

effectiveness of PMTCT program. Currently at most levels of the Eastern Cape health care system there exist:

- General management style and culture that are not always conducive to meeting the challenges of the PMTCT program;
- Top-down approach and unsupportive relationship with their immediate supervisors;
- Lack of ability to produce a reliable data and monitoring information, etc.

1.7.4 Socio-Cultural Influences

Another possible barrier to PMTCT programmes is the extent of socio-cultural influence on PMTCT in Eastern Cape. The population in this area is largely rural-about 66.8%. The province is inhabited mostly by the Xhosa people and other minority tribes like the Sotho; Zulus; Vendes; Koisian, etc. These people are very traditional and maintain their respective cultures. Seemingly certain cultural tendencies have certain demands on pregnant women, especially in terms of where to deliver, with preference being placed heavily on home delivery. A key question that this research therefore seeks to address is “what are the socio-cultural barriers to the successful implementation of PMTCT programmes?” Identification of these barriers will help policy makers as well as improve the implementation of programmes for the prevention of mother-to-child transmission of HIV.

1.8 Conclusion

The last section describes some of the key barriers to implementation of PMTCT, and highlights the importance of this research.

CHAPTER 2: LITERATURE STUDY

2.1 Introduction

This chapter summarises the literature on PMTCT relevant to the research topic. Internationally and nationally there is ongoing research in the field of HIV AND AIDS, and many prevention and treatment modalities have been described. Many of these modalities are based on the PETRA Study (UNAIDS, 1998), which is a placebo-controlled trial with 4 arms:

	<u>Antepartum</u>	<u>Intrapartum</u>	<u>Postpartum</u>
A	AZT + 3TC	AZR + 3TC	AZR + 3TC
B	Placebo	AZR + 3TC	AZR + 3TC
C	Placebo	AZR + 3TC	Placebo
D	Placebo	Placebo	Placebo

The success of these treatment modalities are greatly influenced by the complexities that are associated with mother-to-child transmission of HIV, such as various risk factors to which pregnant women are exposed to, and which poses challenges for the prevention of MTCT in resource-poor regions. The first section briefly summarizes the literature on the factors that contribute to the risk of mother-to-child transmission (MTCT) of HIV, with particular reference to sub-Saharan Africa (including material factors, behavioural factors, obstetrical factors, infant factors and viral factors). Thereafter, interventions identified in the literature that attempt to reduce PMTCT are discussed.

2.2 Risk Factors associated with PMTCT

This section briefly summarizes the literature on factors that contribute to the risk of mother-to-child transmission (MTCT) of HIV, with particular reference to sub-

Saharan Africa, and include material factors, behavioural factors, obstetrical factors, and viral factors.

2.2.1 *Maternal Factors*

- Immune Status:

The risk for MTCT is increased with the severity of immune deficiency. Women with low CD4 counts (<200 cells/ml or less) are more likely to transmit HIV to their infants (SA Department of Health, 2000).

- Vitamin A deficiency:

Studies on MTCT have suggested an association between Vitamin A deficiency in the mother and risk of MTCT. Vitamin A deficiency in HIV infected mothers is associated with a higher risk of HIV transmission from mother to child. Ongoing trials in Malawi, South Africa, Tanzania and Zimbabwe are currently studying whether adding vitamin supplements to pregnant women's diet will affect the risk of MTCT (Semba, Miotti, Chipangwi, et al, 1994)

2.2.2 *Behavioural Factors*

Cigarette smoking, drugs, and unprotected sexual intercourse during pregnancy has been associated with an increased risk of MTCT (Reggy & Simonds, Rogers, 1997).

2.2.3 *Obstetrical Factors*

Genital infections and especially sexually transmitted (STDs) may result in chorioamnionitis. Prolonged rupture of membrane during labour is another common cause of infection (Minkoff, Burns, Landesman, et al, 1995)

However, the risk of transmission is relatively higher during delivery, due to the presence of the human immuno-deficiency virus in blood and mucus in the birth canal. As a preventative measure, various methods of vaginal

washing (lavage) before and during delivery are being investigated in several developing countries. In a trial performed in Malawi, lavage-using chlorhexidine showed no overall difference in rates of MTCT, but did show a significant reduction in cases where membranes were ruptured for more than four hours. It also resulted in significant reduction of infant mortality and morbidity (Taha, Biggar, Broadhead, et al., 1997).

- Mode of delivery:

The mode of delivery may also influence the risk of MTCT. Elective caesarean section births have been shown to reduce the risk of MTCT (Hofemeyer & McIntyre, 1997).

2.2.4 *Infant Factors*

- Breastfeeding:

HIV is transmissible through breast milk. Subsequently breastfeeding is associated with at least one-third of all MTCT (Dunn, Newell, Ades & Peckham, 1992)

- Foetal trauma:

Traumatic births and births where the foetal skin is traumatized from obstetrical procedures increase the risk of MTCT (Mandelbrot, Mayaux, Bongain, et al, 1996).

- Prematurity:

Pre-term births tend to place the infant at higher risk for MTCT as compared to full term births (Reggy, Simonds & Rogers, 1997).

2.2.5 *Viral Factors*

- HIV Viral load:

A high level of circulating HIV virus (viral load) is an important contributor to MTCT. The higher the viral load the more likelihood that MTCT will occur.

There is a higher risk of MTCT in women with advanced HIV disease (AIDS) or documented high viral loads (e.g. >50,000 HIV particles or more/ml) (ACAS, 2001 & 2003).

2.3 Interventions

Resulting from the risk factors discussed above, a variety of interventions have been identified in the literature that attempts to reduce MTCT.

2.3.1 Behavioural Interventions

- **Primary Prevention of HIV:**
Preventing HIV infection among women, and men, of childbearing age is the best method to reduce the possibility of MTCT.
- **Preventing new HIV infections:**
New HIV infection during pregnancy (and breastfeeding) may increase HIV viraemia, which will increase the risk of MTCT. Pregnant women should be advised on safer sexual practices, including the importance of correct and consistent condom use.

2.3.2 Therapeutic Interventions

- **Nutritional supplementation:**
Nutritional supplements (iron, folate, multivitamins and vitamin A) should be routinely given from the initial diagnosis of pregnancy until delivery. These supplements have been shown to result in improved pregnancy outcomes, including reducing the incidence of stillbirth, prematurity and low birth weight.

2.3.3 Obstetric Interventions

- **Vaginal cleansing:**
MTCT may occur during delivery to the presence of blood and mucus in the birth canal. Studies have shown that vaginal cleansing with an antiseptic

solution is associated with reduced MTCT and improved perinatal outcome (Biggar, Miotti & Taha, 1996).

- Artificial rupture of membranes (AROM):
Rupture of membranes for longer than 4 hours prior to delivery is associated with increased MTCT (Mandelbrot, Mayaux, Bongain, et al, 1996). Routine AROM should be avoided in both HIV positive or negative women. AROM should only be done if there are specific obstetric indications and as late as possible. In HIV-positive women other methods of augmenting labour should be considered (e.g. oxytocin augmentation).

2.3.4 *Antiretroviral (ARV) therapy for MTCT*

- Zidovudine:
In recent years ARV has been shown to be able to reduce MTCT by 50-60% if these medications are given during the pregnancy and labour and to the newborn infant. A short course regime of 300mg zidovudine administered orally 12 hourly, given from 36 weeks of pregnancy onwards and 300mg zidovudine administered orally 3 hourly during labour can reduce MTCT by approximately 50% (CDC and Ministry of Thailand, HHS new, 18/02/98). However, the effect of antiretroviral therapy (ARV) on breast fed MTCT, when given during pregnancy, is not yet established.

Mother-to-child HIV transmission (MTCT) is a rapidly and new developing field of medicine and health care. Scientific data emanating from the study results of 1998 and 2000 on the use of ARV regimes to prevent MTCT (UNICEF, 2001), including issues of efficacy and factors affecting optimal choices of ARV regimes in different settings, as well as lessons learnt from the pilot sites in South Africa such as problems in the health care system in general, unequal provision of infrastructure between provinces and sites, budgets and funding, have sufficiently shown that the risk of MTCT of HIV can be greatly reduced with improved antenatal and postnatal care; voluntary

HIV counselling and testing (VCT); antiretroviral drug therapy; and avoidance of breastfeeding.

In view of the above findings (or discussion) and recommendations and measures put in place to enhance the effectiveness of the PMTCT programme, it is clear that the prevention of MTCT programmes are not yielding the required results in most of the PMTCT pilot sites. While the efficacy of ARV regimens in reducing the risk of HIV infection is important, other key components of the project such as: *practicality and effectiveness; safety; drug resistance; acceptability* and *cost to families* of these preventative modalities; and the *socio-cultural* and *institutionalised traditions* of the people for whom these programmes are designed to prevent MTCT of HIV, are important and need to be investigated. For the purpose of MPH degree however, this research attempted to investigate only the *socio-cultural barriers* that affect the efficacy of PMTCT programmes in Gauteng.

The main aim and objectives of this research, as well as a detailed account of how the research was conducted, is described in the next chapter.

CHAPTER 3: RESEARCH METHODOLOGY

3.1 Study Design

This research utilized an open-ended qualitative methodology, with data collection methods including a combination of focus group discussions and in-depth interviews with key informants for. The next section describes briefly why a qualitative methodology has been used for this research.

3.1.1 Use of Qualitative Methods

Qualitative methods were used in this research because it was considered appropriate to answer the research question, and meet the research objectives. According to Patton, qualitative data consists of three types:

3.2 Research Aim and Objectives

There are *three stages* when a baby can become infected with HIV: while the mother is pregnant, at the time of birth and when the mother is breast-feeding. The *aim* of this research was to explore the main *socio-cultural barriers* during the above *three stages* that hinders the successful implementation of PMTCT programmes in East London district (Mdantsane, Zwelitsha and Emthonjeni), in the Eastern Cape Province.

The *objectives* of this research were:

- To explore perceptions around the status and role of women, and how these affect PMTCT during the antenatal, intrapartum and post natal period.
- To identify socio-cultural factors that impact on women's care seeking behaviour (such as, for example, accessing ANC or VCT services)
- To determine socio-cultural perceptions and practices around infant feeding, and identify socio-cultural barriers to exclusive breastfeeding or exclusive formula feeding.

3.3 Study Population

The *target population* consisted of HIV positive pregnant women aged between 15 and 49 years, living in households in the catchment areas (Mdantsane, Zwelitsha and Emthonjeni) served by the research site in East London (Frere Hospital). The groups were divided into pregnant women, their husbands' family (mothers-in-law) and her family. They were selected from those who are able to access health care facilities in Frere Hospital which have PMTCT programmes as well as those who are unable to access care. Ten pregnant women (aged 19yrs and older) were interviewed at the elected sites (which were at the health clinics). Eight health workers implementing the PMTCT programme in Frere Hospital were interviewed. These include doctors, HIV and AIDS counsellors and nurses. Individual interviews were held with 5 mothers-in-law of pregnant women. Focus groups were held with mothers-in-law, and pregnant women (aged 19yrs and older), at their homes.

3.4 Data Collection Procedures

Data was collected from participants in the various groups described in 3.4.1. and 3.4.2. This section describes data collection procedures in greater depth.

3.4.1 Participants

Participants were drawn from the East London district (Mdantsane, Zwelitsha and Emthonjeni), through purposeful sampling. According to Patton, purposeful sampling refers to the selection of participants (or documents or visual material) that will best answer the research question. No attempt is made to randomly select informants (Patton M. Q. 1990).

3.4.2 In-depth Interviews and Focus Groups

The value of the use of in-depth interviews and focus groups discussions for exploring socio-cultural issues, and making them explicit, has been well

described in the literature (Atkinson, Heath & Chenail, 1991). Through the use of multiple data collection methods (in-depth interviews and FGDs), as well as multiple data sources, the researcher was able to explore whether there is any congruence between HIV positive pregnant women's perceptions of the barriers to the use of nevirapine and the perceptions of their mothers-in-law or that of the health workers.

3.4.2.1 *Individual Interviews*

A total of 23 interviews were conducted, of which 10 were with pregnant women (19yrs & older), 5 with mothers-in-law, and 8 with health care providers. Thereafter, data collection was stopped because saturation of data occurred (Creswell, 1998). Saturation is the term used to refer to the point in data collection at which the researcher finds no new themes emerging from the data. An interview guide was used to guide the interviews. However, the interview was allowed to take the form of a conversation, rather than the researcher rigidly following the guide. This was found to be very useful in obtaining relevant information, while at the same time allowing the participant to be able to relax and hence share perceptions more freely.

3.4.2.2 *Focus Groups*

Three Focus groups were conducted, one with each of the following categories:

- Pregnant women (aged 19 yrs and older),
- Mothers and Mothers-in-law and
- Health Care providers (Doctors, nurses and HIV and AIDS counsellors)

Each focus group consisted of 6-8 participants, and a total of twenty participants were reached through this method of data collection. Again, while an interview guide was used, the researcher was careful not to lead the discussions or impose on what was discussed. The researcher allowed the participants to discuss issues among themselves, which helped to ensure content-rich

qualitative data from the natural flow of discussions. The process was interactive, allowing participants to acquire knowledge on PMTCT and relevant aspects of child rearing or HIV prevention in general. The discussion was conducted in a language with which the participants were comfortable, which was mainly Isixhosa, Isizulu and Sesotho. It was only the interview with health workers that was conducted in English. The discussions took a maximum of one and a half to two hours so as not to tire the participants while gathering as much information as possible.

Though the information collected from the FGDs may not be used for projection on the entire population of HIV positive mothers in South Africa, the information collected was content rich, and provided some insight into some of the socio-cultural barriers preventing the use of Nevirapine by HIV positive pregnant mothers, which will be useful to policy makers and health providers.

3.5 Data Management and Recording Procedures

Using an interview guide, the researcher moderated the sessions with the assistance of a trained facilitator. The discussions were tape recorded, transcribed and translated for meaning. While an interview guide was used, the researcher allowed the participants to discuss issues among themselves, to ensure content-rich qualitative data from the natural flow of discussions, as previously indicated. The process was interactive to allow for knowledge acquisition by participants.

The following are attached as appendices:

- App. 1- Preparation and Conducting of Interview
- App. 2- Interview guide with Mother/Mothers-in-law
- App. 3- Interview guide with HIV and AIDS positive pregnant mother
- App. 4- Demographic questionnaire for Individual Interviews and Focus Groups.
- App. 5- Interview Guide with Health Workers

3.6 Data Analysis

The analysis of the data was done using thematic analysis, as discussed by (Creswell, 1998). A computer package was not available to the researcher, resulting in the data being analysed manually. The researcher coded the transcripts from interviews and focus groups, and then developed broad categories under which all the codes could be placed. At this point the researcher revisited the research objectives, and this guided the final selection of themes for presentation and discussion of data.

3.7 Methods for Verification of Data

The criteria of credibility, transferability, dependability, and confirm-ability were applied to ensure the quality of the data in this research, as described below (Patton, 1990):

- Credibility refers to whether or not participants found the account of the research true. Copies of the draft report were discussed with some of the participants. They all felt that the report resonated with their experiences.
- Transferability is based on the idea that accounts may be transferable to other settings through much description. A detailed account of the research methods used in this research was thus provided. Different data sources (health workers, mothers-in-law and pregnant women) were used as well as different methods of data collection (individual interviews and FGD's) for purposes of triangulation.
- Dependability in quantitative research replaces the notion of reliability (or consistency of findings). This has been achieved by an auditing trail, and a detailed description of the research process.
- Confirm-ability – the extent to which findings are qualitatively confirmable – has been achieved by grounding analysis in the data.

3.8 Ethical Considerations

The importance of ethical considerations is addressed by most authors who discuss research design (Patton, 1990; Creswell, 1998). The following safeguards were employed in this study to protect the rights of the participants:

1. Permission to gain access to the site for the study was obtained in writing from the relevant Hospital authorities (Frere Hospital, East London);
2. The research aim and objectives were clearly articulated, both verbally and in writing, so that they would be clearly understood by the Health authorities, the members of different community health development structures, as well as by the in-depth interview and focus group participants;
3. Permission to be interviewed was obtained from the research participants;
4. The interviews were conducted in a language in which the participants are comfortable; this was mainly in Isixhosa, Isizulu and Sesotho, except in a few instances where translation into Tshivenda or Sepedi was required.
5. Research participants were informed of all data collection devices and activities, and they were assured of the confidentiality of the data;
6. The final decision regarding informant anonymity resided with the informants.

3.9 Conclusion

This chapter outlined the research methods used in this study, as well as the procedures used for verification of data and those employed to ensure that the rights of participants are protected. The next chapter presents the outcomes of this research.

CHAPTER 4: RESULTS AND DISCUSSIONS

4.1 Introduction

This chapter summarizes the main findings arising from this research. The main question that this study attempted to answer was: What are the main socio-cultural barriers to the successful implementation of PMTC? The main themes that have emerged from the data have been grouped thematically under the following headings: i) barriers during the antenatal period, ii) barriers during the intrapartum period and iii) barriers during the postnatal period.

4.2 Constraints or barriers during the antenatal period

4.2.1 PMTCT: Voluntary Counselling and Testing

As stated in chapter one, HIV testing and counselling is a critical component of prevention strategies to reduce transmission of HIV from mother to child (Dabis, 1999; Basset, 2002; Mofension & McIntyre, 2000). Unless pregnant women are willing to be counselled and tested for HIV, the encouraging advances made in the use of drugs to reduce perinatal transmission, as well as greater access to treatment now available in South Africa, will be meaningless. HIV counselling and testing also offers the opportunity to identify HIV-infected individuals and channel them into treatment programmes. Through the early identification of the infection, its management can be substantially improved.

PMTCT counselling in South African health facilities occurs in two phases: i) counselling and informed consent for HIV testing, and ii) ongoing counselling and information during the antenatal and postnatal period to support infant feeding and other decisions such as disclosing HIV status. In most of the health facilities in South Africa, women are introduced to the components of the PMTCT programme during a group information session at the antenatal clinic. Thus, all antenatal clients attending for the first time are informed about the PMTCT

programme in a group (but might already have heard about the programme in the community).

All the facilities in this study provided group counseling, although health workers reported that there are some facilities where group counseling is not consistently done. This was attributed to either to a shortage of staff, or a low client load (in which case individual information sessions are done). Following the information session, in most facilities in South Africa, individual pre-test counselling is offered and women can decide whether or not to go for voluntary counseling and testing. In KwaZulu-Natal individual HIV counselling is seen as compulsory in order for women to make an informed choice regarding HIV testing, and the very high uptake of HIV testing in this province may be related to the approach of providing individual counselling to every antenatal client (Tint & Doherty, 2003). The study by NDOH and HST (2003) also found that in Mpumalanga, Eastern Cape, North West and the Northern Cape there were still problems with the employment of lay counselors, and most counseling in these provinces is performed by nurses with numerous clinical duties. The low uptake of HIV testing in these provinces may be attributable to the lack of lay counsellors, although this is not without problems. Data from this research indicate that the high levels of societal stigma could result in women being reluctant to see a lay counselor (especially if the lay counselor resides in the same community as client), although this was an outlier view. There were also instances where confidentiality was not maintained, although this was again not widely reported. Mostly, participants across interviews (professional and lay groups including pregnant women) felt that use of lay health counsellors was very positive step in the PMTCT of HIV programme.

Other barriers identified by participants related to issue such as whether the provider (professional or lay), is perceived as caring and empathetic, and whether they (pregnant women) felt free to attend the ANC clinic. Noteworthy is that most pregnant women (80%) expressed the view that they were free to attend the antenatal clinic, while 20 % of participants felt that they were not free

to do so. The main reason given for not being able to attend was that there was no ANC clinic close to where the participant resided, especially when they have to move between the family home and that of the mother-in-laws in the rural areas. The high cost of traveling to and from the clinic was also cited as a reason for not attending ANC (especially considering the fact that many women were unemployed). Significant also was the fear that health workers would not keep their records confidential. Further barriers identified by some participants were “the bad attitudes of nurses”, no available transport, and lack of time - as stated by one woman: “because I do part time work, sometimes I do not have time to go”. Although extreme views, two participants reported that the husband or mother-in-law respectively, were against their attending the antenatal clinic. It can thus be argued that the attendance of ANC was not constrained so much by cultural factors as by economic factors, lack of transport, and health workers attitudes.

4.2.2 Stigma, Gender and VCT

From the above it can be seen that there are various factors that influence the uptake of HIV testing, which include both health service and community factors. Health service factors include attitudes of professionals, infrastructural problems which lead to a lack of privacy, and issues with confidentiality. These will not be elaborated on here, as it was not the focus of this study. However, it is mentioned here because of its potential to fuel already high levels of existing stigma. The most important community factor, which was a dominant theme across individual interviews and focus groups that influences the uptake into VCT, was social - high level of societal stigma and discrimination, as well as the status of women. Stigma resulted in fear of negative reactions from partners or relatives, leading in turn, to low levels of disclosure by pregnant women to their spouses or partners, or a family member subsequent to HIV testing. Many pregnant women interviewed displayed signs of internal stigma, evidenced by such comments as:

“I felt too ashamed to mention it to my family”

“I felt a disgrace to my family”

“I am ashamed, because I made a mistake”

With regards to community or social barriers, the fear of rejection, abandonment and fear of loss of support related to an HIV positive diagnosis was expressed by most health workers as well as pregnant mothers and family members interviewed as a serious limiting factor to HIV testing. Because a woman is generally the first member of a couple to receive HIV testing and know her status, she is often seen as the one who brings HIV into the family (Varga, 2002). A number of studies have shown that despite high awareness of the presence of HIV and AIDS in the community, it is still associated with stigmatisation and fear among community members (Varga, 2002). Thus, it was not surprising that many pregnant women reported that they found it extremely difficult to disclose their positive status subsequent to HIV testing. This was supported by interviews conducted with health workers, who confirmed that disclosure of HIV positive status was still “a very traumatic experience for mothers”. Thus, many women are reluctant to have a HIV test, and where they do have a test, they prefer not to disclose their status, especially to their partners. This finding was similar to findings reported in the literature (WHO, 2003), which found that rates of disclosure among women in developed countries were higher than in developing country contexts, with rates ranging from 16.7% to 86%. Among the studies that reported disclosure rates to current and/or steady partners the average rate of disclosure was 49%, considerably less than the average rate reported from studies conducted in the developed world (79%).

Analysis of responses as to why women did not disclose their status revealed a variety of responses. Fear of stigmatization, and fear of rejection by their partners were the dominant responses, across interviews. Some reasons for not disclosing included responses such as:

“my husband is already infected...so he knows I'm infected because he's the one who infected me.”

By implication, the above participant is saying that because her husband has been diagnosed as HIV positive, she came to be tested because she knew that she would test HIV positive as well, since they had not used condoms. It also highlights another barrier often referred to by all categories of participants – that lack of communication between partners, male dominance in relationships, and resistance by men to use condoms was contributing to the spread of the HI virus. It was interesting that participants referred to their lack of income within the context of their well-being and their ability to attend antenatal clinic, however, most pregnant women did not link their economic status to a lack of power in their sexual relationships. Most participants however, reported that they were unhappy about the unwillingness of their partners to go for VCT. This is in line with findings from various studies that have shown that despite attempts by counsellors and nurses to offer VCT for couples, the uptake of testing by partners continues to be poor (Varga, 2002). WHO recommends that (WHO, 2000), at least 50% of partners of antenatal clients should be tested for HIV. Given the afore-mentioned discussion, this appears to be quite an ambitious target. Greater attention should therefore be directed towards developing strategies to increase male involvement in the PMTCT programme in the Eastern Cape, especially in East London district (Mdantsane, Zwelistsha and Emthonjeni).

All the sites offering PMTCT services in SA use rapid HIV tests. This policy makes it possible for HIV test results to generally be available the same day except in extreme cases, where a severe staff shortage or stock outs of rapid test kits have been reported (Tint & Doherty). Given some of the barriers such as cost and lack of transport, it is most helpful to the PMTCT programme if clients receive their results the same day as their pretest counseling and HIV testing. The evaluation of the national PMCTC programme has shown that there are large differences between provinces in the uptake of HIV testing ranging from 14% in the North West to 92% in KwaZulu-Natal (Tint & Doherty). In addition to variation between provinces, much variation exists within provinces. For example in the Eastern Cape, the testing uptake rate in the Rietvlei site is 86% (852/995)

whilst the rate in the East London site is 31% (4602/15025). The researchers of this particular survey articulated various reasons for the large differences between provinces in testing uptake. These relate to issues such as testing options outlined in the various policies, and employment of lay counsellors. However, the said survey or study was done in a clinic setting, focusing on health service barriers, and did not explore socio-cultural barriers. The evaluation (Tint & Doherty), also found that the provinces with the smallest drop off between first antenatal visits and women accepting HIV testing, namely Gauteng, KwaZulu-Natal and the Western Cape, have all prioritised the utilization of lay counsellors, either by directly employing them or by contracting NGOs to employ them. Provinces with low HIV testing uptake such as the North West (14%) and the Eastern Cape (34%) are still struggling to employ lay counsellors and many of the pilot facilities still rely on nurse counsellors. While these studies cannot be viewed as conclusive, the results of this qualitative study (on socio-cultural barriers to PMTCT) suggests that use of lay health workers will help to reduce language and other cultural barriers which might facilitate uptake into PMTCT programmes in East London district (Mdantsane, Zwelitsha and Emthonjeni). Because of the high levels of social stigma, it would also be important to strengthen efforts to integrate HIV counselling into reproductive health services, such as family planning services or ANC.

In many provinces including Eastern Cape, women are given the option to receive individual pre-test counselling whilst in other provinces such as KwaZulu-Natal, individual counselling is seen as an integral part of antenatal care and all women receive an individual session with a counsellor. Following this session a woman can decide whether to be tested for HIV or not. It appears that this approach increases the uptake of testing as it may normalise counselling as part of antenatal care and not associate it only with testing for HIV (Tint & Doherty). A number of sexual and reproductive health specialists have asserted that this, and this in turn, will help to reduce HIV related stigma (Taha, Biggar, Broadhead et al, 1997).

Although not a socio-cultural barrier, but linked to stigma, is the lack of space or adequate infrastructure of facilities for VCT, because privacy is required for effective counseling. It was found that facilities with insufficient space for counselling appear to have lower testing uptake rates than facilities that do have sufficient space ((Tint & Doherty). This infra-structural constraint should not be regarded as a reason not to implement PMTCT in a facility; rather, strengthening of facility infrastructure should be seen as an ongoing priority to enable effective provision of PMTCT. Other health service problems identified that need to be briefly mentioned here relate to interruptions in the supply of testing kits to facilities (simply because it takes so much courage for a woman to get to this point). While not common, these interruptions can result in missed opportunities for HIV testing, and de-motivate clients. It is hoped that as the national PMTCT programme expands more rapidly, districts and sub-districts (instead of the national HIV/AIDS directorate) will procure their own supplies, and that this will help to avoid interruptions in service delivery. Ongoing capacity building of staff in management and systems strengthening will also help to obviate this problem.

All the women in this research study said they received their test results on the same day as having VCT (but this is not generalisable due to the purposive nature of the sample). However, the national evaluation (Tint & Doherty), reported that HIV test results were received by 85% (39733/46910) of women who agreed to an HIV test. This is very encouraging since it suggests that rapid tests are being used and that results are most likely available the same day as testing. The largest proportion of clients who did not receive their test results came from Gauteng and the North West provinces, and this should be further explored in another study.

In summary, it can be said that the high level of HIV stigma reported by participants in this research study seems to reflect the situation nationally, and that much more needs to be done to reduce stigma. The average uptake rate for HIV testing (which is a good indicator of levels of societal stigma) in the 18 pilot

sites in 2002 was 56% (Tint & Doherty). While this meets the World Health Organisation's (WHO, 2000), suggested target that at least 50% of pregnant women counselled should be tested for HIV (as part of their recommended routine PMTCT indicators), there is wide variation among sites, with some having a testing uptake rate of below 50%. This is considered to be unsatisfactory and these sites should be targeted for extra support (Tint & Doherty).

4.3 Constraints or barriers during the intrapartum period

The main constraint to counselling and testing during the antenatal period was the fact that many women still reported that they deliver their babies at home due to cultural beliefs or lack of transport to a facility. While most women were planning to deliver in a health facility, there were women, who reported that traditionally, they were expected to be delivered at the home of the mother-in-law, by an elderly woman. This has implications for PMTCT since traditional birth attendants are not necessarily trained or aware of obstetric practices during labour to reduce or prevent perinatal transmission. Health workers also pointed out that some women arrive at hospital for delivery without having "booked" (i.e. attended ANC). In these cases it was difficult to counsel patients due to constraints on privacy (which also made confidentiality difficult) in the labour ward.

There was hardly anything in the literature reviewed by the researcher on this topic of socio-cultural barriers during the intrapartum period, except for a study conducted by NDOH and HST (2003) to evaluate the national PMTCT programme. This evaluation found that very few facilities were offering HIV testing to women in early labour or postnatally. This is partly because health workers do not feel that it is appropriate, and partly because lay counselors are not available in many delivery wards. An evaluation of obstetric services conducted by HST (SA Health Review, 2003; McCoy, Kemp, Ratsma et al, 2003) found that in most of the facilities surveyed, the physical layout of the labour ward indeed made privacy for counselling difficult, which supports the findings of this

study. While women arriving in labour were usually separated from family and/or friends, allowing questions about HIV status and nevirapine to be asked privately, confidentiality was more difficult when this initial evaluation occurred in a room occupied by more than one patient –which was often the case. For example, nurses complained that in rooms where beds are separated only by a curtain, even whispered conversations could be overheard. A few sites offered counselling and testing to women in early labour, a service provided by nurses and midwives. Some patients were given results immediately, others after birth. The National PMTCT Protocol (SA Department of Health, 2001), for the pilot programme states that women who do not attend antenatal care and report to a facility in labour should not have access to antiretroviral drugs because they cannot be adequately counselled and tested. The policy does however recommend early postpartum testing and infant prophylaxis. The policy regarding counseling and testing in labour should be reviewed and postnatal testing should be actively encouraged to prevent missed opportunities for treating infants.

Many participants (including health workers) reported that while pre and post-test counseling was adequate, much more needs to be done in terms of provision of ongoing support. While this was mainly due to a lack of human resources and inability to cope with the demands of counselling for HIV testing in facilities, much more needs to be done at a community level to provide ongoing support to women. Participants felt that members of the community, such as “sangomas, elderly women, church or mosque leaders... should be involved with the MTCT programme, rather than neglecting them”. Given the high levels of stigma identified in this study, the involvement of local NGOs in ongoing support of women – through for example support groups - would be important. However, participants felt that NGO involvement was not sufficient and more needs to be done to harness the potential value of NGOs to PMTCT programmes. For example, NGOs could serve as valuable sources of support for home-based care, infant feeding support and ongoing counseling. This is discussed further in the next section.

4.4 Constraints or barriers during the postnatal period

By far the most dominant theme emerging from the data of this study on socio-cultural barriers during the postnatal period related to infant feeding. Surprisingly, little mention was made of the general nutrition of the mother. The South African National Protocol for the PMTCT pilot sites (SA Department of health, 2001), states that counselling should involve a pre-test session, post-test session and that HIV positive women should be offered counselling at every subsequent antenatal visit. The purpose of these sessions is essentially to assist women to cope with the diagnosis and to make plans to prevent HIV transmission to the infant.

Despite the above recommendation that counselling should occur beyond the context of testing, many pregnant women perceived the need for more support and counselling, stating that they received too little ongoing counselling. This results in a number of challenges, particularly in relation to infant feeding counselling. According to the national protocol (SA Department of health, 2001), infant feeding options are included in the post-test counselling session for HIV positive women along with other information. Because the time immediately following an HIV positive diagnosis is one of confusion, perhaps anger and shock, attempting to convey large amounts of information during this time may often not be appropriate. Ideally this should be done in a follow up counselling session once the mother has had an opportunity to deal with the initial impact of her HIV status, and she has disclosed to at least partner or a family member. Yet issues such as infant feeding options are, in reality, often discussed the post-test counselling session (Tint & Doherty, 2003)

Given the constraints to support at the facility level, strengthening of community links is essential to provide follow up support for mothers both antenatally and postnatally. Ongoing community support can assist with disclosure, infant feeding practices, and reducing stigma would help to link individuals with community resources. Most participants, across interviews, reported that there was a need

for more support groups in communities. Support groups have been shown to be a valuable place where women can share their experiences with others and gain from the group support (Varga, 2002). Unfortunately, difficulties have been reported regarding implementation of PMTCT support groups, and include lack of space within facilities to accommodate the group, difficulty in finding a facilitator for the group, and fear on the part of women of being identified as HIV positive. The latter again highlights the problem of HIV stigma, which appears to be the most serious social barrier to the successful implementation of PMTCT programmes.

For pregnant women known to be infected with HIV, the avoidance of re-infection during pregnancy and lactation is important to lower the risk of MTCT. However, given the reluctance of many women to disclose to their partners, as pointed out earlier, this remains a big challenge. Success can only be achieved if their partners are involved in preventive interventions, particularly VCT and infant feeding counselling. However, the uptake of VCT amongst partners as well as disclosure of test results by women to partners in this study was not promising. These findings are congruent with the results of a study conducted among pregnant women in the Western Cape and in Swaziland (Tint & Doherty, 2003; Varga, 2002), which showed that women felt that being diagnosed HIV positive would result in serious social and domestic consequences, hence they were more likely to disclose to other family members than to their partners. This highlights not only the impact of the stigma, blame and discrimination that characterises the HIV epidemic in South Africa, but also reflects the status of woman in general in our society. While counselling of women should include providing them with skills and support to discuss HIV risk reduction and facilitate disclosure to partners or family members, greater efforts should be directed at empowering them with skills that could enhance their life choices, including their economic status and financial dependence on their male partners.

The national PMTCT protocol (SA Department of Health, 2001), stipulates that care must extend beyond the point of delivery for both mother and child. All

women are advised to return for a post-natal care visit within 3-14 days after discharge, every two weeks in the first month and once a month thereafter. The purpose of these visits is to assess the woman for signs of infection, to provide multivitamins and prophylaxis against opportunistic infections, to provide support for exclusive breastfeeding if this is the chosen feeding method and to provide guidance on safe formula feeding and formula milk supplies to women who have selected to formula feed. These recommendations for maternal care are based on the DOH (2000), Guidelines for Maternity Care in South Africa. The recommendations for follow up of infants in PMTCT pilot sites are based on the South African DOH IMCI clinical case management guidelines, which were adapted in 2001/2 to include care of children infected or affected by HIV and AIDS (SA Department of Health, 2001/2).

Despite the presence of comprehensive guidelines for follow up care, findings of this study was similar to that of the NDOH and HST (2003), which found that very few of the sites are able to provide the appropriate postnatal care required for women with HIV and their families. The challenges to providing effective follow up care are many. These include difficulties identifying HIV positive women and their infants at clinics due to inadequate tracking mechanisms, staff shortages, many women opting not to disclose their status to clinic staff (because of stigma), and poor access to health facilities due to long distances and a lack of affordable transport. Yet effective postnatal care of HIV positive women is important in order to prevent opportunistic infections, to provide nutrition support, to provide routine care, such as family planning, and to link women with other support services and groups. Since many maternal deaths occur in the postpartum period, good postnatal care can help to ensure the survival of mothers, which is critical to the survival of their infants (Preble & Piwoz, 2001). Furthermore, postnatal infant feeding support is essential to help mothers overcome difficulties and to ensure that the chosen method is practiced safely. Supporting the mother in her choice is especially important in a context where HIV related stigma is high.

While postnatal nutrition support of the mother was not a key theme in this study, the research literature strongly suggests that programmes to prevent MTCT should also provide nutrition support to HIV infected women in the postpartum period, particularly those women who are breastfeeding their infants, because they are at a greater risk of weight loss and post partum mortality (Nduati et al, 2001). To relieve pressure on the professional staff, the involvement of community health workers for postpartum support may serve as a cost effective approach to help provinces strengthen the PNC services. The WHO places great emphasis on the importance of postpartum support and recommends that, at least 90% of HIV infected women should be referred to a support network. (41) Ultimately, the de-stigmatisation of HIV and AIDS at both the community level and the health service level may enable individuals with HIV to feel more comfortable disclosing their status to health workers. While this is a long-term aim, some strategies will need to be developed in the short term to improve follow up of mothers and infants as a means to providing improved care.

4.5 Conclusion

This chapter has presented the main findings arising from this research. In answering the main question that this study attempted address - ***What are the main socio-cultural barriers to the successful implementation of PMTC?*** - the data was presented thematically under the following headings: i) barriers during the antenatal period, ii) barriers during the intrapartum period and iii) barriers during the postnatal period. Key socio-cultural barriers identified were presented and discussed under each of these headings. An overarching theme of high levels of societal stigma emerged as the key socio-cultural barrier throughout all these three phases, with serious consequences for infant feeding which also emerged as a major challenge in this research. It is discussed further in the final chapter, which concludes the study and makes recommendations to address some of the main socio-cultural barriers identified.

CHAPTER 5: CONCLUSION AND RECOMMENDATIONS

5.1 Introduction

The central theme that emerged from this study, across interviews and focus groups discussions with pregnant women, mothers-in-law and health workers, was the high levels of HIV related societal stigma which this study concludes to be the key socio-cultural barrier to the successful implementation of PMTCT programmes in East London district (Mdantsane, Zwelitsha and Emthonjeni). This was found to have serious consequences for infant feeding, which by itself, also emerged as a major challenge in this research. These two themes are discussed further in this final chapter, which concludes with recommendations on how to address some of the socio-cultural barriers identified, and makes some suggestions for further research.

5.2 Stigma, Gender and HIV/AIDS

The HIV/AIDS epidemic is affecting women and girls in increasing numbers, and globally, just under half the people living with HIV are female. Every day, approximately 5 500 women are newly infected with HIV, and nowhere is the trend more apparent than in sub-Saharan Africa where women comprise 58% of the existing HIV infections. In most Southern African countries, more than 1 in 5 pregnant women (20-30%) are infected with the HIV virus (UNAIDS, 2002). Many researchers have pointed out that African women are at greater risk of HIV infection, and become infected at an earlier age than men. What emerged from this study, and supported by other research in similar contexts (Varga, 2002), is that stigma and other forms of discrimination or oppressions intersect, so that its effects are often experienced more severely by, for example, women.

HIV positive women face stigma and discrimination in the family, the community and even within the health setting. Women were unanimous in their call for more

support: from support in dealing with the results of a positive test, to facilitating disclosure and making and sustaining choices about infant feeding. In particular, the low rates of disclosure to sexual partners or spouses need attention. These trends points to serious gaps in the AIDS response. Hence:

- All stakeholders and government in particular should work towards and strengthen a coherent, nationally-led AIDS response;
- The AIDS response should include a strong IEC component and should also be directed at mitigating stigma;
- Services that can protect women against HIV must be expanded, and as far as possible, VCT should be integrated into other sexual and reproductive health services;
- Realistic strategies that address the interplay between inequality (particularly gender inequality) and HIV need to be developed;
- The above would include a greater involvement of men in sexual and reproductive health, HIV prevention and PMTCT in particular;
- It is equally important that women are more closely involved in designing and guiding programmes that are meant to serve them;
- The nurturing of strong civil society organizations – support groups, youth groups, womens' groups – can help to improve the reach, accountability and effectiveness of AIDS programmes;
- Greater involvement of faith-based organizations, elders and traditional leaders in efforts to mitigate stigma is needed;
- Support for HIV positive women to disclose their status publically and act as role models will also help to reduce stigma.

In addition to the above general measures, it would be important to remember that efforts to prevent MTCT should relate to, and be considered within, the entire spectrum of HIV and AIDS primary prevention, care, and support activities.

Core PMTCT interventions are those that directly prevent MTCT during pregnancy, labour and delivery, and during the postpartum period for women who are already HIV-infected. The core interventions are those that are known today to be the most effective for identifying HIV infected women and for reducing the risk of HIV transmission during each of these periods.

The main objectives of the core PMTCT interventions are to:

- Reduce HIV transmission from mother to child
- Reduce infant and child morbidity and mortality (AIDS specific and overall)
- Identify and care for HIV positive mothers
- Strengthen HIV and AIDS awareness and response in health services and the community.

These core interventions for PMTCT cannot all be achieved at once. It is important though, to note that a key determinant of success for any preventive intervention is high coverage of the target population with the basic steps, as soon as possible (Tint & Doherty, 2003). Simple measures applied to a whole population will save more lives than complex interventions applied to a limited population. The key to high coverage of the interventions is to integrate them progressively into the standard, recommended package of maternal and childcare outlined in the maternal and child health policy of the Department of Health. In the South African setting, great efforts are being made to integrate PMTCT into routine maternal and child health care, and this need to be supported.

These efforts should be complemented with strong collaborative partnerships between government and civil society organisations, as well as by strengthening co-ordination between the various sectors within government itself.

5.3 Breastfeeding

The advent of HIV and the knowledge that the virus can be transmitted through breastmilk has led to the need for the promotion of breastfeeding to be qualified

by information regarding the risks of HIV transmission through breastmilk. These risks however need to be weighed up against the immunological and nutritional benefits of breastfeeding, and the potential dangers of replacement feeding, even for infants born to HIV positive women. In recognition of the trade-off between harm and benefit, a WHO Technical Task Team has recommended that exclusive replacement feeding should only be encouraged in HIV infected women if it is safe, feasible, acceptable, accessible and sustainable, but that if any of these conditions are not met, exclusive breastfeeding should be promoted (WHO, 2000).

Currently the PMTCT pilot programme in South Africa offers free formula milk for a period of six months to HIV positive women who choose not to breastfeed. It has been aptly asserted that with the low follow up rates displayed in the study by NDOH & HST (2003), and the acknowledgement that routine data cannot be used to track cohorts of infants, very little is known in South Africa about the actual infant feeding practices of HIV positive women nor of the impact of the provision of free formula milk on infant morbidity or on infant feeding practices in the non-HIV positive population, and this constitutes an important area for further research.

Public health concerns have been raised about the decision to supply free formula as part of the package of care for PMTCT. The interim report on the PMTCT pilot programme noted that the uptake of free formula varied considerably between sites with similar socio-economic contexts, and that free formula was being taken up by women under conditions that were not safe or feasible (McCoy, Besser, Visser & Doherty, 2002). It was also indicated that some women who were provided with free formula did not formula feed exclusively and often mixed fed with breastmilk. A more recent study (Tint & Doherty, 2003), found evidence of high rates of intentions to formula feed in both urban and rural sites. The decrease in intentions to formula feed and increase in the intentions to breastfeed have been attributed to a variety of factors including:

- The lack of infant feeding training for health workers involved in PMTCT.
- The stigma associated with the free distribution of formula milk from clinics.
- The unreliable supply of formula to facilities, particularly feeder clinics.

The current PMTCT protocol for the pilot sites (SA Department of Health, 2001), recommends that counselling on safe infant feeding should take place both antenatally (during the post test counselling session) and postnatally before the first feed. Within the antenatal setting, formal counselling is conducted mostly by lay counsellors. Very little is known about the extent to which nurses or doctors reinforce infant feeding options during their consultations with clients. Also, it is not sure to what extent the infant feeding component of counselling is adequately covered the training of lay counselors. This raises concerns regarding the ability of lay counsellors to accurately present infant feeding options to mothers. These problems highlight the fact that the provision of free formula milk does not ensure exclusive formula feeding or optimal nutrition for infants as reliable delivery of supplies is not guaranteed in many settings and the management of supplies at facilities does not appear to take into consideration the needs of mothers and infants (Tint & Doherty, 2003). Additionally, socio-cultural constraints to exclusive breast or formula feeding need more attention, and mothers need to be supported in whatever option they choose given their circumstances.

Another concern among public health professionals is that the promotion of formula feeding in HIV positive women could 'spill over' into the general population (Tint & Doherty, 2003). 'Spillover' is considered to be increased use of formula, either earlier introduction, increased use of formula feeds or stopping breastfeeding altogether in HIV uninfected populations, or populations of unknown HIV status. The provision of free formula by facilities could be perceived by the general population as an official endorsement of formula feeding as being superior to breastfeeding. Together with the low levels of knowledge about the value and benefits of exclusive breastfeeding amongst

health workers, and with the added confusion related to HIV transmission, the policy could lead to an undermining of breastfeeding promotion and a deterioration of child health outcomes. These concerns have been given further justification by a UNICEF study of four countries in Southern Africa reporting that uncertainty over HIV and infant feeding was leading to a dangerous demise in support for breastfeeding (Latham & Kisanga, 2001; Willumsen & Rollins, 2001). There is also evidence that the provision of commercial infant formula increases the potential for, but does not guarantee, exclusive formula feeding. For example, data from Nairobi, showed that at least 30% of HIV-infected women who chose to formula feed and who were provided with subsidised formula milk, did not exclusively formula feed (Latham & Kisanga, 2001). It is possible that when infant formula is offered free of charge, clients might be tempted to choose formula feeding because this option would increase the food security of the household and not because they are committed to exclusive formula feeding. Hence the provision of free infant formula might increase the likelihood of mixed feeding which is thought to be particularly dangerous.

According to the pilot site PMTCT protocol (SA Department of Health, 2001), women who choose to breastfeed should be counselled to exclusively breastfeed for 4 months and to abruptly stop breastfeeding at 4 months. Thereafter they are entitled to receive free infant formula for 2 months. While not enough is known about the feasibility of abrupt cessation of breastfeeding within the South African context, experience within the pilot sites indicates that this is very difficult to achieve. This has been attributed to mainly cultural beliefs regarding length of breastfeeding and difficulty in accessing the free formula supply following early breastfeeding cessation (Tint & Doherty, 2003). Abrupt cessation of breastfeeding at the early age of four months could have serious consequences for the nutritional status of the infant, especially since access to free formula milk is not guaranteed in many settings.

Community support is thus especially important for women's feeding choices in contexts where decisions are not made by the mother alone, and where cultural or family practices are highly influential in determining ultimate practices. A study of social and community perspectives on PMTCT conducted in the Limpopo province (Varga, 2002), found that a common cultural belief in the region is that babies cry because they do not receive adequate food. In relation to exclusive breastfeeding, women may experience immense pressure from family members to mix breast milk with formula milk in order to 'satisfy' the infant. With the kind of social pressure experienced by many women, the current system of counselling within the PMTCT programme is clearly inadequate to provide sufficient support to women in their infant feeding choices. Community health worker and peer support need to be explored to enhance safer infant feeding practices.

In conclusion it can be said that under the present social, environmental and economic circumstances in South Africa, there isn't one single feeding method for all HIV infected women that can be recommended. Hence all HIV infected women should receive appropriate counselling and information on infant feeding options, and be supported to implement their chosen option. To this end:

- Accurate and consistent messages regarding infant feeding should be provided at all health facilities, and through a public IEC campaign. Information on formula feeding should only be provided to women known to be HIV positive.
- An unequivocal message that mixed breastfeeding is the worst option for all mothers and children should be consistently delivered in all health facilities and through public IEC campaigns;
- Training courses and support for counselors and health workers who conduct infant feeding counseling should be regularly reviewed, and ongoing supervision and support provided;

- All facilities implementing PMTCT services should have sufficient numbers of trained nurses and lay counsellors who are able to provide infant feeding counselling and support to women; and
- Strong community-based support groups should be developed and nurtured since they would help to both reduce stigma and provide support the HIV positive woman with regards to effective infant feeding.

5.4 Conclusion

This chapter concluded this study by discussing the central theme that emerged from this study - the high levels of HIV related societal stigma - which was found to be the key socio-cultural barrier to the successful implementation of PMTCT programmes in East London district (Mdantsane, Zwelitsha and Emthonjeni). Because it was found to have serious consequences for infant feeding, which by itself, also emerged as a major challenge in this research, views on breastfeeding were also discussed further in this chapter, and recommendations made on how to address some of the socio-cultural barriers identified. Before making some recommendation for further research, it is necessary to make some comments on the research methodology.

This research used a qualitative methodology in which sampling was purposively done. The results of this research therefore reflect the situation in East London district (Mdantsane, Zwelitsha and Emthonjeni), and cannot be extrapolated to all PMTCT programmes in South Africa. However, given the experience of the researcher as well as evidence in the research literature, it could be argued that the problem of stigma, and gender discrimination, which was revealed in this research would also be present in many other parts of South Africa which share similar demographic characteristics. The recommendations made here would thus also be useful to policy makers and implementers of PMTCT programmes in many parts of the country.

5.5 Suggestions for further research

There is a need to do research on:

- How infant formula is used in the households of mothers who accept free formula feeds.
- To determine how the provision of free formula influences the choices around infant feeding practices in PMTCT sites, as well as effect of the provision of free formula on child health.
- To understand whether HIV positive women are free to make infant feeding choices, and whether they can sustain that decision within the household.
- Participatory and operations research is needed to develop models for effective stigma reduction in communities and effective community engagement to increase support for infant feeding.
- As part of stigma reduction, cases of “best practice” regarding disclosure and ensuring (shared) confidentiality should be documented and widely disseminated.

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7. APPENDIX

APP1. PREPARATIONS AND CONDUCTING THE INTERVIEW

- Issues to consider in planning and facilitating Focus Group Discussions.
 1. Plan and invite participants in advance
 2. Snacks for participants
 3. Transport reimbursement if necessary
 4. Composition of the participants
 5. Training of facilitators and note taker
 6. Secure equipment – recorder, digitizer, batteries, stationary, etc.
 7. Secure appropriate venue
 8. Obtain the necessary permissions

- GUIDE TO CONDUCTING FOCUS GROUPS

1. Determine the number of participants per group (10-12)
2. Homogeneity of group-age, socio-economic status, cultural affinity
3. Mothers and mothers-in-law of pregnant women
4. A group of health workers

- During Sessions

1. Establish rapport
2. Permission from participants for discussion, tape recording and records taking
3. Set rules and regulations governing discussions and dynamics

- The Interview

1. Use guide as a 'guide'
2. Allow interaction and debate among participant
3. Let session be a learning process for participants too

APP. 2- Interview guide with Mother/Mothers-in-law

- Introduction – Provide form for self-filling on biographical and socio-cultural information (Age of respondent, ethnic group, level of education, province of origin, cultural and traditional beliefs, employment status, etc.)

- Guide Questions

Do parents in this community talk to their children about HIV AND AIDS? Why is it so?

1. What is the position of parents in regard to breastfeeding? Are they breastfeeding? If not, why?
2. How important is tradition to you in terms of pregnant daughter/daughter-in-law? What are some of the practices relating to pregnancy?
3. How would you describe your present employment situation?
4. What type of dwelling do you live at the moment?
5. What is the main source of your household income?
6. What type of drinking water is available in your area?
7. How far is the nearest health clinic from your house?
8. Are you aware of the PMTCT services being offered at the health clinic? What about VCT? Have you been tested?
9. What do you see as the role of HIV AND AIDS counselors at this clinic? How have you experienced them
10. What do you think of the services provided in general by health professionals at the health clinics?
11. How can parents contribute to the effective implementation of PMTCT?
12. How do you think that the PMTCT programme could assist in preventing children born to HIV AND AIDS positive mothers from becoming infected?

APP. 3- Interview guide with HIV AND AIDS positive pregnant mother

- Introduction – To fill form.
- Guide Questions
 1. Tell me about your family background.
 2. What is your ethnicity?
 3. Are you married, single/common law?
 4. With whom are you living?
 5. How many living children do you have?
 6. Are you employed? What is the main source of your household income?
 7. The government is promoting Voluntary Counseling and Testing (VCT). Have you and your family considered going for VCT?
 8. Would you like to tell me why you decided to go or not go, what was the outcome?
 9. Are you receiving anti-retroviral treatment?
 10. Who did you inform of your status, and why? What support did you receive?
 11. How easy/difficult is it to get to the clinic?
 12. What do you think about the services offered by the health professionals at the health clinic in your community?
 13. How would you describe your relationship with mother and mother-in-law (mothers')?
 14. What role do they play in your family life?
 15. Are you going to use milk formula or breast feed and why?
 16. Would you like to suggest the best way of implementing PMTCT in your area?
 17. How would you describe your relationship with your husband?

APP. 4- Demographic questionnaire of pregnant women

Guide questions

1. Age of respondent
2. Nationality
2. Home language
3. Place of birth
4. What type of dwelling do you live in?
5. Permanent/Temporary residence
6. What is your source of drinking water?
7. Educational background

APP. 5- Interview Guide with Health Workers

Guide to Questions

1. What is the size of your health facility?
2. Has your health facility started with PMTCT activities?
3. How many of your permanent staff members are involved with the PMTCT programme?
4. Have these staff members received training on the management of PMTCT programme?
5. What are the official working hours of the staff members involved with the PMTCT programme?
6. What do you think are the main socio-cultural constraints in this Community that impact on the PMTCT programme?
7. How would you address these challenges?

APP. 6- RESULTS: An Exploration of the Barriers (Socio-Cultural) To Successful Implementation of PMTCT in the East London district (Mdantsane, Zwelitsha and Emthonjeni)

		Number of Participants
Province	Eastern Cape	32 (100%)
District	the East London District (Mdantsane, Zwelitsha and Emthonjeni)	32 (100%)

- Interview at Clinic and Home**

Research Assistants Name	Starting Time of Interview	Place of Interview
Ms. N. Tuse	08:30	Clinic
Ms. N. Tuse	09:30	Clinic
Ms. N. Tuse	10:00	Clinic
Ms. N. Tuse	11:00	Clinic
Ms. N. Tuse	09:15	Clinic
Ms. N. Tuse	10:22	Clinic
Ms. R. Nozintombi	08:00	Clinic
Ms. R. Nozintombi	09:00	Clinic
Ms. R. Nozintombi	10:00	Clinic
Ms. R. Nozintombi	11:15	Clinic
Ms. R. Nozintombi	08:45	Clinic
Ms. R. Nozintombi	11:00	Clinic
Ms. B. Busisiwe	10:20	Home
Ms. B. Busisiwe	10:45	Home
Ms. B. Busisiwe	11:50	Home
Ms. B. Busisiwe	13:15	Home
Ms. B. Busisiwe	9:30	Home
Ms. B. Busisiwe	10:25	Home
Ms. B. Busisiwe	11:40	Home
Ms. B. Busisiwe	13:00	Home
Ms. B. Busisiwe	10:00	Home
Ms. B. Busisiwe	11:25	Home
Ms. B. Busisiwe	12:50	Home
Ms. R. Nozintombi	10:00	Home
Ms. R. Nozintombi	11:00	Home
Ms. R. Nozintombi	12:00	Home
Ms. R. Nozintombi	10:00	Home
Ms. R. Nozintombi	11:30	Home
Ms. R. Nozintombi	10:20	Home
Ms. R. Nozintombi	11:40	Home
Ms. R. Nozintombi	12:50	Home
Ms. R. Nozintombi	11:15	Home
Ms. R. Nozintombi	10:00	Home

- Respondent's Biographical Data

Age of Respondents	20/19/23/25/21/28/26/34/22/19/32/28/30/27/28/32/19/21/18/26/23/24/30/32/34/29/35/38/26/20/40/28				
Total	32 (100%)				
Race Group	African	White	Coloured	Indian	Other
Number of Respondents	30 (93.8%)		1 (3.1%)		
Total	31 (90.6%)				
Nationality	South African	29 (90.6%)			
	Other: Lesotho	3 (9.4%)			
	Total	32 (100%)			

	Home Language
Afrikaans	1 (3.1%)
English	
Isindebele	3 (9.4%)
IsiSwati	1 (3.1%)
Tshivenda	3 (9.4%)
Isizulu	4 (12.5%)
Isi Xhosa	9 (28.1%)
Sepedi	4 (12.5%)
Sesotho	5 (15.6%)
Setswana	2 (6.3%)
Xitsonga	
Other African Language	
Other European Language	
Indian Language	
Other	
Total	32 (100%)

	Number of Participants Born in Eastern Cape
Yes	25 (78.1%)
No	7 (21.9%)
Total	32 (100%)

	Number of Participants not born in Eastern Cape
Free State	5 (15.6%)
Gauteng	2 (6.3%)
KwaZulu Natal	6 (18.8%)
Northern Cape	4 (12.5%)
Limpopo	4 (12.5%)
North West	3 (9.4%)
Mpumalanga	
Western Cape	
Other Country: Lesotho	3 (9.4%)
Total	27 (84.4%)

	Number of Participants living in another province for more than 3 Months (not Eastern Cape)
Yes	26 (81.3%)
No	5 (15.6%)
Total	31 (96.9%)

	Province lived before moving to Eastern Cape
Free State	5 (15.6%)
Gauteng	2 (6.3%)
KwaZulu Natal	6 (18.8%)
Northern Cape	4 (12.5%)
Limpopo	4 (12.5%)
North West	3 (9.4%)
Mpumalanga	
Western Cape	
Other Country: Lesotho	3 (9.4%)
Total	27 (84.4%)

	Number of Participants (respectively)
Number of years participants moved to Eastern Cape (respectively)	1/3/4/8/6/3/10/15/8/10/2/6/4/4/12/8/10/9/10/15/10/5/20/10
Total	24 (75%)

	Highest Educational Qualification
No schooling	4 (12.5%)
Up to Std 1/Gr 3/ABET 1	
Std 2-Std 3/Gr 4-Gr 5/ABET 2	5 (15.6%)
Std 4-Std 5/Gr 6-Gr 7/ABET 3	8 (25%)
Std 6-Std 7/Gr 8-Gr 9/ABET 4	2 (6.3%)
Std 8/Gr 10/N1	5 (15.6%)
Std 9/Gr 11/N2	
Std 10/Metric/N3	6 (18.8%)
Diploma(s)/Occupational certificates	1 (3.1%)
First degrees/Higher Diplomas	
Honours/Master's degrees	
Doctorates	
Total	31 (96.9%)

	Number of Participants with dependant children
Yes	23 (71.9%)
No	9 (28.1%)
Total	32 (100%)

	Number of Participants with other dependants (i.e. parents family)
Yes	
No	30 (93.8%)
Number of other dependants (respectively)	1/2/2/3/3/2/2/3/1/2/2/1/1/2/3/2/1/2/3/1/3/2
Total	22 (68.8%)

	Present employment situation
Housewife, homemaker, not looking for work	2 (6.3%)
Unemployed, cannot look for work	1 (3.1%)
Unemployed, looking for work	15 (46.9%)
Housewife, homemaker, unemployed, looking for work	
Work in informal sector, not looking for permanent work	3 (9.4%)
Sick/disabled and unable to work	
Living with in-laws and unable to work	2 (6.3%)
Student/pupil/learner	
Self-employed-full time	
Self-employed-part time	
Employed full time	5 (15.6%)
Employed part-time	3 (9.4%)
Others, specify:	
Total	31 (96.9%)

	Number of Participants married
Yes	24 (75%)
No	8 (25%)
Total	32 (100%)

	Number of Participants adhering to traditions and customs in their marriage
Yes	25 (78.1%)
No	

	Who participants live with?
Alone	
Alone with children	2 (6.3%)
Husband	1 (3.1%)
Husband/partner and own children	17 (53.1%)
Husband/partner, siblings and children	
Husband and in-laws	15 (46.9%)
With parents	5 (15.6%)
Other 1: Partner	1 (3.1%)
Other 2: Mother	2 (6.3%)

	Type of dwelling
Brick house	23 (71.9%)
Traditional African hut	3 (9.4%)
Flat/Townhouse/apartment	3 (9.4%)
Outside room/flat/house in a backyard	
In a garage	
In a hostel	
In a mokhukhu	3 (9.4%)
In a caravan	
In a temporary shelter	
Total	32 (100%)

	Main source of household income
Formal salary/earnings which attract tax	30 (93.8%)
Contributions by family members	
Contributions by in-laws	1 (3.1%)
Government pension/Grants (e.g. old age pension, disability grant)	2 (6.3%)
Grants/Donations by private welfare organisation	
No income	

	Source of drinking water
Tap in the house	24 (75%)
Tap in the yard	7 (21.9%)
Tap outside in the street	
Tap a block away	1 (3.1%)
From well	
From the river	
Total	32 (100%)

The means of transport used to travel to the health facility by participants					
	Up to 30 minutes	Up to 1 hour	About 2 hours	About 3 hours	More than 3 hours
Foot	2 (6.3%)				
Bus	5 (15.6%)				
Taxi	18 (56.3%)	7 (21.9%)			
Car	3 (9.4%)				
Train					

- Status of Pregnant Woman (Gender Inequality)

	Number of Participant's first pregnancy
Yes	9 (28.1%)
No	23 (71.9%)
Total	32 (100%)

	Number of Participants who were HIV positive during previous pregnancy
Yes	
No	23 (71.9%)

	Number of Participants who has always been married to present husband or partner
Yes	26 (81.3%)
No	5 (15.6%)
Total	31 (96.9%)

	Number of Participants who had babies with multiple husband/partners
1 Husband/Partner	18 (56.3%)
2 Husbands/Partners	4 (12.5%)
More than 2 Husbands/Partners	
Total	22 (68.8%)

	Head of household participants are staying
Husband/Partner	11 (34.4%)
Mother-in-law	15 (46.9%)
Yourself	3 (9.4%)
Mother	2 (6.3%)
Uncle	
Brother	
Other 1: Father	5 (15.6%)
Other 2:	

	Whom do participants first inform?
Husband/Partner	8 (25%)
Mother-in-law	20 (62.5%)
Mother	10 (31.3%)
Friend	
Sister-in-law	
Sister	
Other:	

	Number of Participants that has a say in decisions concerning pregnancy
Yes	20 (62.5%)
No	12 (37.5%)
Total	32 (100%)

	What happens next as per traditions and customs?
Sent to cut my hair in my family's place (mother)	20 (62.5%)
Sent to antenatal clinic	18 (56.3%)
Sent to traditional healer	1 (3.1%)
Nothing happens	
Other:	

	Number of Participants who has to travel to other provinces to perform function
Yes	19 (59.4%)
No	6 (18.8%)
Total	25 (78.1%)

	Province that participants have to travel (not Eastern Cape)
Free State	4 (12.5%)
Gauteng	2 (6.3%)
KwaZulu Natal	3 (9.4%)
Northern Cape	2 (6.3%)
Limpopo	3 (9.4%)
North West	3 (9.4%)
Mpumalanga	
Western Cape	
Other Country: Lesotho	3 (9.4%)
Total	20 (62.5%)

	Initial period that participants spent during pregnancy (i.e. first 7 months)
Continue to stay with husband/partner	15 (46.9%)
Continue to stay with mother-in-law	15 (46.9%)
Stay by myself	
Stay with my family (mother)	5 (15.6%)
Stay with relative	
Other:	

	Remaining period that participants spent during pregnancy (i.e. last 3 months)
Continue to stay with husband/partner	5 (15.6%)
Continue to stay with mother-in-law	2 (6.3%)
Stay by myself	1 (3.1%)
Stay with my family (mother)	25 (78.1%)
Stay with relative	
Other:	

	Who Participants were allowed to consult on health issues, during pregnancy (i.e. illness, baby's health etc.)
Traditional healers	22 (68.8%)
Hospital/clinic	31 (96.9%)
Home bound treatment	
Visiting nurse	
Visiting Doctor	
Other:	

	Who is allowed to visit participants during pregnancy
Relatives	32 (100%)
Friends	30 (93.8%)
Acquaintances	20 (62.5%)
Social workers/Health workers	
Nobody	
Other:	

- **Antenatal and Childbirth (Drug Use)**

	Number of Participants that are free to visit antenatal clinic
Yes	29 (90.6%)
No	3 (9.4%)
Total	32 (100%)

	Why participants are not allowed to visit antenatal clinic
Not approved by tradition	
Husband say no	1 (3.1%)
Mother-in-law is against	1 (3.1%)
No antenatal clinic in close proximity or province	6 (18.8%)
My family does not approve of it	
Other:	
Total	8 (25%)

	Obstacles that participants encounter, attending antenatal clinic
Movement between my in-laws home and my family home	18 (56.3%)
Cost of travelling to and from the clinic	28 (87.5%)
No available transport	8 (25%)
Afraid that clinic will not keep their records in confidence	13 (40.6%)
Nurses bad attitudes	2 (6.3%)
Other: Because I do part-time work, sometimes I do not have the time to go	3 (9.4%)
Other 2: Limited leave days	1 (3.1%)

	When did participants find out about HIV status?
Husband died of HIV and AIDS related sickness	3 (9.4%)
Went through VCT	30 (93.8%)
Partner died of HIV and AIDS related sickness	1 (3.1%)
Losing wait	7 (21.9%)
Previous child died of HIV and AIDS related sickness	
Other: Getting sick	1 (3.1%)
Other 2: Husband's second wife died of AIDS	3 (9.4%)

	Number of Participants that informed their family about their HIV status
Yes	21 (65.6%)
No	7 (21.9%)
Total	28 (87.5%)

	Reaction received from family when participants informed them of their HIV status
Sign of desperation and rejection	
Stigmatisation and victimisation	
Isolation	
Shocked but supportive	20 (62.5%)
Blaming for being promiscuous	1 (3.1%)
Other: Husband/partner also tested HIV positive	8 (25%)
Other 2: But my family said HIV and AIDS is a white man's disease	1 (3.1%)
Other 3: Expected it	1 (3.1%)
Other 4: My husband's first wife is HIV positive	1 (3.1%)
Total	32 (100%)

	Why participants did not inform their family about their HIV status
Fear of stigmatisation	10 (31.3%)
Fear of husband /partner walking out on them	10 (31.3%)
Had many partners and don't know who is responsible for their status	4 (12.5%)
Lack of education on the part of community about HIV and AIDS	1 (3.1%)
Tradition does not allow them to declare their HIV status	
Other: Husband is infected	1 (3.1%)
Other 2: I am ashamed, because I made a mistake	1 (3.1%)
Total	27 (84.4%)

Did the counselor give the participants the following information at the antenatal clinic		
	Number of Participants	
Information	Yes	No
HIV and AIDS	32 (100%)	
Voluntary counselling	32 (100%)	
Testing for HIV	32 (100%)	
Your right to consent from the test	32 (100%)	
Protecting your family against further HIV infection	29 (90.6%)	3 (9.4%)
MTCT programme	32 (100%)	
Transmission of HIV through breast milk	31 (96.9%)	1 (3.1%)
Feeding options to prevent your child from getting HIV infected	30 (93.8%)	2 (6.2%)
Medical support	22 (68.8%)	10 (31.2%)
Advantages and disadvantages of disclosure	22 (68.8%)	10 (31.2%)
Disclosure to family	30 (93.8%)	2 (6.2%)
Disclosure to spouse/partner	32 (100%)	
Spouse counselling	24 (75%)	8 (25%)
Family counselling	21 (65.6%)	11 (34.4%)
Confidentiality	32 (100%)	
HIV and AIDS related illnesses	20 (62.5%)	12 (37.5%)
How to deal with stigmatisation in the community	19 (59.4%)	13 (40.6%)
HIV and AIDS support group in your area	18 (56.3%)	14 (43.7%)

Were participants given the following information about PMTCT		
	Number of Participants	
Information	Yes	No
HIV positive pregnant woman are given a tablet of Nevirapine to take home with them, which must taken when they go into labour	32 (100%)	
Nevirapine have to be given to babies of HIV positive mothers between 24 and 72 hours after birth	32 (100%)	
Safe feeding practices to avoid infecting babies	32 (100%)	

- **Post Natal-Infant Feeding/Formula (Mixed)**

	Provinces that participants will be delivering their babies
Gauteng	
Free State	3 (9.4%)
Eastern Cape	16 (50%)
KwaZulu Natal	3 (9.4%)
Northern Cape	2 (6.3%)
Limpopo	2 (6.3%)
North West	3 (9.4%)
Mpumalanga	
Western Cape	
Other Country: Lesotho	3 (9.4%)
Total	32 (100%)

	Where would participants deliver their baby?
Clinic/Hospital	17 (53.1%)
At home with my mother	15 (46.9%)
At home with my mother-in-law/husband/partner	
At the Traditional healer	
Other: No clinic in my mother's village	4 (12.5%)

	Why participants chose to deliver at the above mentioned places
Because it is safe for me and my baby	18 (56.3%)
So that my baby could be given dose of Nevirapine	
Traditional is a mandatory	2 (6.3%)
My mother insisted	3 (9.4%)
Lack of finance	2 (6.3%)
Other: No clinic in the village	13 (40.6%)

	When are participants going to give Nevirapine to their babies?
Immediately when they go into labour	
At the 36 weeks when they are expecting go into labour	
They did not take it because they had lost the tablet when they went into labour	
They threw it away because it is against their tradition	
Between 24 and 72 hours after birth	17 (53.1%)
Other: I am not going to, because there is no clinic	1 (3.1%)
Total	18 (56.3%)

	When can participant's babies receive visitors?
Immediately after birth	15 (46.9%)
1 week after birth	7 (21.9%)
1 month after birth	10 (31.3%)
3 months after birth	
1 year after birth	
Other 1: Can afford to stay longer	1 (3.1%)
Other 2: If all goes well	2 (6.3%)

	Who would be allowed to visit the babies soon after birth
Community Health worker	
Doctor	
Mother-in-law to identify the child as belonging to the husband/partner	12 (37.5%)
Other relatives below the age of 18years	1 (3.1%)
Acquaintances/friends	18 (56.3%)
Other 1: Family	20 (62.5%)
Other 2: Parents and partner/husband	3 (9.4%)

	When would participants babies come out of the hut/home/hospital?
Immediately after birth	10 (31.3%)
1 week after birth	6 (18.8%)
1 month after birth	13 (40.6%)
3 months after birth	1 (3.1%)
1 year after birth	
Other 1: As per the Doctor's instruction	1 (3.1%)
Other 2: When the baby is fit to go home	1 (3.1%)
Other 3: Because they have medical aid	1 (3.1%)
Other 4:	

	Number of Participants who's babies would have received a dose of Nevirapine
Yes	17 (53.1%)
No	15 (46.9%)
Total	32 (100%)

	Why participant's babies did not receive Nevirapine?
The baby was delivered at home	13 (40.6%)
The baby was delivered by the traditional healer	2 (6.3%)
Participants went home from the clinic before the end of the 24 hours	
Traditionally only older woman, mother or neighbours are allowed into the delivery room	2 (6.3%)
Other:	
Total	17 (53.1%)

The feeding methods that participants used	
Breast feeding	15 (46.9%)
Formula feeding	17 (53.1%)
Mixed feeding	
Other: Shop in village doesn't sell formula food	1 (3.1%)

Why participants chose the above types of feeding methods	
To avoid infecting their babies	17 (53.1%)
Their mother-in-laws/husbands/partners requires them to do that	12 (37.5%)
Traditionally, it is mandatory	3 (9.4%)
Other 1: Specially since my husband doesn't know	1 (3.1%)
Other 2: I can die alone, but not my baby	1 (3.1%)

Other reservations that participants have concerning formula feeding	
No access to tap water	5 (15.6%)
No electricity	12 (37.5%)
Can not afford to buy formula food after the first six months of grace	28 (87.5%)
There is no shop in the vicinity that sell formula feed	
Causes diarrhoea	14 (43.8%)
Other:	

- Interview with Health Workers

Type of health facility	
Academic Health Service Complex	12 (100%)
Regional Hospital	
District Hospital	
Community Health Centre	
Clinic	
Other:	

Size of their facility	
Total number of beds in the hospital	750 (12) (100%)
Total number of beds in maternity ward	200 (12) (100%)
Total number of personnel with the PMTCT programme	16 (12) (100%)
Other:	

	Has their health facility started with PMTCT activities?
Yes	12 (100%)
No	

	Number of permanent staff members involved in PMTCT programme
Doctors	4 (12) (100%)
Midwives	2 (12) (100%)
Nurses	4 (12) (100%)
Counsellors	3 (12) (100%)
Social Workers	3 (12) (100%)
Other:	

	Have staff members received training on the management of PMTCT
Yes	8 (66.7%)
No	

	Official working hours of staff members involved with PMTCT programme
07:00 to 19:00	Yes (12) (100%)
Half-day	
Other: On shift	1 (8.3%)

	Do they currently need more staff to cope with the demand for PMTCT services
Yes	12 (100%)
No	

	Services that they provide at their health facility
Voluntary counselling	12 (100%)
HIV Testing	12 (100%)
Childbirth facility – Maternity/Midwife/etc.	12 (100%)
Drug (NVP – Nevirapine) administration – ARV	12 (100%)
Infants feeding programme	11 (91.7%)
Baby and mother follow up care	1 (8.3%)
Other:	

	The socio-cultural constraints in this Community that hinders the PMTCT programme
Many pregnant woman do not have control over their pregnancy	5 (41.7%)
Many pregnant woman do not attend antenatal clinics -because of stigmatisation	10 (83.3%)
Many pregnant woman deliver their babies at home	
Social workers are not allowed to visit newly born babies at home	
Formula feeding are not acceptable to many families	6 (50%)
Many newly born babies are introduced to the outside community only after 12 weeks after birth	
Other 1: Financial Constraints	3 (25%)
Other 2: Many pregnant woman are unemployed hence are unable to come to the clinic	2 (16.7%)
Other 3: Many are not ready to disclose their status	1 (8.3%)
Other 4: Lack of staff	1 (8.3%)

	How these challenges are addressed
Getting the mothers-in-law involved in the PMTCT awareness campaign	11 (91.7%)
By involving the husbands and community leaders in the PMTCT campaign	12 (100%)
Providing HIV and AIDS house to house Counselling services	9 (75%)
Compiling data base of all HIV positive pregnant woman in the community by consensus	8 (66.7%)
Providing ARV therapy to those positive pregnant mothers unable to deliver at the clinic	12 (100%)
Providing formula feeding to the infants of the infected mother for a period of six months	12 (100%)
Other 1: And beyond six months	4 (33.3%)
Other 2: Creating health posts in rural areas for PMTCT and education	3 (25%)
Other 3: Financial reward for disclosure	1 (8.3%)

- **Interview with Pregnant Woman and Family**

	Relationship between pregnant woman and family
Very well	20 (100%)
Good	
Fair	
Moderate	
Poor	
Other:	

	Number of Participants that informed their family about their HIV status
Yes	11 (55%)
No	9 (45%)
Total	20 (100%)

	Reaction received from family when participants informed them of their HIV status
Sign of desperation and rejection	
Stigmatisation and victimisation	
Isolation	
Shocked but supportive	9 (45%)
Blaming for being promiscuous	
Other: Husband also tested HIV positive	5 (25%)
Other 2: It is not important, she is a good girl	3 (15%)
Other 3: This is a white man's disease	1 (5%)
Total	18 (90%)

	Number of participants who had this situation before in their family?
Yes	10 (50%)
No	6 (30%)
Total	16 (80%)

	How they celebrate pregnancy in their families
We adhere to the Christian beliefs	5 (25%)
We strictly adhere to our traditions and customs	18 (90%)
We adhere to the Muslim faith	
Other:	

	Who is first informed about their daughters/daughter-in-law's pregnancy?
Husbands	3 (15%)
Mothers	7 (35%)
Mother-in-laws	19 (95%)
Friends	
Sisters	1 (5%)
Brothers	
Other 1: Partner	
Other 2:	

	Immediate step in managing the pregnancy
She is sent to antenatal clinic for consultation	12 (60%)
She is sent home to her mother	16 (80%)
She is sent to Sangoma	5 (25%)
She is sent to stay at the church/Mosque	
Other:	

	Step 2 in managing the pregnancy
She goes for VCT counselling at the antenatal Clinic	11 (55%)
She is sent back to her in-laws after having performed the initial rituals at her mother's home	16 (80%)
She continues to visit the Sangoma	3 (15%)
She continues staying at the Church/Mosque	
Other:	

	Next phase in managing the pregnancy
If she is positive she is advised of the ART therapy at the antenatal Clinic	8 (40%)
She is sent back to her mother during the seventh month	16 (80%)
She continues to visit the Sangoma	2 (10%)
She continues staying at the Church and goes on church/mosque retreats	
Other:	

	How is the delivery administered?
She delivers her baby at the hospital where her baby is given Nevirapine	6 (30%)
She delivers at her mothers place by elderly woman	13 (65%)
She delivers at the Sangoma shrine	3 (15%)
She delivers at the church/mosque by elderly woman	
Other:	

	How are the mother and baby managed?
She and her baby are sent home afterwards to recuperate	5 (25%)
She and her baby are sent back to her in-laws after 3 months	15 (75%)
She and her baby are sent home from the Sangoma shrine after a while	2 (10%)
She and her baby are sent home from the church/mosque to recuperate	
Other:	

	When can mothers and babies be visited?
Mothers and babies can be visited immediately by friends and family	5 (25%)
Mothers and babies can be visited only by immediate family	15 (75%)
Mothers and babies can be visited only after six months	
Mothers and babies can be visited only by church/mosque members	
Other:	
Total	20 (100%)

	Have the family heard about the PMTCT programme?
Yes	10 (50%)
No	7 (35%)
Indifferent	
Not necessary to know	
Other: From a friend	
Total	17 (85%)

	Does the family think it is effective?
Yes, my family have used that services	4 (20%)
No, we cannot access the service	2 (10%)
It is a programme for educated people	
Our traditions and cultures do not make it possible for us to be part of such a programme	
Provide some financial and other incentives, e.g. – food hampers, transport fares, meals at the antenatal clinics, gifts of second hand cloths, provisions, etc.	
Other 1: A neighbour's daughter attended	1 (5%)
Other 2: I suppose it is helping to reduce infection	
Other 3: We don't know	5 (25%)
Total	12 (60%)

	The socio-cultural constraints in this Community that hinders the PMTCT programme (what does family think)
Many pregnant woman do not have control over their pregnancy	18 (80%)
Many pregnant woman do not attend antenatal clinics	18 (90%)
Many pregnant woman deliver their babies at home	16 (80%)
Social workers are not allowed to visit newly born babies at home	
Formula feeding are not acceptable to many families	5 (25%)
Many newly born babies are introduced to the outside community only after 12 weeks after birth	1 (5%)
Other 1: Financial Constraints	1 (5%)
Other 2: Many pregnant woman are unemployed hence are unable to come to the clinic	
Other 3: Many are not ready to disclose their status	
Other 4: Lack of staff	

	Do you think the negative effects of HIV and AIDS is real?
Yes, people are dying of the disease	16 (80%)
Yes, many children are made orphans	15 (75%)
Yes, the external family is under pressure to take on extra responsibilities	7 (35%)
No, people are not dying from AIDS; they are dying from other diseases.	1 (5%)
Other: My husband also died of HIV and AIDS	
Other 2: Not sure	1 (5%)

	How can the community help in addressing these challenges?
Getting the mothers-in-law involved in the PMTCT awareness campaign	18 (90%)
By involving the husbands and community leaders in the PMTCT campaign	17 (85%)
Providing HIV and AIDS house to house Counselling services	14 (70%)
Compiling data base of all HIV positive pregnant woman in the community by consensus	8 (40%)
Providing ARV therapy to those positive pregnant mothers unable to deliver at the clinic	17 (85%)
Providing formula feeding to the infants of the infected mother for a period of six months	14 (70%)
Other 1: And beyond six months	
Other 2: Creating health posts in rural areas for PMTCT and education	
Other 3: Financial reward for disclosure	
Other 4: (a, b, c) Provided HIV and AIDS is a disease for black people	1 (5%)

- Mothers / Mother-in-Laws

	Nationality of mothers/mother-in-laws
South African citizen	32 (100%)
Other:	

	Home language of mothers/mother-in-laws
Afrikaans	1 (3.1%)
English	
Isindebele	4 (12.5%)
I siSwati	
Sepedi	2 (6.3%)
Is Xhosa	9 (28.1%)
Sesotho	6 (18.8%)
Isizulu	4 (12.5%)
Setswana	4 (12.5%)
Tshivenda	1 (3.1%)
Xitsonga	1 (3.1%)
Other African Language	
Other European Language	
Indian Language	
Other: Shangan	1 (3.1%)

	Were mothers/mother-in-laws born in Eastern Cape province?
Yes	22 (68.8%)
No	10 (31.3%)
Total	32 (100%)

	If no, in which province were they born?
Free State	6 (18.8%)
Gauteng	3 (9.4%)
KwaZulu Natal	9 (28.1%)
Northern Cape	5 (15.6%)
Limpopo	5 (15.6%)
North West	2 (6.3%)
Mpumalanga	
Western Cape	
Other Country	
Total	30 (93.8%)

	Marital status of mothers/mother-in-laws
Yes	30 (93.8%)
No	3 (9.4%)

	How they celebrate pregnancy in their families
We adhere to the Christian beliefs	13 (40.6%)
We strictly adhere to our traditions and customs	29 (90.6%)
We adhere to the Muslim faith	
Other:	

	Who do mothers/mother-in-laws live with?
Alone	2 (6.3%)
Alone with children	5 (15.6%)
Husband	18 (56.3%)
Daughter-in-law	
Son and Daughter-in-law	14 (43.8%)
Daughter	4 (12.5%)
Partner	
Other 1: Sons	2 (6.3%)
Other 2: Husband is dead	5 (15.6%)
Other 3:	

	Type of dwelling that mothers/mother-in-laws live
Brick house	17 (53.1%)
Traditional African hut	13 (40.6%)
Flat/Townhouse/apartment	1 (3.1%)
Outside room/flat/house in a backyard	
In a garage	
In a hostel	
In a mokhukhu	1 (3.1%)
In a caravan	
In a temporary shelter	
Other, specify:	
Total	32 (100%)

	Main source of household income
Formal salary/earnings which attract tax	20 (62.5%)
Contributions by family members	
Contributions by in-laws	
Government pension/Grants (e.g. old age pension, disability grant)	15 (46.9%)
Grants/Donations by private welfare organisation	
Other sources/specify main source: Labourer's income	1 (3.1%)
No income	

	Who is first informed about their daughters/daughter-in-law's pregnancy?
Husbands	3 (9.4%)
Mothers	12 (37.5%)
Mother-in-laws	23 (71.9%)
Friends	
Sisters	
Brothers	
Other 1: Partner	1 (3.1%)
Other 2:	

	Immediate step in managing the pregnancy
She is sent to antenatal clinic for consultation	18 (56.3%)
She is sent home to her mother	20 (62.5%)
She is sent to Sangoma	3 (9.4%)
She is sent to stay at the church/Mosque	
Other:	

	Step 2 in managing the pregnancy
She goes for VCT counselling at the antenatal Clinic	21 (65.6%)
She is sent back to her in-laws after having performed the initial rituals at her mother's	20 (62.5%)
She continues to visit the Sangoma	4(12.5%)
She continues staying at the Church/Mosque	
Other:	

	Next phase in managing the pregnancy
If she is positive she is advised of the ART therapy at the antenatal Clinic	15 (46.9%)
She is sent back to her mother during the seventh month	20 (62.5%)
She continues to visit the Sangoma	5 (15.5%)
She continues staying at the Church and goes on church/mosque retreats	
Other: To prepare herself for delivery	1 (3.1%)

	How is the delivery administered?
She delivers her baby at the hospital where her baby is given Nevirapine	14 (43.8%)
She delivers at her mothers place by elderly woman	19 (59.4%)
She delivers at the Sangoma shrine	3 (9.4%)
She delivers at the church/mosque by elderly woman	
Other:	

	How are the mother and baby managed?
She and her baby are sent home afterwards to recuperate	13 (40.6%)
She and her baby are sent back to her in-laws after 3 months	18 (56.3%)
She and her baby are sent home from the Sangoma shrine after a while	1 (3.1%)
She and her baby are sent home from the church/mosque to recuperate	
Other:	
Total	32 (100%)

	When can mothers and babies be visited?
Mothers and babies can be visited immediately by friends and family	14 (43.8%)
Mothers and babies can be visited only by immediate family	20 (62.5%)
Mothers and babies can be visited only after six months	
Mothers and babies can be visited only by church/mosque members	
Other:	

	Number of mothers/mother-in-laws that heard about the PMTCT programme
Yes	14 (43.8%)
No	17 (53.1%)
Indifferent	
Not necessary to know	
Other: From a friend	1 (3.1%)
Other 2: Only upon arrival	1 (3.1%)

	Does mothers/mother-in-laws think it is effective?
Yes, my family have used that services	5 (15.6%)
No, we cannot access the service	3 (9.4%)
It is a programme for educated people	
Our traditions and cultures do not make it possible for us to be part of such a programme	
Provide some financial and other incentives, e.g. – food hampers, transport fares, meals at the antenatal clinics, gifts of second hand cloths, provisions, etc.	2 (6.3%)
Other 1: A neighbour's daughter attended	3 (9.4%)
Other 2: I suppose it is helping to reduce infection	2 (6.3%)
Other 3: I don't know	8 (25%)
	23 (71.9%)

	Does mothers/mother-in-laws think the negative effects of HIV and AIDS is real?
Yes, people are dying of the disease	30 (93.8%)
Yes, many children are made orphans	29 (90.6%)
Yes, the external family is under pressure to take on extra responsibilities	16 (50%)
No, people are not dying from AIDS; they are dying from other diseases.	
Other: My husband also died of HIV and AIDS	1 (3.1%)
Other 2: I can't say	2 (6.3%)

	Can mothers/mother-in-laws suggest way of improving the PMTCT programme
Extend the programme to all rural areas	32 (100%)
Provide transport to convey pregnant woman to the service centres	21 (65.6%)
Intensify the educational programme on PMTCT	27 (84.4%)
Train members of various communities to assist with the PMTCT programme: i.e. Sangomas, elderly woman, Church/Mosque leaders (any body involved in delivering babies)	24 (75%)
Find ways of adding value to the existing traditions and cultures, by integrating it into the implementation of the PMTCT programme, rather than neglecting it	27 (84.4%)
No, it is not going to help with our problems	1 (3.1%)
Other 1: Possible financial support	2 (6.3%)
Other 2: Sangomas are very close to the community and must be trained to assist with the programme	1 (3.1%)
Other 3: Not Sangomas, they are cheats	1 (3.1%)
Other 4: Due to lack of infrastructure in the rural areas, some pregnant woman cannot get to the clinic	1 (3.1%)
Other 5:	