is confusing because the child is made from a man’s sperm and the father is HIV-positive. Why the child comes out negative really confuses me. (FGD with men, Moretele)

Older community members – both males and females – said they did not know much about PMTCT services. For instance, it emerged from discussions with elderly women that although PMTCT is often talked about at clinics and in the community, they themselves lacked information about the process:

We don’t know but we hear about it, that a pregnant woman must come to the clinic so that HIV is not transmitted to the baby – how transmission occurs we don’t know. (FGD, female community elders, Senqu)

During FGDs the facilitators sometimes assumed reverse roles as providers of information about PMTCT instead of receiving information, as was the case with elderly women from the Eastern Cape, North West and Free State provinces. For instance:

Facilitator: Have you heard about the PMTCT [explained in Setswana] programme?

Group: No.

Facilitator: You have never heard of it?

Group: No.

Facilitator: No single person here has heard of it?



Group: No.

Facilitator: There is a programme called PMTCT. The Department of Health has put in place a programme through which infection from HIV-positive mothers is prevented to their babies. I am here to do research concerning this programme.

Group: We have never heard of that. (FGD with older women, Moretele)

Various reasons can be inferred for the different levels of knowledge among the participants. A key reason is embodied in the observation made by participants about the ways in which information about PMTCT services is communicated. Most participants said that communication about PMTCT takes place mainly at health facilities. Health centres are frequented mostly by women – either pregnant or not. According to participants in the various categories of

FGDs, most men do not use health facilities; hence they miss out on information about PMTCT:

Females know more about it because they are the ones who frequent healthcare centres. Females know that they are HIV-positive when they come to the clinic because of pregnancy. Chances of me coming to the clinic are very slim; sometimes I get to know (about PMTCT) after she has been to the clinic. (FGD with men, iLembe)

The notion that PMTCT is a mother-centred intervention reverberated throughout the discussions with men. This notion was largely expressed as a form of a protest, with most of the men feeling that they are deliberately excluded from the process. They regarded this as unacceptable and as a feature that set the PMTCT programme up for failure:



What I can say is that this whole business you are talking about [PMTCT] is mother-centred. So, I think they need to broaden our knowledge as well, as to how this thing works, for, if they mainly talk to women, most of us...like myself, I know there are certain pills, but how they work I don't know, and actually I don't care. But if it's mother-centred, then I don't see it being successful. (FGD with men, Nongoma)

As mentioned, HIV-positive mothers appeared to be fairly well informed about PMTCT services, and unlike other groups who had only a superficial understanding of the programme they typically possessed a fairly detailed understanding of it. Further engagement with these women, however, revealed a few PMTCT issues they were not knowledgeable about and which needed to be communicated to them. Perhaps the most important was why PMTCT is not 100% assured if the protocol is indeed followed by an HIV-positive woman. There were participants in the focus groups whose children had tested HIV-positive, despite them having followed all the procedures communicated by their healthcare providers. These participants were confused and did not understand what could have gone wrong:

I tested HIV-positive when I was pregnant, then I gave birth to my baby who turned out HIV-positive too. I had done all the PMTCT protocol to protect her, but still. I told my mother and sister as well as my partner; they were all supportive. It's just that my baby is not well right now. (FGD, HIV-positive women, Nongoma)

When I tested HIV-positive then they checked the baby and advised that I do not breastfeed but use formula. Even then it is not clear because as we speak my baby has been admitted to hospital as she is sick. (FGD, HIV-positive women, Nongoma)

There is a need to be cautious when considering the case of patients whose babies test HIV-positive and who may claim that they were misinformed about the actual efficacy of PMTCT intervention or who claim to have correctly followed the PMTCT procedures. It is not clear from the FGDs with HIV-positive pregnant women whether their healthcare providers had communicated PMTCT as offering complete protection from vertical transmission or else had explained that there was still some risk of an infant contracting HIV.

It also emerged during the discussions that some women deliberately broke certain rules communicated to them

by their clinic regarding PMTCT procedures. In KwaZulu-Natal, for example, a few women admitted to having deviated from suggested PMTCT procedures because they were either pressured to do so by their family members or else found the procedures incompatible with their personal situation. For instance, some women admitted that they practiced mixed-feeding, despite being told not to do so by healthcare workers:

Facilitator: Do you sometimes mix-feed?

Participant 9: Yes I did, and fed him some Purity soft porridge; I could not sleep with the baby crying because he was not full.

Participant 8: A baby cannot get full with liquids only; even you as a grown up, you cannot live on porridge all the time.

Facilitator: When do you start feeding them porridge?

Participant 9: At three months....

Facilitator: Doesn't that cause any problems?

Participant 9: No, not at all they grow up very well. You cannot see that they are sick; they are nice and plump. (FGD, HIV-positive women, iLembe)

This extract illustrates two important points. First, a child's positivity is not always a product of a mother's lack of knowledge about what she should do to prevent this. The excerpt above shows that mothers may flaunt the rules because their own judgement of what constitutes adequate nutrition may supersede biomedical expertise. Second, there is a need to be explicit about the actual risks involved in various infant-care practices. At the moment it seems that women are merely instructed on what to do without being given sufficient information about the rationale for certain restrictions; allowing them to introduce their own variations without realising that these involve HIV transmission risk. The notion that an infant cannot be "full" or adequately nourished through breast milk alone needs to be countered with the fact that 'breast milk is enough'. The challenge is how to communicate this given the norm of mixed feeding outside the context of HIV.

The level of knowledge about PMTCT services among the healthcare workers varied depending on the portfolio that the individual occupied. Healthcare workers who were directly involved with pregnancy and reproductive-health

issues knew more about PMTCT compared to healthcare workers who were only partially involved with these issues. The NGO representatives were generally evasive in response to questioning about their knowledge of PMTCT issues. This may be due to insufficient information at their disposal as leaders of organisations, combined with expectations that they should ‘know more.’ Most of the NGO representatives said that they attended PMTCT training workshops – but this did not seem to be happening on a regular basis. Hence, they often lacked confidence when talking about their knowledge of PMTCT services:

My knowledge of PMTCT is, maybe, somebody is pregnant and has to go to the clinic to get tested: if I test [HIV-] positive this means I can get treatment, maybe the nevirapine or something like that, or maybe during labour so that the treatment can make the virus dormant. I get my information from attending workshops, like, last time when attending a workshop on PMTCT, they told us a woman can breastfeed a child for six months; now they have changed – they said I can breastfeed my child for three months. You know information changes all the time. (interview, NGO representative, Moretele)

NGOs – including CBOs – are an important link between health facilities and communities. But limited knowledge among them about PMTCT means that communities will either get incomplete information from them or will not be educated at all. An NGO leader in KwaZulu-Natal mentioned that NGOs ‘speak the language of the community’ – therefore, the government should use them as an entry point into the communities.

Sources of information are also an important factor to consider when dealing with varied levels of knowledge about PMTCT services. During the research it emerged that men and community elders learn about PMTCT mainly from media and other informal sources, such as personal conversations. On the other hand, women (particularly pregnant women) mostly learned about these services directly from a clinic. Community leaders and NGO representatives benefited from their regular interactions with healthcare workers through attending workshops:

I work with the Department of Health because I was nominated by other chiefs to represent them, so I serve in board meetings and also serve in the LSA [local service area]. (interview, male community leader, Senqu)

I have got this knowledge through the workshop organised by the Department of Health. So usually we attend the workshops and they provide us with information about PMTCT, pamphlets and all the stuff. And then during the workshops we used to take some notes and take that information and bring it to our manager as a monthly report. (interview, female community leader, Free State)

The context of learning is important in relation to the types of details that it provides. For instance, informal learning through radio broadcasts is not likely to provide sufficient, detailed information about PMTCT. People might hear about these services and the importance of utilising them, but not in great detail:

We do hear them talking about it, like on the radio. They say the doctors do help if a mother has that problem, that he can give a mother something to protect her child. That’s all we hear. (FGD with older men, Senqu)

The participants who learnt about PMTCT from a clinic seemed to possess far better understanding of the service:

We know that when you are HIV-positive, after you have tested and you are maybe pregnant, they are going to give you treatment. At some point when you have labour pains, it is when you take the pill – but you don’t drink it, you must take [it] to the clinic or hospital and tell them you are on the programme. You are then monitored so as to take it at an appropriate time, because sometimes you would drink it only to find that the baby was just turning. (FGD, women aged 18–50, Moretele)

The clinic staff explained to us, when we come here as pregnant women, that if you are HIV-positive you will be given treatment. Then the day you go into labour, there is a pill called nevirapine that you take and [your] child will be safe. (FGD, women aged 18–50, Free State)

The findings discussed so far point to varied levels of PMTCT-related knowledge among the participants. These variations are a product of many things, such as where and how information about PMTCT is communicated and how the various actors are positioned in relation to PMTCT communication in the health system. For example, men’s lack of knowledge seems to be both a product of their under-use of public health facilities as well as a product of where they are socially positioned in this sector once they access it vis-à-vis





women (that is, as marginalised and less important actors). Therefore, the focus of the PMTCT programme appears to be on women, even when men are also attending the health facilities providing the service. This calls for a shift in mindset among healthcare providers at these facilities, towards engaging men as equally interested and important actors in issues related to pregnancy and PMTCT. Most of the men participating in this study expressed a need to know more about PMTCT services, yet they felt that health facilities either neglected them or treated them as insignificant actors in matters of pregnancy and PMTCT.

Older community members felt equally marginalised on pregnancy and PMTCT issues. These actors saw themselves as key stakeholders in pregnancy and PMTCT, first because they are parents and therefore have inherent interests in the pregnancy of their children; secondly, because they felt that they have expertise, which they may share with these mothers on how to take care of their pregnancy and raise a child.

### 5.1.2. HCT as a point for initiating PMTCT

HIV counselling and testing is recognised – and recommended – by the World Health Organization (WHO) as a necessary first step towards safer pregnancies; therefore, women are encouraged to check their HIV status before becoming pregnant in order to make informed choices earlier during their pregnancy. At all the study sites, participants from all categories indicated that most people were not in favour of testing for HIV. Most people tend to test for HIV only when they are already sick or are pregnant:

People test only when they are sick. You would start getting sick and then I would tell you ‘Go to the clinic’ – so they would tell you that it is about time that you take a blood test. The only people who test mostly are women; men would wait until he can’t walk anymore. (FGD, women aged 18–50, Moretele)

My brother...what I can tell you is...do you see us as we are sitting here now in this clinic? ...I can tell you that out of all of us here only two people can agree to be tested. I’m trying to tell you that here at the clinic they can actually check this thing; they only prick you here. But I tell you; only two people can agree to be checked among all of us here. The point I’m trying to make is that people don’t want to come to the clinic to check ‘whether I have this thing or I don’t have it’. (FGD with men, Senqu)



People are scared to do an HIV test. Even myself I don’t know my status because I’m too scared to go there. Even our parents are also scared to tell people that [in case] I died of AIDS; they will always cover up with other things, such as TB, witchcraft, ancestral calling or other diseases. (FGD with men, Moretele)

The participants provided a number of reasons why people in the general population are reluctant to undertake an HIV test. First, the idea of a voluntary HIV test was resisted because most people interpreted the results as meaning the person could get sick soon and then die from opportunistic diseases caused simply by the stress of testing positive. An HIV-positive result was described as being too difficult to accept, leading to this stress. This was a general sentiment throughout the interviews and FGDs:

People do not go for VCT, because...now I'm speaking about the home-based carers that I'm always in contact with. When I speak with them they will say people are so afraid to test. They are afraid because they still feel that once you are HIV-positive, it is a death sentence. ARVs are available to them, the awareness is there, but I really don't know. (interview, NGO representative, Senqu)

You see, for me to know that I'm [HIV] positive would mean something else because I'm better not knowing if I'm positive or not. Now if I test, and find positive results, my life will be miserable and I'll be having this feeling that, 'Eish, I will die.' I know that when they counsel you they say it is not the end of life, but fear, you see. Right now I don't know my status and I am living freely. (FGD with men, Nongoma)

Second, stigma was highlighted as a main reason for refusing a voluntary HIV test. Stigma was said to manifest itself through the ways in which society perceives and treats an HIV-positive person as an outcast or inferior to other people. One man elaborated on the problem of social exclusion and marginalisation for someone who is HIV-positive:

The point I'm making is that the main reason why we stay with this thing: we become thin [sibhityela esibrukhwani], yet not checking ourselves, it's because we don't want to be discriminated during cultural rituals [emigidini]. Because this is rural areas and we are poor, so for me to eat meat I must wait until a certain family has slaughtered a cow or maybe making a ritual, then I go and get that piece of meat. Now if I publicly disclose my HIV [status], that will result in being discriminated now and people will laugh at you. (FGD with men, Sengu)

The fear of social discrimination due to being HIV-positive was expressed in relation to the context in which the participants were living. In four of the study sites – Senqu, Nongoma, iLembe and Moretele – participants said their fear of stigma due to an HIV-positive test result emanated from the fact that these are rural areas where personal information and gossip circulates quickly. Even the health facilities where HIV-testing takes place were not trusted with handling the confidentiality of HIV-test results:

...Like myself I have never been there [to do an HIV test] and I'm not sure if I will go there anytime soon.... So if I do it, it will mean I will have to tell X that I'm so and so, and I don't know if he will not go and tell Joe, and then

the whole kwaNongoma ends up knowing, as this is a small area. (FGD with men, Nongoma)

I have never gone for counselling nor do HIV tests. Maybe if I can get counselling I'll change my mind, but as for now I'm scared to do tests. There is pre- and post-[test] HIV counselling. I do not want to be counselled by these local girls because once you've tested HIV-positive the whole village will know that I'm HIV-positive. I will not test in Hamanskraal at Jubelee Hospital because before you know it, the whole village will know your status. (FGD with men, Moretele)

The fear of finding out one's own HIV status was generalised across the sites. Notably, there were gender dimensions to people's resistance to do an HIV test, with men being most resistant to testing. Men were said to resist HIV testing until such time that they are sick, whereas if a female partner has undergone an HIV test, men said that they would rely on her test result to presume their own:

What I have noticed with these young people and the PMTCT programme – as young people we impregnate girls. After impregnating a girl and the baby is born we go around saying, 'You see my baby is alive, it means I do not have AIDS because my girlfriend has a baby.' We now know that women get tested and start the PMTCT programme. When the baby is three-months old we go around bragging that 'As you can see me, I am not HIV-positive as my baby is alive.' That is what is happening. I remember a friend of mine, we were talking about that and I was saying, 'Why don't you go for HIV testing?' and he said, 'My baby is four-months old; it means I am also fine'. (interview, NGO representative, Nongoma)

Interviewer: Do men openly go for VCT?

Participant: It's where we are still experiencing problems, especially young men. Even when they have been diagnosed with HIV, they do not go for treatment. They don't want to queue for treatment. (interview, male community leader, Eastern Cape)

There were few cases related by participants in the focus groups whose experiences either confirmed or contrasted these constructions. For example, one participant shared his experience of having resisted an HIV test until he was too sick:



Like in my case I was very sick at some point and I needed to do a blood test before I could receive help, so that time I had to know whether I'm HIV-positive or not. (FGD with men, Nongoma)

In the Free State, at least two participants said they had tested voluntarily without being sick. These different experiences show we cannot lump community members as people who share an equal fear about an HIV test. While there are people who resist testing because they fear the personal consequences to their health and the unfavourable responses from their community, some are able to overcome these fears and undertake an HIV test.

Lack of HIV testing was described as a serious concern by the healthcare workers because it interferes with the effective uptake of PMTCT services. For example, if people were agreeing to HIV testing, women in general would make better-informed choices about pregnancy. And, because an HIV-positive status does not mean a woman should be deprived of having a family, testing would enable women to plan their pregnancies properly, including doing CD4 cell count tests to determine their health status. Knowing her status would also help a woman with decision-making in regard to when to have children, meanwhile using a contraceptive method suitable to her:

Being positive doesn't mean that you can't have children. Now, all you need to do is make sure that you know the status, and that you plan accordingly. You can be on your method, and then after that you can try and check your CD4 [cell count]; if it's okay you agree with your doctor and healthcare worker, and get on the [PMTCT] programme. As long as the child is going to be delivered safely. We're not only advocating taking care of the child – [care for] the mother is also needed. So for her to be able to space her children she needs to build a method that is going to help her sustain her strength post-delivery. (interview, district coordinator, KwaZulu-Natal)

The findings on the participants' attitudes to HIV testing indicate that HCT was not popular or commonplace in the communities studied. This is notwithstanding nationwide research conducted by Shisana et al, which indicated that HCT uptake has risen among South Africans – particularly among the youth<sup>45</sup>. Fear of HIV/AIDS stigma and fear of

<sup>45</sup> Shisana et al (2009)



confronting one's HIV-test result appear to be the two main barriers to testing. These findings indicate a need to intensify HIV/AIDS education, including debunking common myths about the virus, which persist. Likewise, the fear of stigma cannot be tackled only at an individual level; rather, social mobilisation is needed to change societies' negative perceptions towards PLHIV.

### 5.1.3 The health system and clinics as points for initiating PMTCT

It was a general finding that clinics are a first point of communication about PMTCT services to pregnant women. According to HIV-positive women this communication takes place either in waiting rooms or during ANC classes. There are PMTCT programme classes that HIV-positive pregnant

women are 'enrolled in when they have checked/tested your HIV status' (FGD HIV-positive women, iLembe). Other participants (women aged 18–50) did not specify where or when within the clinic setup this communication took place.

For women to be enrolled in the PMTCT programme, certain procedures have to be followed, as indicated by various participants:

Each woman that goes to the clinic for the first visit, she must be given VCT [counselled], and after that she must be tested. Then if you find that she is HIV-positive, you will draw the blood for a CD4 count and send it to the laboratory. If her CD4 count is less than 350<sup>46</sup>, you must start her on ART or you refer. We implement dual therapy – AZT and nevirapine – at 28 weeks. We just follow the PMTCT policy. (sub-district manager, Free State)

To start with, we have got VCT – that is where first-timers are voluntary counselled and tested so that they know their status. When they are tested and know their status, if one is [HIV-] positive, she goes on for PMTCT if she is pregnant. Then, she enters the PMTCT programme where we will be looking at the CD4 cell count. If the CD4 cell count is below 350<sup>47</sup>, that individual has to be started on ART. Within the PMTCT programme, at 28 weeks, they are given NVP and AZT, but with NVP you educate your client not to take it. She must only take it when she is in labour, and she must report to the health professional at what time she took this NVP. (PMTCT coordinator, Eastern Cape)

Okay, as an entry point to PMTCT we've got VCT. There are areas where pregnant women register, then they go to the waiting station where they get group counselling and group education. After that they go and see their nurse. (PMTCT coordinator, KwaZulu-Natal)

Apart from the PMTCT enrolment procedure described by various participants, it is important to note that healthcare workers expressed lack of patients' privacy, due to limited space in most health facilities, as a concern. According to some healthcare workers this might impact on PMTCT uptake:

Okay, the issue of privacy. There is no privacy for our patients, but in the near future we will be moving into a new

building. PMTCT will be moving out there, but for now it is a problem because we're sharing with doctors, patients, and you know? We have clients all seated in one area, so, during health education, there are reservations...there were things we could not talk about. (FGD, healthcare workers, iLembe)

Communication that is taking place in an open space while women are registering on the PMTCT programme for the first time, may impact on achieving trust and confidentiality. Also, some women may choose not to return in such circumstances. Furthermore, some women might not have enough time to ask questions, or they might be embarrassed to do so in front of others. These problems were also attributed to various systemic or structural issues, such as lack of space or shortage of staff to disseminate PMTCT information and pay attention to the needs of individual clinic users:

Yeah, it's time-consuming [PMTCT]. If it's one midwife among all these pregnant women, it becomes a problem, and the infrastructure as well, because you find that you have enough counsellors but no space to do [it]...the physical space is an issue. (PMTCT coordinator, KwaZulu-Natal)

PMTCT is supposed to be integrated into antenatal care and the view among HCW that they are unable to discuss PMTCT-related issues because 'there is no PMTCT space' raises a major concern.

This section has discussed some of the communication requirements for PMTCT and the structural constraints faced by healthcare workers in these districts. It emerged during the FGDs that one of the most difficult challenges to early and effective uptake of PMTCT services is posed by existing cultural beliefs about pregnancy in the selected communities. In KwaZulu-Natal, in particular, the participants alluded to a general attitude that regards pregnancy as something private and not to be discussed with anyone. Women who are pregnant prefer to hide rather than disclose their pregnancy, either to their families, partners, community members or healthcare workers. The main fear about openly disclosing pregnancy was that a pregnant woman might be sent evil spirits, either to inflict an illness on her or to terminate the pregnancy. According to a PMTCT coordinator who shared this observation, this belief may impact on PMTCT uptake in that a pregnant woman may delay in

46 During the study period, the cut-off was 200 except in the Free State.

47 At the time of the study this had not yet been implemented and the cut off of 200 pertained.





enrolling for antenatal care, thus missing out on opportunities for both herself and the baby:

Like I said, cultural beliefs don't allow them to tell everyone. So now if you come to the clinic, maybe someone that I know that stays in my vicinity, will know that I'm pregnant, they're going to tell someone else that I'm pregnant. If you tell people that you are pregnant early, you're not going to maintain that pregnancy, something bad is going to happen. (PMTCT coordinator, KwaZulu-Natal)

The gap between the woman's pregnancy diagnosis and her reaching the health facility means that the woman starts in late on the PMTCT programme. Comments about culture and its impact on early detection of HIV during pregnancy were limited to one study site in KwaZulu-Natal. However, the finding that women in general may take longer to seek medical check-ups during pregnancy was a generalised

finding. The implications of this conduct for successful uptake of PMTCT services are described below:

You find that the [private] doctors [general practitioners] don't have time to pre-test counsel them. The woman is still trying to deal with the issue of being told that you are [HIV] positive, and not knowing what to do after...they don't get in the programme early. By the time they reach us [public health facilities – clinics/hospitals] they are over 28 weeks [pregnant] and we are supposed to start initiating the dual therapy immediately for at least four weeks [before the baby is born], [the delay in initiation] 'does not put the child at an advantage' to make sure the child is protected from getting mother-to-child transmission of HIV. (interview, deputy district manager)<sup>48</sup>

You know, at the end of the day you have to start early all investigations regarding not PMTCT alone, so that you can

<sup>48</sup> Note that where DoH participants are mentioned, the name of the district is omitted to protect their confidentiality.

treat early, or intervene early, whatever method of intervention. So when you book late, you find that sometimes if the mother is...you find that for them to start training you for adherence it becomes a waste of time, for the woman may deliver before.... (interview, PMTCT coordinator)

Another barrier to PMTCT, according to healthcare workers, is the long waiting hours pregnant women must endure to be seen for HCT. This problem was said to be a result of staff shortages and high workloads at the facility, with long waits resulting in women losing interest and sometimes not undergoing the testing. Counselling was described by health professionals to be a challenge when facilities are understaffed; thus its success heavily depended on having sufficient staff on site:

The other issue has been the counselling rate. Most of our sites haven't been doing well in that regard because of our process mapping.... So the priority was to give this client the antenatal care and then counselling afterwards. (interview, PMTCT coordinator)

According to some of the healthcare providers interviewed, training clinic staff working in the PMTCT programme remains a challenge because it is often difficult to establish whether healthcare workers comprehend all aspects of the PMTCT intervention and whether they pass on accurate information to HIV-positive women:

Well, they got their training. It might not be immediate, it can start small, but eventually, you know, everyone has to get trained if he is providing the service. But it's just that sometimes it's not easy to have everyone come out for training because services have to be delivered. Yeah, that's our big challenge. (FGD, healthcare workers, Nongoma)

The findings in this section indicate that women's first contact with a clinic opens an opportunity for communicating information about PMTCT and other sexual and reproductive health matters. One problem is that some pregnant women begin using health services late in their pregnancy. This creates problems for effective communication and implementation of PMTCT services; first, because information about these services needs to start early so as to give a woman enough time to evaluate her options if she is

HIV-positive; second, when a woman tests HIV-positive she needs time to deal with, and accept, her test result.

#### 5.1.4 Other sites as points for initiating PMTCT

The previous section reported on clinic facilities as entry points for disseminating information about PMTCT services among women of reproductive age. However, earlier in the report it was mentioned that most community members do not receive PMTCT information directly from clinic facilities, and more often people learn about PMTCT from the media and other informal sources. Given problems at clinic level a multi-pronged approach is necessary. This section looks at sites of PMTCT information other than clinics. In particular, we focus on efforts by various branches of the Department of Health and different NGOs to reach out to the broader population rather than limiting the target group to pregnant women.

The study identified evidence of at least five different sites where PMTCT information was communicated outside the health sector, as described below.

##### A. PMTCT awareness promoted to elderly women

This outreach activity was reported in Senqu sub-district. Healthcare workers there would go to the gatherings of elderly women to educate them about PMTCT issues, especially with a view to building up support for their daughters and daughters-in-law who choose not to breastfeed. This was a follow-up to the JHHESA initiative, which organised community dialogues at this site to discuss PMTCT. Healthcare workers reported that service centres were set up using halls within a town to cater for older people's needs, such as by providing full meals. Healthcare workers used such gatherings as an opportunity to educate especially elderly women about PMTCT:

We do target old people – that is mothers-in-law and so on. We have service centres that are under a NCD [non-communicable disease] manager, these service centres whereby old people are chilling during the day and go back to their homes in the afternoon. We go there; talk to them about PMTCT. We tell them to support their daughters-in-law. We tell them when they see their daughters-in-law not breastfeeding, they should not be against the idea. They should ac-



cept it just because it may help when the daughter-in-law is HIV-positive and so on. (FGD, healthcare workers, Senqu)

#### B. *Outreach at taxi ranks and among taxi drivers*

A PMTCT coordinator reported an initiative by healthcare workers in an area of the Free State province which involved staff members visiting taxi ranks in order to speak to men about the need to support their female partners and take an active role in fatherhood. The interviewee expressed disappointment that the campaign had come to a halt due to a lack of funds and time for it among the healthcare workers. However, she hoped the campaign would continue should funds become available.

#### C. *Discussions at taverns*

This was another community campaign initiated in the Free State Province. The strategy was to reach men in places where they socialise, and to talk to them about PMTCT. The idea was to educate men about their role in PMTCT, and to target many men in a restricted space. Also, taverns were targeted because of their relaxing environment, where there was an opportunity to engage men in discussion. The healthcare workers also distributed print information in the taverns: “We have got other males that are going around to where males are; you find them in shebeens and all that, so that they can talk about all these issues.” (healthcare provider, Free State).

#### D. *Education at initiation schools for males*

In both the Eastern Cape and Free State provinces, initiation schools for males were being targeted as places to educate younger men about the PMTCT programme and the benefits of being involved in supporting a partner. Typically, adolescents and young men who are undergoing circumcision rituals stay there for an extended period and are educated about what it means to be a man and their responsibilities in society. A health provider described how they educated the leaders of male initiation-rites who in turn could pass on the messages to the young initiates: “Yes, we do communicate with male initiation leaders. We also have a committee in which these leaders serve. I sometimes provide them with health education.” (healthcare provider, Free

State) The quality and extent of such communication and education was not established, but it is nonetheless of note that healthcare providers see the need and opportunity for such work.

#### E. *Door-to-door education campaigns*

This initiative was reported in Senqu, Eastern Cape Province, as an effective way of reaching people and addressing any questions related to health. To carry it out, healthcare workers explained that once a month their offices were closed, leaving the local service area manager to manage the sub-district office. Their target audience was young people, hence they also visited schools.

There was also evidence of proactive campaigns led by a number of NGOs. For example, in Ulundi local municipality in Zululand District, KwaZulu-Natal Province, the DoH has teamed up with a CBO called ‘mothers to mothers’ (m2m), which is comprised mainly of women who are HIV-positive. These women meet other women at the hospital and follow up with them to provide PMTCT information and support.

#### F. *Other types of outreach*

The researchers came across other types of PMTCT-related outreach in the communities. Especially, the presence of JHHESA at the study sites (sub-districts) has contributed to the development of community initiatives for PMTCT. For instance, after JHHESA had initiated dialogues on PMTCT, healthcare workers in kwaNongoma, KwaZulu-Natal Province, took it upon themselves to mobilise community support for PMTCT, such as through community discussions.

These observations show that some community-led PMTCT-related activities are already underway and seem to be targeting relevant audiences. However, the research did not uncover evidence of knowledge about these activities among the FGD participants. Also, some key informants complained that community outreach efforts are difficult to sustain mainly due to lack of funds. The fact that healthcare workers were reportedly taking part, however, is encouraging, although such community programmes may be ultimately more feasible or effective if they are run by volunteers who have more time to invest in them.

## 5.2 Obstacles to PMTCT uptake

This section discusses two issues that were identified as obstacles to PMTCT communication and implementation: disclosure and infant-feeding practices. Disclosure is discussed in relation to its importance in enabling women to freely use PMTCT services and in terms of the difficulties that non-disclosure imposes on them. Infant-feeding practices are discussed in relation to the barriers that women experience in fulfilling PMTCT-related infant-feeding protocols.

### 5.2.1 Lack of disclosure

Disclosure of one's HIV status is normally associated with increased support for a person with HIV or AIDS, and it makes it easier to access HIV/AIDS-related services and adhere to treatment programmes. This study did not set out to investigate disclosure among HIV-positive women or other HIV-positive people in the communities, yet the disclosure behaviour of PLHIV emerged as a prominent theme in the research. Findings from the FGDs and interviews with key informants show that PLHIV have difficulty disclosing their HIV-test results for various reasons. Chief among these is a fear of social stigma and discrimination.

For a woman enrolled in the PMTCT programme, the non-disclosure of her HIV status presents specific challenges to her ability to implement certain PMTCT protocols. For example, if she must use ARVs for a specified period, the ARV protocol may be difficult to adhere to if she has not disclosed her HIV-positive status:

Some have a problem of disclosure about their HIV status at home. It becomes difficult to those on treatment to take medication as they now have to explain what the particular pill is for, if they did not disclose. (FGD, healthcare workers, Nongoma)

The problem of non-disclosure was also felt at the level of the health facility. Staff at one clinic expressed frustration about what they considered conflicting messages given at the health facility about clients' disclosure and their management of clients' HIV status. For example, it was said that DoH guidelines prohibit healthcare workers from recording a patient's HIV status in their folder; yet at the same time health officials encourage openness and a non-judge-

mental attitude towards cases of HIV infection. In support of the latter, healthcare workers expressed a concern that codes are used to refer to the HIV status of a patient as this was perceived to perpetuate a lack of disclosure, which may also lead to self-stigma:

Like for instance, when a person is ill and the doctor does the diagnosis, he writes something else instead of 'HIV-related illness,' then the person holds to that when knowing that it is not so. As long as 'HIV' is not written on paper, people will always not disclose it. (interview, healthcare provider, Free State)

Our interviews with various participants explored perceptions about why disclosure was difficult for pregnant women and the community in general. Fear of stigma emerged as a main barrier to disclosure, with some people indicating that someone with HIV is not treated equally in the community; he or she may be seen as socially inferior, and disclosure may lead to rejection by the individual's family or community:

For me all I can tell you is that this AIDS doesn't exist here; it doesn't exist at all. You will hear that someone has it, but he will tell you directly that he doesn't have it.... The next thing you hear is that he died. The main problem here is that this thing is hidden; if you dare speak openly about HIV they will beat you up. So it's something that doesn't exist, yet it is killing the population...even if someone dies from it you will be told he died from a cold; they don't say he died from [AIDS]. (FGD with men, Senqu)

Comments like this were expressed across the sites, indicating fears of stigmatisation and rejection as the main reasons for concealing HIV-test results. In interpreting these comments, however, there is a need to be aware of the gap that normally exists between discourse and practice. As it will be seen from the discussions about breastfeeding, the fear that HIV-positive people will be discriminated and rejected in their families does not always reflect the true attitudes of family members towards a person's HIV-positive diagnosis. Older people in the communities often felt strongly that HIV-positive women should disclose their test results in order to receive help and support. There were also no reported instances among the participants of women having been rejected by their families and communities because of having HIV.





HIV-positive female participants generally feared that if they disclosed their HIV status to their family, they would be perceived as responsible for transmitting HIV. Thus silence was perceived as a safer option. Women generally lived in fear of their mothers-in-law, whom they frequently described as insensitive and judgemental. Interviews conducted with community elders (including mothers, grandmothers and mothers-in-law), however, contradicted these accounts of them as insensitive and uncaring to their daughters-in-law. Mothers-in-law showed a keenness to help and support their daughters-in-law, and they cited lack of disclosure as a main barrier to their involvement. These different responses suggest a lack of communication about HIV in households. Women hold certain views about their mothers-in-law which do not perfectly represent the latter's true feelings about HIV in relation to their daughters-in-law. Thus, the public discourse that exists about them is not always reflected in their actual behaviour.

Men were often portrayed in the same way as mothers-in-law. The participants described men as unwilling to discuss HIV issues with their partners, saying that when a woman discloses to a man he is likely to respond in a violent way. Even so, comments from the FGDs with mothers supplied no evidence of violence against HIV-positive women by their partners, although it seemed to be a widely held view that impacts heavily on how women chose to manage their HIV-test results. The literature review suggests that in other parts of the world, women hold similar beliefs about their male partners (as being potentially violent in this situation).<sup>49,50,51</sup> There seems to be a public discourse about men that portrays them as inherently violent, yet researchers' direct engagement with men or their female partners has contradicted that discourse. Perhaps this points to a need to improve communication between partners by speaking openly about their views and feelings for one another.

The findings in this section indicate that non-disclosure of HIV status remains a critical challenge among PLHIV, and that for HIV-positive mothers it remains a key challenge for successful implementation of PMTCT. More encouraging, however, is the support and keenness that family mem-

bers seem to have for women close to them to disclose. This requires improvement of communication in the household.

### 5.2.2 Infant-feeding practices

Infant-feeding is a critical aspect of PMTCT services and communication. It emerged from the literature review as an area where there is substantial misinformation and confusion between healthcare workers and pregnant women. Part of the enquiry was to find out whether or not there were clear guidelines regarding infant-feeding at the study sites, whether these guidelines were clearly understood by the staff, and whether they were being properly communicated to pregnant women. The literature review noted that staff may be biased towards one form of infant-feeding, leading to concealment of vital information that could enable a woman to make an informed decision about feeding her infant. Or staff may be coercive and therefore give women no opportunity to make up their own minds.

The district managers and PMTCT coordinators at all sites reported having clear policy guidelines on infant-feeding. The policy guidelines state that a woman must either exclusively breastfeed for six months or else use bottle-feeding. Importantly, women must not mix-feed:

We emphasize exclusive breastfeeding, at least for six months, and then if it's formula they must not mix-feed, we also emphasize on that one. And the dangers now of formula-feeding, or if using a bottle – so if you opt for formula at least be aware of the dangers, or at least use the cups instead of the bottles. (district PMTCT coordinator)

The official policy guidelines state that women should be given a choice between either exclusively breastfeeding or formula-feeding. A woman must therefore choose the form of infant-feeding that suits her own needs and situation. One district manager stresses this point and how women may be supported in making such a choice:

Interviewer: How do they communicate breastfeeding or feeding options?

Participant: Feeding options, because during training we are training them to know that they don't have to force a mother to take any option. The decision must be for [particular to the needs of] the mother. At the same time, they should look at things like affordability. If the mother now

49 WHO & UNICEF (2007)

50 Zambia Central Board of Health (2004)

51 King et al. (2008)



chooses to take formula-feed, she should be able to know if this mother will be able to afford to buy this milk, because yes, of course they are given the milk at the clinic, but at times the milk gets out of stock, so what is she going to do? So, when they counsel them, they also give them such information so that the mother can choose the correct option that she will be able to sustain it for that period of six months. (interview, district manager)

An important aspect in the communication of infant-feeding options was said to be counselling. A district coordinator stressed the importance of counselling mothers, saying it must be an ongoing process until such time that a mother has fully understood it and can make an informed decision about her preferred infant-feeding option:

Every contact session that you have with this mother, you need to go back and re-counsel this mother to understand it. By the time they deliver, at least they've got an idea of which

option they have. Because you can't assume that everyone is...not going to be able to formula-feed. Some people...they don't have a problem with formula-feeding their children. Some don't have a problem breastfeeding, as long as they know what to do. (interview, district coordinator)

The infant-feeding guidelines, as shown in the above narratives, encourage consultative communication with mothers and are based on the principle of choice and the notion that a feeding option must be informed by the individual mother's socio-economic conditions. However, additional engagement with the various categories of participants showed that the actual implementation of these guidelines was quite complex. The complexity existed at all levels: first, among the health managers and PMTCT coordinators who must oversee these services; second, among the health-care workers who must communicate information about PMTCT services; and last, among mothers who must adopt their choices to their home life.



District managers and PMTCT coordinators reported that health facilities are pressured to be ‘baby-friendly’. According to these participants being baby-friendly means that they encourage breastfeeding among mothers. This was clearly outlined by one district manager:

Participant: There’s also the baby-friendly hospital initiative.

Interviewer: Oh, could you tell me a little about that?

Participant: That’s...what words do I use? They’re just trying to promote breastfeeding by using this initiative. They accredit the hospitals when they get to a point when they’ve actually fulfilled all the requirements regarding that. And then the hospital becomes accredited as a baby-friendly hospital. We haven’t got to a point where we have got baby-friendly clinics, but it is moving in this direction. (interview, district manager)

#### Another respondent noted:

So being baby-friendly means that you’re advocating for breastfeeding – exclusive breastfeeding, you know – and so sometimes people impose their views on clients because they want to achieve this status; we all want it to be 100% baby-friendly, and then [we] overlook the real person that you need to be dealing with. (interview, PMTCT coordinator)

Here, the vision of ‘baby-friendly’ facilities – an ideal promoted by the WHO globally in the interest of promoting child health and decreasing infant and child mortality – seems to be at odds with the principle of a mother’s choice for either of the two infant feeding options. It seems as if by being baby-friendly, health centres are seen in a good light compared to health centres that are not promoting breastfeeding; meaning a bias in such facilities against exclusive formula feeding which may be the desired option in a particular case.

From the perspectives of healthcare workers, the complexities in implementing the infant-feeding guidelines are vast. First, healthcare workers said they worry about whether or not women clearly understand the various options at their disposal. In one district, healthcare workers shared experiences where, despite giving women sufficient information on what infant-feeding guidelines to follow, they somehow manage to break them. For example, some women would mix-feed despite being warned against the dangers of mixed-feeding for a specified time:

Even with the feeding, they talk about formula-feeding but they don’t advise them to use bottles; but every mother comes to the outpatient with bottles. They are mix-feeding. Some PMTCT mothers are only starting with the Purity [infant formula-feed] at three months. How do you educate that mother when she was told, ‘Six months exclusively breastfeeding or formula-feeding?’ What do you do? (FGD, healthcare workers, iLembe)

Second, several healthcare workers reflected on the challenges to their own communication of PMTCT services as posed by the health facility’s need to be baby-friendly. In one district where the policy was being encouraged, healthcare workers said it was sending mixed messages: on the one hand, they must give women choices, but, on the other hand, they are encouraged to work towards achieving a baby-friendly status:

How do you balance the model of a baby-friendly clinic and the choice of feeding method for the client, as baby-friendly stresses on breastfeeding? DoH says it is their client’s right to choose a feeding method. Now as a healthcare worker you have to ‘coerce’ the mother to breastfeed. On one hand you have to tell her she has a right to choose...you are trying to build, but in an improper way. (FGD, healthcare workers, Nongoma)

Some healthcare workers expressed a sense of powerlessness regarding their own role in influencing a mother’s infant-feeding choice. Some policy experts recommend that healthcare workers look at a woman’s economic status in order to decide whether she can afford infant formula,<sup>52</sup> which would include her individual ability to meet the ‘affordable, feasible, accessible, safe and sustainable’ (AFASS) criteria.

There is another problem with formula-feeding, with PMTCT. Because in the workshops that we attend for PMTCT, they say you look at the status of the mother: if that mother can afford to formula-feed or to breastfeed [you encourage her to continue]...if the mother cannot afford to formula-feed, you let the mother continue with breastfeeding. (FGD, healthcare workers, iLembe)

52 Department of Health (2008a)





Healthcare workers sometimes felt that despite whatever advice they give, its realism and implementation are subject to the specific conditions that women face in their homes and living environment. The formula feeding option may expose a child to other health risks. For example, the issue of clean water in some deep rural areas remains a challenge when making formula for the baby, which means that the child will be susceptible to acquiring certain water-borne diseases, as described below:

If a woman chooses formula she must use a cup, not a bottle, as there are complications. There is not enough water and electricity in these areas. Electricity is only for cooking, meaning there is no heat to warm the baby's milk. In certain areas there is no water and electricity. I tried to speak to [the] municipality about provision of better water services, as you find that in one pond a cow drinks, a donkey pisses,

human beings fetch water for drinking. You find a despicable situation. (FGD, healthcare workers, kwaNongoma)

In such cases, applying the AFASS (acceptable, feasible, affordable, sustainable, safe) principles for infant nutrition in circumstances where there is no safe water supply, formula feeding should be ruled out. The quote above suggests that some healthcare workers themselves do not adhere to the AFASS criteria in the advice that they give to women; pointing to a need for better communication of the criteria to carers.

There was also the issue of working mothers, which the healthcare workers referred to as a challenge to proper PMTCT communication and adherence to infant-feeding guidelines. Working mothers give their children to someone else to look after them (mainly grandmothers and nannies). "It makes it difficult for us to ask – we don't know



whether the mother did disclose [to the carer] her own status or not". (FGD, healthcare workers, iLembe). This was said to present serious challenges for follow-up visits, as some mothers do not disclose their HIV positive status to child carers.

The above discussions have dealt with the communication and implementation of PMTCT infant-feeding guidelines from the perspective of health providers. The findings show that while there are clear guidelines to follow regarding how to communicate infant-feeding options, these guidelines are sometimes difficult to adhere to due to factors within the home and outside the realm of the healthcare facility. Other difficulties that were experienced in regard to communication and implementation of these guidelines occurred at the community level and the report now focuses on mother's experiences of this.

Almost all participants – including HIV-positive mothers – commented on what they thought were the main challenges faced by women in implementing infant-feeding options at home. These comments stressed three issues. First, women are not isolated units, but they live in a society and the society shares certain understandings of what constitutes 'correct' and 'acceptable' infant-feeding conduct. In the case of all the study sites, the acceptable conduct was that mothers should breastfeed as a primary infant-feeding practice; breastfeeding was seen as healthy for babies:

The child who is breastfed is more healthy than the child who was not, because the one who is breastfed gets all the right things, like vitamins, from the mother. The bottle is not healthy because some people are careless; they leave the bottle uncovered and flies will be all over it. (FGD with men, Moretele)

It emerged during the discussions that mothers who do not breastfeed are not seen in a good light. They may be perceived as not being committed to motherhood or else as having other motives – such as needing to look sexually attractive, or needing to resume sexual relations soon after delivery. This view was shared by participants at all the sites:

Most women prefer to formula-feed because they think their breasts will not look nice if they breastfeed. Some do not want to breastfeed because they can run their errands as they like; they will leave the baby with the granny and go their own way, all looking smart. You see her looking smart

in jeans, meanwhile she has left a small baby at home. (FGD, community women iLembe)

As men we believe that if the mother is breastfeeding she won't be troublesome because the child would be healthy. But if the child is not breastfed, he/she will get weak and unhealthy. If the mother is in a hurry to stop breastfeeding you ask yourself questions and you suspect that maybe she wants to do other things. With breastfeeding it is easy to keep an eye on her because she will be home most of the time. (FGD with men, Moretele)

Young mothers in particular were cited by one discussion group of community elders as not being committed to motherhood: they were described as being in a rush, as immediately wanting to resume sex and other youthful lifestyles (like drinking) after giving birth, often leaving their baby in the hands of a grandmother:

These girls give birth; when the child is two or three months they are going out to sleep with men again. We stayed six months in the house; you did not even see the father. But now they sleep around before they even heal. (FGD, female community elders, Free State)

These narratives indicate that breastfeeding is a favoured practice in the study sites and that a woman who does not breastfeed is badly judged and stigmatised. The preference for breastfeeding, however, does not happen to the exclusion of other infant-feeding practices. The dominant view shared in all the FGDs and individual interviews was that it is expected of a mother to give a child other foodstuffs while still adhering to breastfeeding as a primary feeding method. Mixed-feeding was said to start as early as three months, or even sooner. This was based mainly on the notions that a child who is only breastfed will not be satisfied or else the mother cannot produce enough milk:

When a baby cries a lot and the mother does not have enough milk, we give them water, soft porridge at two months. (FGD, community elders, Free State)

As soon as the child starts crying they say she/he is hungry; they feed her soft porridge, little bit watery, then they say, 'Now she has eaten; now she will fall asleep.' They do not say that the child needs to be breastfed for six months or a year, and that it is then that we can feed the child soft porridge. They feed the child porridge, sometimes even if the

child is a day old. So, this is the kind of culture I see around here. (interview, female community leader, Moretele)

My baby for example would be breastfed but would not get enough; you find that the baby is not full and still hungry and is crying. If there is cow's milk you can boil that and feed the baby. Sometimes you find that the baby is big and feeds a lot and the mother is slim and goes hungry often. (interview, male community leader, Nongoma)

There are immediate HIV risks posed by this practice. PMTCT protocols dictate that HIV-positive women should not mix-feed at all; however, this seems to contradict the expectations of society. Participants were therefore asked to describe the potential communication barriers in a context where women are expected to mix-feed, and breastfeed as a first priority, and how to overcome such barriers. Their responses are explored further below.

So far, the report has discussed the culture of breastfeeding and the impact that it has on infant-feeding options for HIV-positive mothers. HIV stigma emerged as another issue that has a strong impact on these decisions. The FGDs and interviews indicated that until HIV/AIDS stigma is addressed at the community level, attempts to communicate and implement PMTCT guidelines will be compromised. Stigma impacts in many ways. First, stigma makes it difficult for pregnant women to openly disclose to their husbands and mothers-in-laws, or to whomever they are accountable for explaining their infant-feeding choice. Families have a strong interest – and influence – on how a baby should be fed, and in the communities studied, they often push for breastfeeding as a main feeding practice. Women who choose not to breastfeed were said to face the pressure of having to justify their decision to their family, while stigma makes it very difficult for the mother to openly cite HIV infection as a reason for not breastfeeding:

First of all you arrive home after testing and you don't tell your mother that 'I tested positive.' Your mother would say, 'Breastfeed the baby.' You will not have another reason not to do so because you didn't tell her. Secondly, you are afraid of people outside, because during PMTCT you are taught as a group that [you] can breastfeed your child for three months and wean the baby and get formula milk from the clinic. That's why women breastfeed when HIV-positive, it is fear of others; you don't care about yourself. (FGD, women aged 18–50, Senqu)

Stigma in particular was said to impose barriers to a mother's choice to bottle-feed, because the communities seemed to associate bottle-feeding with an HIV-positive status for the mother. A woman who chose not to breastfeed was said to incur the risk of being labelled HIV-positive:

Mothers fear discrimination by formula-feeding. They leave the formula behind as it draws unnecessary attention for her, with questions such as, 'Why are you using this formula, what is wrong with you?' They end up leaving formula and mixed-feeding. (FGD healthcare workers, kwaNongoma)

Infant-feeding is regarded as the domain of women, and choosing not to breastfeed has not been a problem in the past when the reasons for not breastfeeding were openly known (such as when a mother has insufficient milk). But now the choice is often linked to a mother's HIV status, as the community usually perceives a mother who does not breastfeed as HIV-positive. Interviews with mothers revealed that they were generally knowledgeable about various guidelines regarding infant-feeding. However, these guidelines may be difficult to implement due to associations between some behaviours and HIV and mothers' fear of negative reactions from family and community members.

Health providers, NGO representatives, and PMTCT coordinators portrayed cultural preferences about infant-feeding as being rigid and inflexible for the specific needs of women. For example, they described grandmothers and mothers-in-law as stubborn in their insistence that a mother must breastfeed. However, interviews with female community elders revealed another side of the issue. Older people were often open to the idea of a mother not breastfeeding if she had a sound reason for choosing to formula-feed and communicated the reason. Hence, they identified lack of disclosure as a main contributor to the misunderstanding that occurred between family members and mothers.

The study found that the elderly women did not have sufficient information about the various options for HIV-positive pregnant women. Hence, in one FGD, community elders were initially puzzled by the idea that an HIV-positive woman might not breastfeed, with one participant asking: '*How is the baby supposed to survive?*'; another remarked, '*It does not sit well with us.*' This group was adamant that a healthy child is a child that receives breast milk. But as





soon as the rationale for not breastfeeding was explained, this group changed their mind; they felt that women who are HIV-positive should completely refrain from breastfeeding for the safety of a child. They further stressed that the disclosure of this information is crucial for them in order to accept her decision. This view was similarly expressed by older men who took part in FGDs:

Our daughters-in-law have this thing that even if they know they are sick they don't tell them at home. She keeps on breastfeeding her child. And you may find that this child was not affected after she took that pill, but as soon as she breastfeeds her or gives her isicakathi [medicinal plant]— because maybe a grandfather says, 'Ey, a child from this family must be breastfed; she must eat inqodi [porridge]' – and this child is not supposed to eat those things. Now the child gets infected; he gets sick and a mother gets sick too. (FGD with men, Senqu)

Furthermore, the men argued for a need to change certain cultural beliefs and practices regarding childrearing if they contradict with the needs of a child. This appeal is made in the extract below:

We cannot rely on things from the past; that our parents used to do this to us and then use it to deal with our present challenges.... It's no longer useful to adhere to certain traditional practices that [declare] 'a child used to be breastfed until she is this old.' That has passed now. Now we have diseases that are killing people here, which force us to change our ways of life and follow on the footsteps of progressive people. That's all we need. We need to come to terms with the fact that the past is gone; all we need to do is find new ways of living, according to the challenges that we face.... And when it comes to a child, people must completely abandon this mentality that 'These are my rules!' Those people who are hard-headed end up destroying the whole community, because if you don't want a child to be treated according to a doctor's prescriptions, that problem that she is having ends up affecting everyone that is associated with that child. (FGD with men, Senqu)

This quote indicates that cultural beliefs are not static, but change based on the circumstances that people live in. It also indicates that while men and elders were portrayed as stubborn groups with respect to infant-feeding options, some of them were beginning to change in recognition of the fact that the life of a child is more important than a need

to adhere to certain cultural beliefs and practices. This does not indicate a wholesome acceptance of women choosing not to breastfeed, however; at least in one site the participants felt that women should be more specific about why they choose not to breastfeed, lest they be perceived as irresponsible:

The problem is that people who have these children are still very young; the pregnancy happens unexpectedly, so the child is not well taken care of the same way a planned child is. So, you will never know if the mother of the child is being irresponsible by not wanting to breastfeed or if it is because she has been told not to because of her HIV status. (FGD with men, Moretele)

So far, the findings discussed in this section indicate the importance of having a clear and direct communication strategy about various infant-feeding options that a woman may adopt, at all levels. First, communication needs to clarify the notion of 'baby-friendly' clinics, and how to reconcile this with the belief that women are allowed to choose what infant-feeding option to adopt. Second, healthcare providers need to be direct and clear in communicating various infant-feeding options to women, their risks, advantages, and so on. Most importantly, the findings indicate a strong need for better communication between pregnant women/mothers and family members/communities. A PMTCT communication strategy that considers mothers and mothers-in-law is of greater importance. It emerged during the fieldwork that elderly women play an active and direct role in raising young children, mainly as caregivers. Health providers reported that children are oftentimes left entirely in the hands of a grandmother, for instance, who then raises them in the ways that she knows to be good for a child.

The communication barriers so far identified as having an impact on infant-feeding choices are both institutionally and socially situated. Other barriers to successful implementation of the chosen feeding option are less about poor communication and more about the structural constraints and inefficiency of health facilities. For example, the unavailability of infant formula at some sites was found to lead to mixed-feeding. If women opt for exclusive formula-feeding and then find that there is no formula milk at the local health facility, they tend to switch to breastfeeding. This is especially the case among poor people who are unable to afford formula.

It was also described how follow-ups of mothers that are discharged from the hospital post-delivery, or who do not give birth in hospital after having received antenatal services pose a challenge for healthcare workers. This appears to be mainly due to a lack of transport for conducting follow-ups. The healthcare workers expressed consistent frustration about this:

Tracing clients is a huge problem. How can you trace a client if you have no resources to do that, as the DoH does not provide us with that? (FGD, healthcare workers, Nongoma)

We are trying to engage the fieldworkers to try and make sure that those clients that are pregnant...that they follow them up. Transport problem...the roads are bad and the EMR service does not have cars as much as we'd like them to have. (interview, district coordinator)

At one clinic we had 67 women who were HIV-positive, but when delivery time came only 35 women delivered their children at the facility. (interview, sub-district manager)<sup>53</sup>

The participants' comments on infant-feeding presented it as a complex and difficult process to communicate and implement as part of PMTCT. Though various health facilities possess guidelines for healthcare workers to follow, the complete communication and implementation of these guidelines may be hampered by institutional, communal and structural constraints at the specific location (district, sub-district, facility).

### 5.3 Engagement of men

In most research and intervention work, men's involvement is identified as the missing link in achieving the successful uptake of PMTCT services.<sup>54</sup> This study investigated the roles of men in the studied communities concerning pregnancy issues, particularly PMTCT; the fieldwork also solicited ideas on how men can be more effectively engaged, or how PMTCT programmes can be communicated to men.

Participants at all the study sites, including male participants, acknowledged the crucial role that men could play in the PMTCT programme. Most participants described men as being uninvolved in pregnancy issues, except as

providers of money and material things for their pregnant partners. They said a man's role is traditionally understood this way. Such a man will know little or nothing about the wellbeing of his child and usually does not accompany his partner to the clinic during her checkups. One participant shared his experiences to illustrate this point:

Like, I have a child of my own; and by the time she was pregnant, from three months I gave her money, until now. She used to go to the clinic every now and then, and she needs money for that, so I would give her the money. So all I can say is that our task as men is to give her money until she finishes with pregnancy. And after the child has been born you buy her/him clothes. (FGD with men, Nongoma)

During FGDs the male participants engaged in serious and tense debates on whether their present roles as material providers were sufficient or not, or if they needed to do more in order to support their partners. The majority felt strongly that their present role as material providers is not enough because a woman might need more than material support. Many participants felt that men should play an active role as fathers and carers of pregnant partners:

I think there is a really a big lack there. A man must also be involved in the pregnancy; it mustn't be a problem for a mother alone; a man just forks out the money. But I also need to know what is happening, how the child is growing, and whether there are any complications (FGD with men, Nongoma).

You should be there for her as you are the one who made her pregnant. Go to work and come back to take care of her. If she goes to the clinic and you are on a day off you should go with her, go home when you are done, and help her cook at home as she is carrying your baby. (FGD with men, iLembe)

Men also acknowledged a need to be more active in their partner's pregnancy; however, this is sometimes made difficult because men are typically not socialised to play that role. Participants in Senqu, for example, said it was unusual (and awkward) to find a man going to the clinic with his partner. Men and women in this society are expected to consult separately even if they are intimate partners:

A man gets sick alone, and then he decides to come to the clinic. And a woman gets sick alone and she decides to come to the clinic. And sometimes they advise each other; when

53 This situation reflects rural areas only, as the vast majority of South African women deliver at health facilities.

54 Frizelle et al. (2009)





one is sick the other says, 'Go to the clinic.' But not seeing us going together...No!. (FGD with men, Senqu)

There was a time when my wife was sick; I had to be there too. I had never done that thing before, but I had to obey the instructions. Because I had to be there and see all these things that they were doing to her. I felt like I would rather have been dead...because we grew up not coming any closer to women's things – if a woman is sick you don't go there. Now you are being told: 'Sit here; you must see what's going on to your wife.' It was difficult for me; I was sweating all over as if I was ndifakwe emgqomeni – I was being put in a dustbin. But they said: 'Old man, you will sit.' So they did everything while I was sitting next to her. But I must say I was really not pleased with that. You wouldn't even share that with other men because they will laugh at you; they will discipline you [laughter]. (FGD with men, Senqu)

These findings point to a need to engage further with men on the definition of their roles as partners. Here it seems that although the role of being a partner encourages mutual

support during difficult times, it is limited because it does not encourage partners' direct involvement in each others' health matters. Men and women are expected to deal with their health issues separately.

The study also asked women to describe what they perceived to be the role of men and what they expect from their male partners during pregnancy, PMTCT and management of their HIV-test results. The women participants related experiences that generally concurred with the men's observations: that men perceive pregnancy and childrearing to be a woman's affair. Several female participants shared stories about partners who were absent in their lives, either because they denied paternity or they utterly refused to accompany them to the clinic or to do an HIV test:

Mine does not want to test. But when I told him the results... he just said, 'Aahh!' He does not even want to hear anything now. When I say, 'When are you going to test?' he says 'I will go.' But when it is my time to take pills he would say, 'Have

you taken pills?’ Or if we have been away and it’s about time that I take pills, he would drive in a very high speed so that we get home on time for me to take pills. But what about him? When will he test? I have been telling him for a long time to test. (FGD, HIV-positive women, Free State)

It happened to me. When I told him that I am sick, he vehemently denied having infected me and said I did not get [HIV] from him...he said he is not part of it and called it off...(FGD, HIV-positive women, iLembe)

However, the notion that men are not supportive of their partners was not a generalised finding. There were some participants – particularly in KwaZulu-Natal – who related their experiences of men who had supported them during and after their pregnancy, as well as after finding out their HIV-positive status. Although most of these men refused to test for HIV themselves, they were described as being supportive of their partners – such as by reminding them about medication or accompanying them to the clinic for checkups:

If I want to get to hospital in the morning for my ANC classes, he would bring [me] with no fail. On Sundays transport is scarce, so he brought me in the morning. He was very supportive. I did not have a problem. (FGD, HIV-positive women, Nongoma)

The reasons for men’s limited involvement in pregnancy and PMTCT issues were explored with both male and female participants, and older and younger participants. Among female participants, particularly women elders, males’ absence was viewed negatively as a sign of being irresponsible. Female elders in the Free State, for example, felt that ‘men these days are useless’; when asked about what role men should play in relation to PMTCT, one elderly woman quipped: ‘Men, do what?!’ Another participant in the same group said men who support their partner during pregnancy ‘do not exist.’ These responses point to a sense of helplessness among certain of the women participants, in terms of having men take part in issues surrounding pregnancy. In effect, these women expected little support from men during pregnancy.

Interviews with male participants produced complex and rich accounts of why men are frequently absent during a woman’s pregnancy. The men commonly refused to be labelled irresponsible, but preferred to dwell on the barriers

they normally encountered in trying to play active roles as fathers and supportive partners. Male participants in the Free State described their lack of involvement in pregnancy as a product of deliberate efforts by women and the government to exclude them. Men in that FGD complained that women wanted them only as ‘sperm donors’ or else they only wanted a child in order to access a government grant, and once that was achieved a woman would seek no further engagement with the man:

Lots of girls fall [pregnant] and when you look at it you find that there are no fathers. This causes a lot of misunderstanding because men are looking at providing love and building families, but women are into the grant money. When you approach the girl’s mother she covers up for her so that they can get mealie meal through the grant. (FGD with men, Free State)

Come to think that I made the first mistake, then the second one [referring to impregnating a partner]. Now, really how much money have I made that these people are getting? I support these people with my body, they are benefitting and I am not. When I say to her, ‘Come and stay with me together with the child,’ she would ask me about the money. (FGD with men, Free State)

These men tended to perceive the government as being on the side of women, in all aspects. Mainly, the government was perceived as taking on a role of being a guardian and protector of pregnant women – giving them grants, and in the process alienating men. Most participants in this group felt that as long as women are treated as individual units who make decisions without needing men, most men would refrain from being actively involved in a partner’s pregnancy:

Everywhere you go men are complaining.... This worries men a lot – that’s why women and children are given first preference. These grants given to children, when the father in the family is unemployed and the child receives this grant, he/she provides/feeds for the father in the house. This shows that our government does not respect us. (FGD with men, Free State)

Male participants also referred to the social context of a pregnancy as a barrier to their participation in pregnancy and childrearing. They said that women get pregnant out of



wedlock and have unplanned pregnancies, and that some of these pregnancies are a consequence of a 'one-night-stand' rather than occurring in a stable partnership. This was also cited as a barrier to a male's involvement, as seen in the comment below:

This support from a man will happen in a marriage situation. With regards to the tavern situation, the support is unlikely because both of you were drunk and just fooling each other. You just happen to score that night. There was no commitment at all. It is easy if the woman is your wife. It is the truth because right now in our area, people are so unfaithful in their relationships. They have multiple partners; you find that within four months the same girl has had three guys and at the end of the day she falls pregnant. As a man you cannot be 100% sure because there has been too many of us within a very short space of time. One of us will agree to the pregnancy just because he loves her, or maybe he has a job. One cannot really accept that because, yes, you did not use a condom, but then you are not sure if she used a condom with the others. The girl ends up alone and the child becomes fatherless because we are not sure who the father is. You'll just hear rumours that the child is yours. You're lucky if the child is yours, but in most cases these children are not ours because the girl had slept with a number of guys. (FGD with men, Moretele)

One male participant in KwaZulu-Natal raised the issue of approach as an influential factor in a man's willingness to participate in pregnancy issues. He said the way in which a woman approaches her partner affects how he reacts to efforts to involve him. The participant felt strongly that a woman should approach a man with caution and respect; this will soften him to listen and maybe take an active role in her pregnancy:

...It depends on how much she shows respect or lack of it, then a man will let her go alone. If they are in good terms and the woman asks, he will definitely go. Women have a communication problem. Your love gets replaced by that of her children, she asks her children to accompany her to the clinic and ignore you as her man to do your job of showing your love for her. You also want to show you care but she only wants your attention at her own convenience; when you want her attention she pretends like she does not need you; then you have to constantly plead. The time you ignore her it looks like you have affairs outside. (interview, male community leader, Nongoma)

These narratives lend credibility to the men's observation that they cannot be simply labelled irresponsible if they are inactive in pregnancy and childrearing. There is a need to interrogate the social context of pregnancy, government support systems, and the existing community assumptions about men (for example, that they are disinterested in fatherhood) and how each of these impact on men being actively involved in women's pregnancies.

There was little evidence of attempts to engage men in PMTCT issues. There is a major unmet opportunity – to involve men through their affinity with the idea of being a responsible father and someone who protects his children and partner. Men's inclination to want to feel in control, needed and respected is not reflected within the current PMTCT programme model. Even family planning (an important PMTCT method) is viewed as a woman's business, while an attitude of joint responsibility and support is generally not created. It was mostly only older men who felt they had a role to play in a woman's pregnancy. Hence, clinics appear to be the realm of women; and men have few opportunities to be counselled or informed about PMTCT processes and their partners' support needs.

## 6 Conclusions

Overall, the research produced rich and detailed data on the challenges facing the selected study sites (sub-districts) in implementing the PMTCT programme and communicating information about PMTCT services to pregnant women and other stakeholders. Most of the problems and challenges with this have been identified by previous research and this study mainly substantiates them.<sup>55</sup>

The findings indicate that communication about PMTCT services at a facility level is generally adequate and informed by sound policy guidelines. However, the greatest shortcoming seemed to occur in extending PMTCT communication beyond the health facility into components of the population, particularly male partners, non-pregnant women, mothers-in-law, and other community members. This shortcoming appears largely due to lack of capacity at local health facilities, with most having limited expertise on PMTCT, a lack of resources for community outreach work, staff shortages, and minimal use of volunteer workers. Interviews with sub-district managers and PMTCT coordina-

55 Frizelle et al. (2009)

tors indicated that most acknowledged these problems but had sound suggestions on how to address them.

South Africa is a culturally and racially diverse country, with significant socio-economic inequalities and language differences. Therefore, a PMTCT communication strategy needs to seriously take into account the impact of cultural norms in the uptake of PMTCT services. In this study we have discussed the culture of breastfeeding; lack of pregnancy disclosure; and a general understanding of fatherhood as meaning that a man is a mere provider of material things, as key cultural factors that inhibit the successful uptake of PMTCT services and also impacting on men's involvement in PMTCT. A good understanding of the different forms of social organisation and the cultures in which they are embedded is essential in dealing with variances in individuals' sexual behaviour and in developing socially acceptable health messages. Cultural sensitivity should be the norm to achieve buy-in to a health campaign, as communities and individuals must ultimately take ownership of the messages.

The role of men in PMTCT issues has been debated in this study. The research drew strength from its intense engagement with men regarding what they perceived to be their role in relation to a woman's pregnancy in particular, and to HIV-prevention work in general. Of great importance was men's acknowledgement of their limited roles as supporters of their partners in terms of pregnancy issues, and their expressed willingness to correct this and to be directly involved from the start of pregnancy, rather than act only as providers of money or material resources. For this to happen, changes are needed at the levels of health facilities and society as well as in the nature of sexual partnerships. The male participants' incessant complaint that they did not feel welcome at public health facilities should not be overlooked, as this is an attitude that can directly impact on their investment in active fatherhood. An equally important subject mentioned by men relates to pregnancy as a generally unplanned event, sometimes resulting from casual sexual relations, making it difficult for a man to willingly accept responsibility for a woman's pregnancy.

The findings reveal that a PMTCT communication strategy should aim to make an impact on a range of groups within communities as well as broader society, as opposed to pregnant women only. This emerged clearly in how community elders (both men and women participants) used pregnancy issues as an opportunity to express their dissat-

isfaction with moral decay in society and the perceived marginalisation of moral behaviours in the new democratic dispensation. A constant referral to notions like 'we used to do like this,' 'these kids don't listen,' 'the government is giving them rights' and 'we cannot tell them anything' was a call by the respective participants to be listened to, rather than seen as unneeded. The comments of men and community elders revealed a need for a PMTCT intervention to adopt a cautious approach in strongly targeting pregnant women – giving the impression of (the government programme) taking over as a primary protector of these women at the expense of making others (e.g., men, mothers-in-law) feel unneeded or alienated. The issue of child support grants was mentioned as one example where men feel that women are given more freedom and independence – consequently making men feel dispensable.

Overall, the findings highlight a need to move away from targeting the individual (i.e., HIV-positive pregnant women) as the only target for PMTCT intervention, towards considering the individual's familial, social, and political environments. This aligns with the social ecology model that was proposed as a suitable model for PMTCT intervention. Specific recommendations based on this model are outlined in the next section.

## 7 Recommendations

The recommendations made here are structured in terms of the four levels of the social ecology model (see p.10) of social and behavioural change.

In terms of this model social and behavioural change must be anchored in the different domains at which behaviour is mediated. The full range of determining conditions for change to be secured; and communication strategies need to be crafted accordingly.

There is a clear need for this in the context of PMTCT given that PMTCT responses require buy-in and support at societal, community, social network and individual levels. Change at one level may be either facilitated or obstructed by unsupportive conditions at another level.<sup>56</sup>

PMTCT communication has to this point been aimed mostly at pregnant women and they have been left to deal with the problems created by the lack of communication in their immediate networks and broader community con-

56 Frizelle et al. (2009)



texts. This has burdened pregnant women with the need to communicate and explain their needs to largely uninformed and unsupportive familial, cultural and social contacts. This has certainly been the cause of some infants becoming HIV infected, because of failure of women to successfully follow PMTCT protocols on their own.

For PMTCT communication and intervention to effectively benefit HIV-positive pregnant women and their babies, all women of reproductive age and their family members (including men and in-laws), should be incorporated in PMTCT communication strategies. Communication strategies should also be aimed at creating systemic conditions conducive to PMTCT and communication strategies at this level are also spelled out.

### 7.1 Primary prevention of MTCT

The most primary level of PMTCT is prevention of HIV infection among girls and women.

#### *Individual level*

- Build awareness of the value of preventing HIV infection as a primary means for preventing HIV infection among future children.
- Build awareness among young women of the linkages between sexual and reproductive health and encourage the use of dual protection from both pregnancy and HIV.
- Build awareness in young women of the elevated risks of engaging in inter-generational sexual relationships with older partners.

#### *Social network level*

- Promote the idea in new couples that the surest way to ensure protection of their children from HIV is by avoiding concurrent relationships that expose them to HIV. Include couples as targets of HIV prevention campaigns.
- Programmes for preventing HIV infection in sero-discordant couples must be introduced, alongside awareness building of the possibility that a sexually engaged couple may be sero-discordant. This must begin with promoting of HIV testing in couples.
- Promote consistent use of condoms to avoid risks of HIV infection of mothers in pregnancy and lactation; as couples often stop using condoms after a woman conceives.

#### *Community level*

- Communicate the need to protect the future generation of children by protecting the next generation of mothers from becoming HIV infected.
- Build on community concern to protect children and use this in promoting HIV prevention, so that the connection between adult HIV status and childhood HIV is grasped and subscribed to as a concern.

#### *Societal/systemic level*

- Advocate for and support guidelines and programmes focusing on inter-generational sex to prevent high levels of HIV incidence while young women have little power to negotiate safe sex relationships.
- Develop national guidelines for promoting HIV prevention in couples, including in sero-discordant relationships.

### 7.2 Secondary prevention of MTCT

Given the high rate of unplanned pregnancies reflected in this study, prevention of unwanted pregnancy among women of child-bearing age must be considered a PMTCT priority.

The following communication interventions are suggested for bringing about social and behavioural change in this area.

#### *Individual level*

- In order to prevent MTCT, programmes aimed at prevention of unintended pregnancies among (HIV-positive or HIV-negative) females of child-bearing age must be reinforced. Prevention of unintended or unwanted pregnancy must be included as an important HIV prevention method in education programmes.
- Introduce a programme to offer voluntary sterilisation for women and men affected by HIV, who decide not to conceive more children; and remind HIV-positive pregnant women of their right to terminate pregnancy within the prescripts of the Choice on Termination of Pregnancy Act should they choose that option.





- Include family planning consultation and counselling in ART programmes as well as HIV support-group education.

*Social network level*

- Promote health talks for couples at health facilities where links between family planning, HIV protection, HCT and PMTCT are made clear.
- Encourage couples to test for HCT together, since it has been shown<sup>57</sup> that couples who test together tend to adopt HIV-prevention measures and engage more actively in PMTCT.

*Community level*

- Orient communities to the use of contraception and family planning as important HIV prevention tools.

- Actively promote contraception and family planning in support programmes for people with HIV.

*Societal/systemic level*

- Advocacy for introducing family planning as a method of PMTCT should be aimed at all government, workplace and civil society programmes supporting people with HIV.
- Involve family planning/contraception counselling and HCT service providers more directly in promoting and supporting PMTCT education.
- Advocate for a national programmatic focus and strategy for ‘positive prevention’ which includes emphasis on reproductive health decision-making for people with HIV.

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<sup>57</sup> Betancourt et al. (2010)



### 7.3 PMCT programme enrolment

Given problems of late enrolment of women for PMTCT programmes and difficulties experienced in preparing and supporting individuals and families through PMTCT, the following recommendations are made:

#### *Individual level*

- Messages promoting HCT should also include encouragement for women to discover their HIV status prior to falling pregnant or as early in the pregnancy as possible. Pre-established cognitive links between HCT and preventing MTCT will help prepare mothers to eventually subscribe to PMTCT protocols when they present to antenatal clinics.
- Lay counsellors and HCT service providers must routinely provide information on MTCT and its prevention, in the case of HIV-positive and HIV-negative HCT outcomes, for pregnant and non-pregnant women, and for men as well as women.
- Information about the risks of passing on HIV to babies during pregnancy, labour, delivery, and breastfeeding should be displayed at all clinics and in public communication campaigns.
- Ensure that PMTCT education begins early and is part of all HIV prevention education, especially that which targets young women before they fall pregnant.

#### *Social network level*

- Women's groups at community level should be encouraged to actively endorse and support HIV prevention in pregnancy, childbirth and infant feeding.
- HIV-positive mothers who have successfully gone through PMTCT should be used to encourage women attending ANC clinics to partake in PMTCT programmes; following the lead of proven successful programmes such as 'mothers2mothers'.<sup>58</sup>

#### *Community level*

- Include elderly women (e.g., grandmothers, mothers-in-law) in PMTCT communication strategies as they are often in positions to either support or obstruct women following PMTCT protocols.

- Promote involvement of both parents in all matters that concern their children.
- Talk about PMTCT in community meetings rather than restrict it to clinic level communication.
- Educate community members about the availability of PMTCT services.

#### *Societal/systemic level*

- Assess the qualities and adequacy of counselling for PMTCT, as well as the training of HCT counsellors who may not be in a position to provide clients with PMTCT-related guidance and support.
- Include PMTCT as an intrinsic component of all maternal health services and programmes.
- Ensure that the national AIDS helpline offers up-to-date advice about PMTCT and promote this resource.
- Ensure that the branding of baby-friendly facilities is not inconsistent with PMTCT policies and choices.

### 7.4 PMTCT programme support

There is need to implement broadened support for pregnant women following PMTCT protocols.

#### *Individual level*

- Positive and motivating stories about women with HIV having uninfected infants should be used to promote PMTCT, linking the ideas of healthy children and the mother knowing her HIV status.
- Counselling support and follow-up should be a prominent part of PMTCT programmes.
- The notion that an infant cannot be "full" or adequately nourished through milk alone needs to be well communicated. This is a challenge given the norm of mixed feeding outside the context of HIV.

#### *Social network level*

- People who are close to pregnant women should be engaged in PMTCT home visits, in order to sustain support for them (such as from men, in-laws and parents).
- Home-based carers should be engaged in supporting household level PMTCT.

<sup>58</sup> <http://www.m2m.org/>

- Women who have been through PMTCT should be enlisted and trained as counsellors and supporters to women following PMTCT protocols.

#### *Community level*

- Messages that HIV infection from mother to child can be prevented must be promoted by community leaders and other influential communities, and their messages should encourage community members to support women undergoing PMTCT.
- It must be realised that the bulk of community welfare and support initiatives are served by civil society organisations rather than the health services. Through community organisations involved in home-based care, HIV/AIDS support, and community awareness and education campaigns, there are good opportunities to disseminate information and to promote knowledge of PMTCT. Government linkages with support organisations must be built so that support and education capacities in communities can be harnessed in support of PMTCT.

#### *Societal/systemic level*

- PMTCT must be fully integrated into antenatal care and the view among healthcare workers that they are unable to discuss PMTCT-related issues because ‘there is no PMTCT space’ must be addressed as a major concern.
- It must be ensured that healthcare workers are fully appraised of AFASS (affordable, feasible, accessible, safe and sustainable) criteria in the advice that they give to women.
- Implement programmes to support HIV-positive pregnant women and their partners, through partnership arrangements between the DoH and community organisations involved in HIV/AIDS care and support.
- Provide facilities apart from clinics, where support for PMTCT can be provided and advice sought; where there can be privacy and the opportunity to be counselled and to talk to other women also following PMTCT protocols.

### *7.5 Infant feeding options*

The study has found that women find it difficult to adhere to PMTCT infant feeding recommendations and this is exacerbated by a lack of understanding and support as well as by stigma attached to HIV/AIDS. The following recommen-

dations are made to address this at different levels where the problem manifests.

#### *Individual level*

- Women are often confused about the reasons behind infant feeding protocols and tend to lapse in following them. There needs to be close support and counselling of women through the entire process, so that lapses are easily detected and support for consistent following of feeding choices is provided in the form of counselling and help facilities where advice may be sought.
- Women should be specifically coached to deal with the difficult situations they face at home and in the community where others often do not accept or understand their efforts to prevent MTCT.
- Messages on the adequacy of breast-milk for infant feeding must be emphasised.

#### *Social network level*

- Women engaged in PMTCT need psychological support and this should be provided by women experienced in the trials and tribulations of PMTCT and in support groups with other women also following PMTCT protocols.
- The implementation of a nationwide mothers-to-mothers peer-support programme is recommended, wherein HIV-positive mothers are used as mentors to support similar women.
- Messages on the adequacy of breast-milk for infant feeding must be emphasised at this level as well as the individual level.
- Women must be encouraged to motivate pregnant friends and relatives to seek antenatal care services as soon as they suspect they are pregnant.

#### *Community level*

- Community education about infant feeding needs in PMTCT needs to be included in general HIV/AIDS awareness building at community level to address the many obstacles and cultural beliefs about infant feeding that are a challenge to women.
- Cultural leaders and elderly family members in particular should be educated about these matters as their beliefs are often at odds with PMTCT needs.



#### *Societal/systemic level*

- Service providers need to find simple ways of communicating the rationale for exclusive breastfeeding and avoiding mixed-feeding. This would enhance adherence to PMTCT protocol as men are often not supportive because they have not been explained the rationale for PMTCT practices.
- The availability of infant feeding formula must be made consistently available at all sites where it is needed.
- Ensure linkages between non-medical infant feeding programmes and PMTCT services.

### 7.6 Involvement of men

There is a need to promote men's involvement in all aspects of sexual and reproductive health. PMTCT communication must highlight the involvement of men and not only target women and infants. The following are opportunities for engaging men where their involvement is likely to significantly improve PMTCT outcomes.

#### *Individual level*

- Promote men's early involvement and support for PMTCT by appealing to and building on their feelings, though often unacknowledged, of protection and care for their offspring. This should be done by developing men's recognition of the values of 'fatherhood', building on their interest in caring for and protecting their children. The male participants in this study commonly saw themselves as not appreciated and included in PMTCT. They have latent needs to be more engaged in these issues and these can be built upon.
- Men in this study expressed a need to be educated about PMTCT services and pregnancy issues. The provision of such education is an important foundation for men's involvement in the PMTCT programme.

#### *Social network level*

- Use communication campaigns to build images of men as fathers. The national Brothers for Life campaign, for example, provides good opportunities to promote positive images of 'being a father' which should incorporate support for PMTCT.

- Develop appreciation of the need for dual protection and STI/HIV prevention methods among the partners of pregnant women. Promote primary prevention based on appreciation, not only of the risk of infecting their partner, but the mother of their children who may pass HIV to their children.

#### *Community level*

- Engage male community leaders as promoters and supporters of PMTCT; and promote greater male involvement in clinic and hospital committees.
- Inspire individuals to view bringing up children as the responsibility of both parents, not the woman's alone; which will assist in gaining men's support for PMTCT

#### *Societal/systemic level*

- Create a welcome space for men in health facilities. This can be achieved in part by promoting the availability of male nurses and caregivers at health facilities. This is important given that men in the study indicated they were only comfortable revealing personal issues when they were not in the company of women
- Develop a national strategy for men's involvement in PMTCT.
- Promote male-friendly clinic services and involve men in clinic and other health committees.

### 7.7 Recommendations for further research

- Explore the effects of different cultural practices on women's management of pregnancy and infant care (including breastfeeding) and use these to inform protocols for PMTCT.
- Examine what role elderly men (e.g., grandfathers, fathers-in-law) can play in encouraging PMTCT uptake. This group was not sampled in this research and their roles in PMTCT is unexplored.

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