HUMAN SCIENCES RESEARCH COUNCIL

CHILD, YOUTH & FAMILY DEVELOPMENT

SOCIAL AND COMMUNITY PERSPECTIVES ON PREVENTION OF MOTHER-TO-CHILD TRANSMISSION OF HIV: FREE STATE

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TABLE OF CONTENTS

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EXECUTIVE SUMMARY

Aims

The aim of this study was to collect information about socio-cultural and community dynamics of PMTCT with the potential to inform the implementation and effectiveness of Free State's PMTCT programme.

Study Sites

The study sites were two Free State communities (one urban, Mangaung, and one rural, Frankfort) where PMTCT programmes had been implemented in local clinics for approximately 6 months.

Methodology

The study methodology used the narrative research method consisting of a four-step process:

1) Key informant narrative workshops in each site, with PMTCT nurses, counselors, clients and support workers from community based organizations, to develop a series of case studies of typical female clients who go through the PMTCT programme. Key events were then role-played during these workshops to explicate the social dynamics surrounding behaviour outcomes.

2) A community-based survey based on the narrative workshop with 250 respondents in each site (N = 500) consisting of a total of 100 males (25+ years), 100 females (40+ years), 100 ever-married females (25-39 years) who have been pregnant, 100 never married females (25-39 years) who have been pregnant and 100 female teenagers (15-19 years) who have been pregnant. The latter three are the three common index types making use of PMTCT services.

3) A series of eight focus group discussions (FGDs) per site, (a total of 16) with 1) older females (40 + years), 2) civic and social opinion leaders, 3) health care professionals involved in PMTCT service provision (i.e. nurses and counselors), 4) community health workers, 5) males (25+ years) and 6-8) each of the three female index case profiles.

4) A series of in-depth interviews (IDIs) with 1) health care professionals involved in PMTCT service provision, 2) community health workers, 3-5) females fitting the three index case profiles. In each study site, a maximum of 5 IDIs was conducted in each group, resulting in a maximum number of 25 per site (50 total).

Results

HIV/AIDS Knowledge

Awareness of HIV/AIDS Most questionnaire respondents (98%) have heard of HIV/AIDS and FGD and IDI participants vividly describe the impact of HIV/AIDS, namely the number of people who are sick and dying in their communities, particularly youth and women.

Accurate knowledge of transmission routes Most respondents have accurate knowledge of transmission routes. Four percent of respondents gave incorrect responses on routes of transmission. Vertical transmission is not a prominent feature of respondents' knowledge on HIV transmission with only one respondent mentioning this route.

Beliefs about HIV/AIDS Most respondents have accurate knowledge that a person can have HIV and still look healthy (90.2%) and there is no cure for HIV/AIDS (80.2%). However, about one fifth of respondents believe there is a cure or are unsure. Female teenagers are significantly associated with believing there is a cure for HIV/AIDS.

Preferred sources of information and responsibility for HIV/AIDS education Overall, respondents see health professionals and peer educators (including those living with HIV/AIDS) as preferred sources of information and primarily responsible for educating others about the disease. Study participants also emphasize the need for multiple approaches to community education using as many formal and informal networks as possible.

Knowledge of vertical transmission through breastfeeding Almost three quarters of respondents know that babies can be infected with HIV through breastfeeding. Teenagers (61%) were least likely to know that HIV can be transmitted through breastfeeding and never married females (85.7%) most likely to know. Again, teenagers (42.6%) followed by ever-married females (29.6%) were least likely to know how HIV can be transmitted during breastfeeding.

Knowledge of prevention of vertical transmission during and after birth Approximately half of respondents have correct knowledge on prevention of vertical transmission during and after birth. Males have more knowledge about preventing transmission after birth while females have more knowledge about prevention during birth. Overall, teenagers, particularly in Mangaung, and older females (40+ years) were significantly less likely to give correct information on prevention.

Knowledge of PMTCT services in the area Under half of respondents (41.%) are aware of PMTCT services in their areas with men and female teenagers being significantly less likely to know about these services than females 25 years and above.

Major Findings General knowledge about HIV/AIDS is high. However, about half of respondents have accurate knowledge about prevention of mother-to-child transmission. Knowledge among teenagers is consistently lower than other females. Less than half of all respondents know about PMTCT services in the areas in which they reside.

Infant Feeding Practices

Introduction of solids Median age for the introduction of solids is three months. However, older females (40+ years) say it is six months.

Feeding The majority of respondents (80%) say mixed feeding is normal practice between birth and four months. More respondents in the rural site and more males than females say this is the norm. Although over 90% of females under 40 years of age say this is the norm, just under 60% of women over 40 say mixed feeding is the norm. Respondents were almost equally divided on whether traditional herbs were given to babies orally during the first four months of life.

Beliefs about mixed feeding Almost three quarters of respondents think breast milk is inadequate during the first four months and therefore mixed feeding is necessary. More males (90%) believe this than females (67.3%) and four fifths of females under 40 agree as compared to just under half of females over 40 years. Almost two thirds of respondents believe mixed feeding is normal, however a third say mixed feeding indicates the mother does not care for the child properly. Almost all males think mixed feeding is normal practice in contrast to half of females. The majority of older females (40+ years) believe that mixed feeding shows lack of care, while over half of married and never married females and over four fifths of teenagers believe it is normal practice.

Beliefs about exclusive breastfeeding (EBF) Almost two thirds of respondents believe EBF is natural and ensures the baby's health, while almost a third believe that it is not correct to EBF. Seventy percent of males believe it is wrong while almost the same percentage of females believes EBF is normal and protective. The majority of never married females and females over 40 years think it is normal and protective while about half of married females and teenagers think this way.

Attitudes towards not breastfeeding Over half of respondents believe that a woman is not taking good care of her baby if she does not breastfeed. Almost seventy percent of men and half of female respondents believe this. More older females (40+) and teenagers (69% for both) believe this than never married (22%) and ever married females (34%).

Infant feeding information Respondents' primary sources of information are nurses and clinics, followed by mothers, older people and then experience.

The role of fathers in infant feeding decisions Almost two thirds of respondents believe that fathers are rarely or not involved. However, from focus group and interview participants, it is clear that infant feeding decisions involve a number of key players,

usually mothers and mother-in-laws but also fathers, and take place within a broader social dynamic around cultural beliefs on best practice and who is empowered to make decisions.

Major findings Opinions on infant feeding vary considerably based on gender and age. Overall mixed feeding appears to be the norm, while breastfeeding is seen as a valuable part of infant feeding. Overall, there is general disapproval of those who do not breastfeed, however, this opinion depends on respondents own circumstances within their communities, i.e. whether they have a job, for example. Older females (40+ years) appear more inclined to exclusive breastfeeding and less predisposed to mixed feeding than other respondents.

HIV/AIDS Stigma

Caring for infected individuals The majority of respondents say that they would care for an infected individual in their homes.

Attitudes towards interacting with infected individuals Ninety percent of respondents said both male and female teachers who are infected should be allowed to continue teaching. However, rural respondents were significantly less likely to agree with this than urban respondents. Over two thirds of respondents said they would buy food from an infected person and be treated by a nurse or doctor who was infected.

Disclosure Almost three quarters of respondents feel it is advisable to disclose if one is HIV positive. Urban respondents and males are significantly more likely to support disclosure than rural respondents and females particularly older females (40+ years). Breaking the silence around HIV/AIDS and getting grants were the main reasons respondents gave for disclosure. Stigmatization, rejection and shame were the main reasons for non-disclosure. Never married females and teenagers are most likely to disclose to their mothers, while ever married females and males are most likely to disclose to their partners.

Treatment of HIV/AIDS infected individuals Just over a third of respondents say infected individuals are rejected and ridiculed, while almost a half of respondents say they are treated reasonably well or like everyone else. Urban respondents and males are significantly more likely than rural respondents, females and particular older females (40+ years) to say that a person who discloses will receive a positive response. If a woman discloses, half of respondents feel she will be treated the same as a man who discloses, but male respondents are significantly more likely to think this than females where just over 40% say she will be treated worse than a man. Just over half of respondents think a family with a family member who is HIV positive will be treated worse than other families. Rural respondents and females are again significantly more likely to think they are treated worse than other families. Despite these responses, almost three quarters of respondents said they would not want to keep the fact that a family member was HIV

positive a secret. However, focus group and interview participants overwhelming emphasize the stigma associated with being HIV positive.

Major Findings Despite respondents' willingness to care and interact with people who have HIV/AIDS and their feeling that people ought to disclose, stigma is high, and from focus group data and the narrative findings (see below), it is unlikely that many people disclose. Females, in particular, believe that females are treated worse than males if they disclose. Rural respondents are also more likely to think those who disclose will be treated worse than other people.

Results of the Narrative Workshop

In the narrative workshops, key informants created case studies of the three likely client types that attend antenatal clinics: ever-married females (25-39 years), never married females (25-39 years) and teenagers (15-19 years). The case studies were built around six key events: 1) The counseling experience, 2) The HIV testing experience, 3) Initial infant feeding decisions, 4) Labour and delivery, 5) Infant feeding at home and 6) Returning for the baby's HIV test.

From the case studies developed during these workshops, three major issues emerge. The first is that a combination of factors influence the choice whether to test for HIV or not. Women may decide to consult their partners first and depending on the partner and the woman's concern about how likely she is to have the disease as well as concern for the baby's health, she decides whether to have a test. In smaller rural communities, fears that confidentiality may be compromised, also influence decisions to test.

The second theme and possibly the key issue is disclosure of HIV status. Disclosure to partners is particularly difficult because of blame, fear of abuse and abandonment. Women, if they disclose, are likely to disclose to someone other than their partner. Whether a woman discloses also impacts on other aspects of PMTCT particularly the infant's risk of contracting the disease through unsafe feeding practices. Disclosure may occur at the point where the infant's protection from HIV is about to be compromised by another caregiver within the household.

The third issue is carrying out safe feeding choices. Cultural beliefs about what is best practice may mean the introduction of other liquids, traditional herbs and solids. Considerable pressure is put on mothers who do not conform to expected practice particularly with married women where power dynamics between the husband, mother-in-law and mother come into play. Married women may compromise safe feeding practices especially if they feel they cannot disclose. Single women may be able to adhere to safe practices more easily while teenagers may be able to adhere if they can disclose. Even with disclosure, cultural beliefs about what is nutritionally best for the child may still result in the introduction of other foods.

Narrative Story Questionnaire Results

A composite case study was created and transformed into a series of questions to establish overall patterns of behaviour through the PMTCT programme.

The Initial Counseling Experience The majority of respondents said that the counseling experience would be a positive one and that the main character in the case study, Lerato would be comfortable in asking questions and getting all the necessary information, and that the experience would encourage her to test. However approximately one fifth of teenagers felt that the counselor would not treat her well enough to make her comfortable to ask questions and almost a quarter felt the counselor's attitude would not encourage her to test. Although fewer respondents felt that a nurse would treat Lerato well, they nevertheless felt that a nurse was the most appropriate person to do the counseling. Respondents were equally divided as to whether Lerato would prefer someone to support her during the counseling or not. Married females chose the husband followed by the mother as the most likely support persons, while single females and teenagers chose the mother and then the partner.

The HIV Testing Experience Respondents were more or less equally divided on whether Lerato would want to test with her partner or spouse. Just under two thirds of married females thought Lerato would want to test with her spouse. The majority of respondents said Lerato would take an HIV test and that she would opt for test now-results now. If Lerato decided not to take the test immediately, responses indicated that over 40 percent of respondents thought Lerato would not return to take the test. If she opted for test now results later between a fifth and a third of respondents said she would not come back for the results. Six percent of respondents felt Lerato would not disclose her status to anyone if she were HIV positive. The majority of married females felt Lerato would disclose to her partner while other index types said the most likely person would be her mother. Most respondents felt that the reaction to this disclosure would be supportive except among married women. Over half of respondents felt that Lerato's confidence would be kept although married women particularly in Frankfort did not think so. Over two thirds of respondents felt that Lerato's husband would react badly to her disclosure. Never married females and teenagers were more likely to opt for a negative reaction than married females.

Initial Infant Feeding Decisions Overall three quarters of respondents felt Lerato would opt for exclusive formula feeding (EFF) to ensure the health of the baby.

Labour and Delivery Over half of respondents felt Lerato would not disclose to staff that she was HIV positive. Most common reasons were lack of confidentiality, ill-treatment and stigmatization.

Infant Feeding at Home Mothers are the most likely people to be involved in decisions on infant feeding among never married females and teenagers. With married females,

mothers-in-law are the most likely decision makers. Most never married females and teenagers felt that the decision maker would encourage exclusive breastfeeding. However, the majority of married females felt the decision maker would encourage mixed feeding. Although over half of respondents overall said the decision maker would support an exclusive breastfeeding choice, at least 40 percent felt that there would be some opposition to exclusive breastfeeding. Just over 40 percent said if Lerato chose EBF she would be able to do so at home but an almost equal number said she would end up mixed feeding. Three quarters of never married females compared with a quarter of married females and teenagers felt Lerato would be able to stick to exclusive breastfeeding. Almost a third of the latter two index types said she would end up mixed feeding. If Lerato chose exclusive formula feeding, over three quarters of respondents said there would be opposition to this choice. Almost half of respondents felt she would be able to continue with her choice when she got home and just over 40 percent said she would end up mixed feeding. Again married women (about a third) were less likely to think she would be able to maintain EFF as were teenagers, while the majority of never married females felt she would be able to maintain the practice. About half of respondents felt there would be some stigma attached to obtaining formula milk from clinics. Teenagers, particularly in the rural site, were more likely to think there would be some form of stigmatization. Just over half of respondents felt that obtaining formula milk from the clinic would be a deterrent to Lerato choosing formula feeding. Again teenagers were more likely to think this way. Almost two thirds of respondents said that Lerato would not disclose her status on her return home. Over three quarters of teenagers were likely to think this, while almost two thirds of never married females and two fifths of married females thought so. More respondents in the rural area said it would be unlikely that she would disclose.

Resuming Sex If Lerato met a new boyfriend just over half of never married and teenage respondents said she would not disclose her status when the issue of sexual relations arose. Less than 15 percent of married women felt Lerato would not disclose to her husband when it came time to resume sexual relations. However over 80 percent of all respondents felt Lerato would discuss condom use, and over three quarters of all respondents felt they would use a condom. Between 70 and 75 percent of respondents felt condom use would be maintained.

12 Month HIV Test Approximately three quarters of married and teenage respondents felt Lerato would bring her baby to the clinic for the 12 month HIV test. However, only half of never married females thought she would do so. The most common reason for not returning was fear of knowing the baby's status and assuming the baby will be positive like the mother. If the baby tested positive, over 90 percent of ever-married females would disclose to the partner while an equal number of never married females would

disclose this to their mother. Three-quarters of teenage respondents would disclose the baby's status to their mother.

LIST OF TABLES

1

INTRODUCTION

This report is the third in a series of studies on the social and community aspects of prevention of mother to child transmission (PMTCT). The aim of these studies was to identify social issues influencing the South African Government's PMTCT pilot program. The first study focused on communities in the catchment areas of two PMTCT sites in Limpopo Province in 2002. This study was extremely well-received nationally and led to funding from the Center for Disease Control (CDC) South Africa to conduct similar PMTCT research at PMTCT sites in KwaZulu-Natal and Free State Provinces in 2003. This report presents the findings from research conducted in Free State Province.

1.1. Background[1]

Mother-to-child HIV transmission (MTCT), or vertical transmission, is the most common source of HIV infection in children under the age of 15 years. At least 90 percent of all HIV infections in children are a result of vertical transmission; and the vast majority of these (90%) take place in sub-Saharan Africa (UNAIDS 1999, Coutsoudis et al. 2002). In South Africa alone there are over 100,000 children living with HIV/AIDS (ibid). Without intervention, the risk of transmission is about 25 to 35 percent in developing countries (UNAIDS website). In South Africa it is estimated to be around 31 percent (Akue et al. 2000, HST 2002).

Transmission of HIV can occur during pregnancy, labour, delivery or via breastfeeding. Risk of MTCT depends on mother's viral load, length of labour, mode of delivery, gestational age (whether the baby is born prematurely), the health and well-being of the nipple and infant feeding regimens. The risk of vertical transmission is lowest during the first two trimesters of pregnancy, increasing dramatically during labor and delivery, and in the post-partum period if the infant is breastfed. Besides the factors noted above, the risk of post-partum HIV transmission varies according to the frequency and duration of breastfeeding as well as whether the infant is mixed fed (given solids and other liquids in

[1] This section is drawn from the KwaZulu-Natal report, adapted and updated.

addition to breast-milk). Infants appear to be at greatest risk for MTCT after birth if they are mixed fed[2] (UNAIDS Technical Update 2000).

Most research exploring the impact of PMTCT interventions has focused on the effect of antiretrovirals specifically nevirapine (NVP) and the relative risk (reduction) of various infant-feeding regimens. With regard to nevirapine, current recommendations are for a single dose for the mother during labour (within two hours of delivery) and a dose for the infant within 72 hours of delivery. Such "short course" NVP regimens can lead to anywhere between 37 and 50 percent *reduction in risk of vertical infections* which would have occurred in-utero and during delivery (Newell 2001). A recent HST review of research on PMTCT interventions suggests peri-partum NVP leads to a drop in the absolute proportion of vertical transmissions (in utero and during labor and delivery) from 23 percent (without maternal-child NVP) to 13 percent (HST 2002).

Table 1: Risk of MTCT (UNAIDS Technical Update 2000)

- 30-35 percent if no drugs administered and infant is predominantly breastfed for 24 months
- 20 percent if no drugs administered and infant is not breastfed
- 10 percent short course of antiretrovirals and infant is not breastfed
- 15-25 percent short course of antiretrovirals and infant is breastfed depending on mode and duration

Breast milk is the optimal nutrient for infants from birth to between four and six months of life, and has important psycho-social and emotional benefits. However, in the presence of maternal HIV infection breastfeeding leads to an increased (post-partum) risk of vertical transmission of between 14 and 29 percent, depending on maternal viral load (Preble and Piwoz 2001, Coutsoudis et al. 2002)[3]; though there is some evidence that breast milk's immune factors help delay the onset of AIDS and AIDS-related complications in HIV-infected infants (Coutsoudis et al. 2002).

Furthermore, while United Nations agencies' current policy on infant feeding and HIV is one of informed choice[4], in many developing country settings – such as many parts of South Africa – the practice of mixed feeding remains for many reasons a social and cultural

[2] The practice of "mixed feeding" can be defined as feeding an infant a mix of breast-milk, other liquids, solids, and even commercial formula.

[3] Because viral loads are highest around the time of infection, the risk of MTCT through breast-milk is greatest if the mother is infected early in the post-partum period. With regard to the figures cited above, the post-partum risk of MTCT is increased by 14% for women with established HIV infections compared to 29% for women infected during lactation.

[4] In reality this translates into a recommendation of "exclusivity" in feeding; that is, to encourage women to either exclusively breastfeed or to avoid breastfeeding altogether in favor of breast-milk substitutes.

norm[5]. The results of at least one South African study (Coutsoudis et al. 1999, 2001; Taren 2000) revealed that exclusive breastfeeding was associated with the lowest and mixed feeding with the highest relative risk of MTCT compared with formula feeding; at 15 months post-partum the HIV transmission rate among exclusively breastfed infants remained lower than in mixed or formula fed infants. Mixed infant feeding is generally considered to confer the greatest risk of post-partum vertical HIV transmission (Coutsoudis et al. 1999, Preble and Piwoz 2000). The same HST review, cited above, suggests an overall vertical transmission rate of 20-22 percent in the presence of peri-partum NVP and mixed infant feeding (up to 12 months post-partum), compared with 13 percent with NVP and exclusive formula feeding. Finally, the risk of MTCT is reduced to almost nil (2-4%) with NVP, proper delivery procedures, and formula feeding (no exposure to breast milk); making MTCT virtually preventable under ideal conditions. However, thus far such (optimal) conditions have nearly always been found in industrialized countries (Coutsoudis et al. 2002).

Nonetheless, while current infant feeding recommendations tend toward either extreme of exclusivity, the balance of risks between HIV transmission and the (harmful) effects of various infant feeding regimens is unknown. For example, in one Kenyan study, formula fed infants had a 40 percent reduction of HIV transmission compared to exclusively breastfed infants. However, the overall 24 month mortality rates were similar for both groups. The study also found that during the first three months of life infants in the formula fed group had much higher rates of diarrhea, dehydration and respiratory infection (Nduati et al. 2000). Moreover, some data suggest that the risk of vertical transmission from breastfeeding declines significantly over time up to 12 months post-partum (Akue et al. 2000, Coutsoudis et al. 2002).

Issues surrounding prevention of mother-to-child HIV transmission (PMTCT) are currently at the forefront of HIV prevention and care efforts in South Africa. This is reflected in the nationwide (government) clinic-based PMTCT pilot program; and efforts to expand or roll out such services. There is growing consensus among those involved in implementation of PMTCT interventions that questions remain concerning community-based factors influencing the potential success of such efforts. In addition, there is a recognized need for proper communication and information strategies to accompany clinic-based PMTCT programs to function in tandem with existing services as well as accompany the development of new ones.

[5] By some estimates only 31 percent of mothers in sub-Saharan exclusively breastfeed their children (Preble and Piwoz 2000).

1.2. Aims and Objectives

This study's overall aim was to collect information about socio-cultural and community dynamics with the potential to influence the implementation and effectiveness of Free State's PMTCT programme. The data collected will be used to:

- Inform a communications/IEC strategy surrounding the PMTCT program
- Inform upon factors affecting infant feeding choices and practices
- Feed into a broader monitoring and evaluation framework for the program as a whole.

The study also served as a local capacity-building exercise by contracting the research fieldwork to a local Free State non-governmental organization (NGO), Child and Family Welfare Society, Bloemfontein.

Similar to the KwaZulu-Natal study, the following priority topics were explored in the Free State study:

- Level and quality of knowledge, attitudes and practices surrounding HIV/AIDS in general and PMTCT in particular
- Women's PMTCT-VCT experiences including dynamics of women's uptake of the service and HIV testing choices
- HIV/AIDS-stigma and disclosure particularly in relation to vertical transmission with regard to family members, community networks and health service staff
- Factors influencing infant feeding preferences and regimens; and thus the efficacy of programmatic infant feeding recommendations
- Socio-behavioral impact of PMTCT-VCT both intra-partum and post-partum
- Post-Test support needs
- PMTCT staff/provider perspectives.

This work stems from a growing recognition of the need to approach medical interventions such as PMTCT from a contextual and community-oriented perspective (Bond et al. 1999, Mukuka and Siyandi 1999, Nyblade and Field 2000). While the central focus of this study is on women's experience of PMTCT services, for a number of reasons it was also deemed important to characterize the knowledge and beliefs of the community at large. Individuals do not accumulate and interpret information, make choices or act in a vacuum. In order to gain perspective on women's PMTCT experiences – and by extension identify factors affecting the efficacy of PMTCT services – it is necessary to understand the stance of their family members and other influential figures in their communities. In addition, and related

to this first point, in order to be effective, a PMTCT communications/IEC strategy would likely have to target a broader audience; not simply women themselves. Thus, by focusing on the community at large we are able to collect information which will both inform a community-wide communications strategy as well as serve as a baseline to assess community changes in knowledge, attitudes and perceptions surrounding prevention of mother-to-child HIV transmission over time. This study also allows the voices of expertise of counsellors, community health workers and clinic staff to be heard; both in order to provide quality PMTCT care but also – *equally importantly* – to cope with the personal and professional challenges this service presents for those who offer them. We hope the research strategy used in this study has helped give communities a voice in addressing their health problems.

1.3. Study Sites

The work was undertaken in the catchment areas of (communities surrounding) two public sector primary health clinics (PHC) both offering PMTCT services (i.e. the South African government's PMTCT protocol). When the research was conducted, each site's PMTCT programme was between six months and one year old. Selection of sites was based on sites having similar PMTCT programme lengths, one site had to be urban and the other rural. Manguang /Bloemfontein was chosen as the urban site, while the catchment areas of the Frankfort PMTCT progamme including farms, township and surrounding villages/settlements formed the second site.

Each district was approached through the provincial co-ordinator. HSRC researchers presented the results of previous PMTCT studies in Limpopo and KwaZulu-Natal provinces to PMTCT co-ordinators in each district and explained the process of the research. Each district assisted in co-ordinating the first step in the research process (See Chapter 2).

1.4. Ethics

Ethics approval was granted by the IRB of the Nelson Mandela School of Medicine at the University of KwaZulu Natal.

2

RESEARCH METHODOLOGY[6]

This research uses a methodological approach called the narrative research method (NRM). NRM is a combination of qualitative and quantitative methods grounding human behaviour in its situational context. The purpose of the NRM is to systematically identify 1) the most typical pattern(s) of events and decision-making leading to a particular behavioural, in this case, health outcome and 2) key context-specific factors that impact human behavior. The key element of the narrative approach is a narrative workshop in which participants explore a health issue through constructing a generalized case study. This case study is the basis for subsequent data collection steps. The case study illustrates the circumstances surrounding and situations concerning an individual's experience of the research topic (*in this case a woman's experience of the PMTCT program*). The case study maps out situation or context-specific decision-making and behaviors relevant to participation in the PMTCT program. A primary aim of NRM is to illustrate alternative "pathways" with the potential to differentially affect behavior and ultimately health status. The NRM has also been described as a "life history approach" to health research that allows for a situation-specific examination of decisions and behavior, and releases us from a "linear" way of looking at behavior. The method allows the flexibility to explore the full range of possibilities for a situation, while at the same time quantifying likely outcomes by incorporating a survey component. From a programmatic viewpoint, it provides a perspective on the circumstances necessary for an intervention to be successful. In this way, it has the potential to guide the placement of intervention strategies.

The narrative method comprises a four-step process: 1) a key informant workshop, 2) a community-based survey, 3) a series of focus group discussions (FGDs) and 4) a series of in-depth interviews (IDIs). The case study derived in the key informant workshop is explored in each subsequent data collection step. Each method provides a different "angle" on the case study -- for example FGDs generate data on social norms and community perspectives while IDIs yield information on individuals' personal experiences with the topic the result of the study is a holistic and detailed picture of the various social environmental factors influencing the outcome(s) of the case study.

[6] The description of the research methodology is drawn form the Limpopo and KwaZulu-Natal reports and modified to reflect the research process that happened in Free State Province.

The NRM approach allows triangulation of data as it uses both qualitative and quantitative data collection methods. It is also participatory (community-based, community driven) in that it provides a non-confrontational forum to discuss potentially sensitive social issues, and has the potential to serve as a training or values clarification tool for health care professionals and others involved in program implementation. Each step of the narrative method is described below.

2.1. Key Informant Workshop

The key informant workshop is the first step in the NRM. It is a one-day workshop consisting of no more than 15 key informants. Key informants are individuals who have some experience with or perspective on the research topic, in this case lay counsellors, those involved in community mobilization, clinic staff, etc. The idea behind working with such individuals is to solicit the opinions of those who know the situation well enough to be able to provide an informed perspective but who are also able to distance themselves enough to offer a more objective or broad assessment of the behavior and motivations of those involved in the case story. Thus, the narrative workshop differs from a focus group discussion format in that the participants are purposely selected due to their previous experience with and perspective on the topic under study.

The group constructs a hypothetical case of a pregnant woman faced with the decision to join a PMTCT program. This case is then developed into a series of storylines (complete with real characters, discrete episodes, and a well-defined beginning, middle and conclusion) that will help explain the likely issues and outcomes that arise within a PMTCT program. In this study, workshops were held in English and South Sotho, tape recorded, transcribed and where necessary translated into English.

Workshop participants shape the story to reflect their experiences. They "fill in" what they feel are the most important factors and players in a given situation. Participants then role-play key episodes from the narrative they construct, while others in the group critique the narrative play and develop and change it until they feel that it accurately depicts a likely outcome. Workshop participants develop alternative storyline endings, based on the role-plays and subsequent discussion. While a main storyline with key events is developed, the workshop may result in several alternative endings depending on the decisions characters make and circumstances in which they find themselves in the course of the story.

This research involved two workshops, one in each study site. Key informant participants were health care professionals who were currently involved in PMTCT-related activities (ANC nurses and nurse counselors), AIDS counselors based at local clinics where PMTCT services were offered, community health workers and health education volunteers, and

women who had been through PMTCT programmes. All participants volunteered to take part and were recruited by a liaison person at each PMTCT site.

The case study and process of constructing the narrative identify issues, dynamics and factors influencing a woman's participation (or non-participation) in the PMTCT program. The process also begins to explicate the determinants of, and obstacles to putting PMTCT-related messages and information into practice, as well as the quality of the programmatic experience from both a provider and client perspective. Use of a hypothetical case study allows informants to explore issues not necessarily possible when eliciting information about personal experiences or situations. The narrative workshop is a reflective exercise assisting those involved with the program itself to develop a more self-critical awareness of factors influencing individuals' abilities to adhere to programme recommendations and, ultimately, change their behavior.

In order to capture the heterogeneity of PMTCT users, we modified the NRM process to include case studies of three hypothetical client "index cases". Based on discussions with provincial and local health service representatives, the index case profiles were of women considered to be the most likely "client type" to utilize public sector PMTCT services in Free State Province. The three profiles are shown in Table 1 below. The case studies of each index type are represented by a decision-making tree or story organogram that graphically depicts the case study and its multiple endings.

Table 2: Index case profiles, Free State 2003

Index case	Rural vs. Urban Setting
Ever Married Pregnant Woman (second pregnancy), financially dependent on husband; aged 25-39 years	1 case study per site
Never Married Pregnant Woman (second pregnancy) unemployed, no matric., no steady partner, lives at home, aged 25-39 years	1 case study per site
Currently or Recently Pregnant Teenager/Teen Mother, first pregnancy, still at school, living at home, age 15-19 years	1 case study per site

In this study, we derived *three case study organograms for each of the index case or index client types*. While we collected three index case studies for each site (a total of 6), rural and urban storylines were deemed similar enough to collapse them into one case study for each index case (See Appendices A and B).

2.2. Community-based Narrative Survey

The second step of the NRM is a community-based questionnaire/survey. The narrative questionnaire consists of two main sections: 1) knowledge-attitudes-practices (KAP) component and 2) narrative vignettes that correspond to the case studies developed in the key informant narrative workshop.

The KAP component included the following sections: 1) socio-demographic information, 2) infant feeding issues, 3) HIV/AIDS and PMTCT knowledge and attitudes, and 4) AIDS-related stigma.

The narrative vignettes, based on the key informant workshops, comprise eight hypothetical narrative episodes from the case studies. These episodes span the entire length of the story (both intra-partum and post-partum): 1) initial counseling experience, 2) HIV testing choice and experience, 3) infant feeding decisions, 4) labor and delivery, 5) infant feeding dynamics at home, 6) resuming sex, 7) infant's 12-month HIV test, 8) life beyond 12 months.

The data collected in this segment provides statistical validation of the likelihood of alternative situational outcomes or story endings developed in the key informant workshop. For example, the questionnaire tells us the likelihood of a woman accepting (or refusing) a test result once she has gone through counselling. The questionnaire also tells us who is the most likely person(s) to whom a woman would first disclose her HIV status and how this person would react to her disclosure.

The narrative portion of the questionnaire addresses each of the three index client types (i.e. ever-married female, never-married female, teenager). For this portion of the questionnaire (see section below) three groups of women were interviewed, each fitting the profile of the index client. When the narrative story was "pitched" or described to the respondent, it was framed in reference to the index type fitting the respondent's profile. That is, for teenage questionnaire respondents, the story line was described in reference to a pregnant teenager, for married adult respondents the story was about a pregnant married woman, etc. Thus, each participant type answered questions in reference to a case study story that potentially mirrored her pregnancy or PMTCT-related experiences.

2.3. Participants and Sampling

The questionnaire was administered to five groups of respondents: ever pregnant teenagers (aged 15-19), ever married adult females (aged 25-39), never married or single adult females (aged 25-39)[7], males (aged 25 years or older), and older females (i.e. females aged 40 years or older). In order to participate in the study, respondents had to satisfy a residency requirement of having lived in the study community for a minimum of one year. This requirement was to ensure that respondents would be able to provide a sufficiently informed local perspective.

A sample size of 250 per site (total N=500) was derived with 50 observations for each respondent type in each site. Index females answered both parts of the questionnaire (KAP and narrative vignettes) while males and older females responded only the KAP component.

The questionnaire was piloted in an open-ended format with 25 respondents in two study sites similar but unrelated to the field sites.

A modified cluster sampling methodology described in Lemeshow and Robinson (1985) was used. This sampling technique was chosen for the following reasons: 1) communities were judged to be sufficiently homogeneous and 2) the method is inexpensive and easy to administer. Table 3 below illustrates the sample profile of the questionnaire participants.

Table 3: Questionnaire sample profile. Free State 2003 (N=500)

Profile Type	Mangaung	Frankfort	Total Sample Size
Teenagers; 15-19 yrs, ever pregnant (*index type*)	50	50	100
Single/never Married Females, 25-39 years, ever pregnant (*index*	50	50	100

[7] These first three groups fit the index case profiles, and thus were known as "index females" or "index types" for purposes of data analysis.

type)			
Ever Married[8] Females; 25-39 years, ever pregnant (*index type*)	50	50	100
Older Females, 40 + Years	50	50	100
Males (aged 25 +)	50	50	100
Total Sample	250	250	N=500

2.4. Focus Group Discussions

The third step of the NRM was a series of eight focus group discussions (FGDs) per site to assist in exploring issues arising from the key informant workshop and in expanding information given in the questionnaire. FGD's provided information on broader community-level attitudes and opinions concerning PMTCT-related issues. Issues covered in the focus group discussions included community responses to HIV/AIDS, HIV-related stigma, (for health care workers and community health workers) workplace related stress caused by HIV/AIDS, infant feeding issues, family and household decision-making dynamics and (for index participants) commentaries on episodes drawn from the narrative portion of the questionnaire.

Focus groups consisted of: 1) older females (aged 40 years and above), 2) civic and social opinion leaders, 3) health care professionals involved in PMTCT service provision (i.e. nurses and counsellors) 5) community health workers[9], 6-8) each of the three female index case profiles from the narrative case studies. All focus group discussions were held in South Sotho, tape-recorded, transcribed and translated into English. Wherever possible, FGD participants were recruited from the questionnaire sample in order to ensure continuity.

[8] Married status was defined as having undertaken any civil, religious or traditional ceremony that conferred marital status socially and/or legally. Females in long-term stable relationships (common-law married status) were also classified as married.

[9] This group is defined as community-based individuals and groups who are not part of the formal health care system but who provide direct or indirect support to health services. In many South African communities, community health workers are volunteers who give valuable assistance in ways that the health services are not able to respond by providing; home-based care, counseling, food distribution and health education. The Provincial Department of Health requested this group be included in order to explore the relationship between health service providers these "informal" providers of care and services as the basis for finding ways to improve the synergy between these groups.

2.5. In-Depth Interviews

In-depth interviews (IDIs) were conducted with health care workers and females fitting the index case profiles. In this way, the data complemented information collected in previous study segments by providing insight on personal experiences with PMTCT. IDI participants included: 1) health care professionals involved in PMTCT service provision; 2) community health workers, 3-5) females fitting the three index case profiles. In each study site, a maximum of five IDIs was conducted in each group, resulting in a maximum sample size of 25 per site (50 maximum total). All IDIs were conducted in South Sotho, tape-recorded, transcribed and translated into English. Wherever possible, IDI participants were recruited from the questionnaire sample in order to ensure continuity.

3

RESULTS

This chapter consists of three sections. The first section reports findings of the questionnaire, focus group and in-depth interviews on 1) knowledge of HIV/AIDS and MTCT in particular, 2) infant feeding practices, beliefs and decisions and 3) HIV stigma generally and relating to MTCT. The second section describes case studies developed through key informant narrative workshops, focusing on different behavioual outcomes in relation to key events in the PMTCT process and the contextual factors that impact these outcomes. The third section contains results from the questionnaire on the narrative vignettes that were developed from the narrative workshop case studies.

3.1 QUESTIONNAIRE, FOCUS GROUP, INDEPTH INTERVIEW RESULTS

3.1.1. Questionnaire Respondents' Socio-Demographic Characteristics

This section gives an overall picture of the sample of respondents including age, length of residence, language group, education level, employment status, household heads and living conditions.

Sample Size

Following the study design, 20 percent of respondents were males (N=100) and 80 percent females (N=400). Females above 40 years (N=100), ever-married females between 25 and 39 years (N=100), never married females between 25 and 39 years (N=100), and female teenagers between 15 and 19 years (N=100) comprised 25% each of the female sample.

Criteria for Participant Inclusion

For all participants, individuals had to have resided in the study community for a minimum of one year. Index participants had to have been pregnant to be included in the study. Married status was defined as having undergone a traditional, religious or civil ceremony or being in a common law marriage (defined as a stable cohabiting union of a

minimum of three years). Divorced women were considered "ever-married" and could be included in the 'ever married' category. Teenagers were defined as aged 15 to 19 years. Male participants had to be young adults or older, with a minimum age of 25 years.

Participant Age

Among males, mean age was 42.64, med:40.5, ranging from 25-82 years of age. Among older females (40+) mean age was 55.55, med:53, and the ages ranged from: 40-85. Among index participants:

1. Ever married females mean age was 32.97, med:33, range:25-39.
2. Single/never married females mean age was 30.57, med:30, range:24-39.
3. Teenagers mean age was 17.94 years, med:18, range:15-19.

Language

Table 4 gives the proportion of different language groups in the sample. The majority of respondents were South Sotho speaking followed by Zulu and Xhosa.

Table 4: Language profile of respondents, Free State 2003 (N = 500)

	%
South Sotho	58.2
Zulu	17.4
Xhosa	11.4
Tswana	7.8
North Sotho	4.2
Afrikaans	.8
Ndebele	.2
Total	100.0

Length of Residence

Mean length of residence for men was 19 years. Older females' mean length of residence was 13.96 years. Among index participants, length of residence for the three index groups was:

1. Ever-married females mean residence was 13 years.
2. Single/never married females mean length of residence was 13.67 years.
3. Teenagers' mean length of residence was 8.7 years.

Education

Overall, 5 percent of respondents had never attended school, 9.4 percent had completed primary school (Std 5), 16. percent had matriculated (Std 10) and 4.8 percent have undertaken some form of post secondary training of which the majority (2.6%) had taken short diploma courses. Education levels are also broken down by participant category.

1. Among males, 11 percent had completed Std 5, 22 percent had matriculated and 5 percent had done post secondary training. All male participants had some formal schooling.
2. Among older females (40+ years), 21 percent had no formal schooling, 13 percent had completed Std 5, 4 percent had matriculated and 5% had done post secondary training.
3. Among ever-married females, 5 percent had completed Std 5, 21 percent had matriculated and 8 percent had some post secondary training. All ever-married females had some formal schooling.
4. Among single or never married females, 4 percent had no formal schooling, 7 percent had completed Std 5, 25 percent had matriculated and 5 percent had post secondary training.
5. Among female teenagers 15-19 years, all had some form of schooling, 11 percent had completed Std 5, 8 percent had matriculated and 1 percent had post secondary training.

Employment

Unemployment was high across all gender and age groups. However, Table 5 shows that unemployment among males (59%) is lower than among older females (40+ years) and female index types.

Table 5: Employment status by gender and index type, Free State 2003 (N = 100 per group, Total N = 500)

	Males %	Older Females (40+ yrs) %	Ever Married Females (25-39 yrs) %	Never Married Females (25-39 yrs) %	Teenagers (15-19 yrs) %
Unemployed/Pensioner	59	73	85	75	77
Unskilled Job	10	2	6	10	0
Semi-skilled Job	18	20	1	6	0
Skilled Job	13	5	8	8	1
Student	0	0	0	1	22

Household Head

As household circumstances may impact on choices in relation to the narrative story in the questionnaire, head of household was reported for index participants. Among ever-married females, 55 percent said their husband is the head, followed by 26 percent who stated they are the household head and 11 percent whose fathers are heads of household. Among never married females, 52 percent said their mothers are the household head followed by self (24%) and fathers (12%). Among teenagers, 48 percent said their mothers are the head of household, 24 percent said their fathers are heads of household followed by 8 percent whose grandmothers are head of household.

Toilet Facilities and Access to Indoor Running Water

Living conditions also impact on infant health and issues relating to infant feeding. Sanitation, that is toilet facilities and access to clean water also indicate levels of infrastructural development. Tables 6 and 7 provide an overview of these features by site. Over half or respondents in Mangaung and Frankfort have outdoor flush toilets (Mangaung 52.4%; Frankfort 62%) followed by outdoor pit systems (Mangaung 33.2%; Frankfort 22%) and then indoor flush toilets (Mangaung 13.2%; Frankfort 16%).

Table 6: Toilet facilities by site, Free State 2003 (N = 250 per site)

	Mangaung %	Frankfort%
Indoor Flush	13.2	16.0
Outdoor Flush	52.4	62.0
Outdoor Pit, Pit Latrine, Bucket	33.2	22.0
Field Toilet	1.2	0.0

Less than half of respondents in Mangaung (32%) and less than a quarter in Frankfort (22%) have access to running water inside their homes.

Table 7: Access to running water inside the home by site, Free State 2003 (N = 250 per site)

	Mangaung %	Frankfort%
Yes	32.0	22.0
No	68.0	78.0

Energy Sources

Table 8 presents main energy sources for cooking by site. In Mangaung, 78 percent of respondents make use of one energy source for cooking while all Frankfort respondents use at least two energy sources for cooking. Mangaung respondents' main sources of fuel are electricity and paraffin. Main sources of fuel in Frankfort are electricity and coal.

Table 8: Energy sources for cooking by site, Free State 2003 (N = 250 per site)

	Mangaung %*	Frankfort%*
Electricity	71.6	63.6
Paraffin	46.4	10.8
Wood	1.2	3.6
Coal	0.8	52.4
Gas	2.4	8

* Percentages do not add up to 100% as respondents could give more than one energy source

Home Appliances

In order to give a broad indication of respondents' socio-economic status, respondents were asked about the following home appliances: television, car, refrigerator, radio, cell phone or landline/telephone. Table 9 shows that there is little difference between sites. Approximately two thirds of respondents own a television and over 80 percent own a radio. Over two thirds of respondents own a refrigerator. Cell phone ownership is over 33 percent in both sites, but few respondents have a landline. Car ownership is below 20 percent in both sites.

Table 9: Home appliances by site, Free State 2003 (N = 250 per site)

	Mangaung%	Frankfort%
Television	68.8	63.6
Radio	82.8	86.4
Refrigerator	66.8	68.0
Cell phone	38.0	36.0
Landline	12.0	14.4
Car	14.0	17.6

3.1.2. HIV/AIDS General Knowledge and Sources of Information

Most respondents (98% overall) have heard of HIV/AIDS. FGD and IDI participants vividly describe the impact of HIV/AIDS on their communities particularly the number of youth and women who are sick and dying. Respondents' knowledge of how HIV is transmitted is shown in Table 10. The majority of respondents (93%) give sexual

intercourse as one of their responses[10] when asked how HIV is transmitted. A further 49.8 percent said blood or bodily fluid contact can transmit HIV. Blood transfusion (7.2%), needles/injections (5.2%), razors (1.6%) and then STD's (.8%) were also given as routes of transmission. Only one respondent gave vertical transmission during pregnancy or labour as a transmission route. Six respondents (1.2%) did not know how HIV is transmitted and fourteen respondents (2.8%) suggested incorrect routes of transmission, namely shared toothbrush, toilet, food, handshakes, unclean water, kissing, oral contraception or mosquitoes.

Table 10: Knowledge of HIV transmission routes, Free State 2003 (N=500)*

	%
Sexual Intercourse	93.0
Blood Contact/ Bodily Fluids	49.8
Blood Transfusion	7.2
Needles/Injections	5.2
Razors	1.6
STD's	0.8
Vertical Transmission	0.2
Incorrect Responses	2.8
Don't Know	1.2
Missing	2.0

* Multiple responses allowed

Overall 90.2 percent of respondents believe that a person can be HIV positive and still look healthy while 5.5 percent of respondents disagreed with this statement and 4.3 percent were unsure. In the urban Mangaung site, 93.4 percent of respondents believed correctly that a person can still have HIV and look healthy while in the rural Frankfort site, 87 percent believe so ($p = .018$). There is little difference between females (90%) and males (91%) who agree that a person can have HIV and still look healthy and no significant differences between teenagers, never married and ever married women.

The majority of respondents (80.2%) correctly believe there is no cure for HIV/AIDS at the present time. However, 11.6 percent believe there is a cure and 8.2 percent were unsure, a figure of almost 20 percent. There was a significant difference at the 5 percent level ($p = .044$) across sites with 76.5 percent of urban respondents correctly agreeing that there is no cure for HIV/AIDS while 83.8 percent were correct in the rural site. However, 77.7 percent of female respondents believe there is no cure of HIV/AIDS as compared to 90 percent of males ($p = .006$). Table 11 shows that there are also differences across the three index types

[10] Multiple responses were allowed with no prompting from interviewer.

as to whether HIV/AIDS can be cured or not with teenage females more likely to be associated with saying there is a cure than never married females or ever-married females aged 25 to 39 years.

Table 11: There is a cure for HIV/AIDS by index type, Free State 2003 (N=300)

Females	Yes %	Unsure%
Teenagers (15-19 yrs)	21.0	10.6
Never Married Females (25-39 yrs)	12.2	11.2
Ever Married Females (25-39 yrs)	6.1	10.2

Overall, most respondents would prefer to receive information from: clinics or hospitals (49.8%), community health workers or peer educators (23.8%), experts (18.4%), media (13.4%) and people living with AIDS (11%).[11] Teenagers differed slightly with first four choices being clinics (52.7%), people living with AIDS (14.7%), schools (8.5%) and community health workers or peer educators (8.5%) followed by media (4.7%). Overall, respondents' did not list preferences for phone information lines (.2%), family friends or relatives (1.2%), government (1.2%) and NGOs (2%) as sources of information.

Respondents felt it was primarily the responsibility of the health community to educate the community about HIV/AIDS-related issues. Health community chosen by 34.6 percent of respondents was followed by everyone in the community (19.4%), people living with AIDS (17.2%), experts from outside the community (16%), media (7.4%), parents (6.4%), government (4.6%), teachers (2.4%), churches (2.2%), siblings (.8%), peers (.6%) and self (.2%).[12]

Focus group and interview participants' comments on information and education emphasized utilizing multiple approaches to community education that combine both formal and informal networks to reach community members. Again, participants emphasized the role of health care professionals.

Community and government must come with ideas to organisations that will help people with HIV/AIDS. (Focus Group - Males, Mangaung).

The pastors are there to help in this regard and they are the most stable societal norms, when they talk people listen. I mean they must be part of the projects of HIV/AIDS that are formulated because by only talking people are listening and become convinced (Focus Group – Community Social Leaders, Frankfort).

[11] Note percentages add to over 100% because participants were permitted to specify more than one option.
[12] Note percentages add to over 100% because participants were permitted to specify more than one option.

You learn from the counsellors, from the clinic . . . people talk to the sisters about HIV/AIDS . . . I think doctors and nurses influence public opinion about HIV/AIDS (Focus Group – Ever-married Females, Frankfort).

The peer groups, peer groups, only peer groups . . . Some come to us the health workers to seek for information, some talk to their boyfriends . . . The posters and the pamphlets of HIV/AIDS . . . The radio and the television . . . and the school, they talk (Focus Group – Health Care Workers, Mangaung).

Radio, T.V, newspaper, seSotho newspapers must be written . . . counsellors, volunteers and pastors (Focus Group – Community Social Leaders, Frankfort).

People who live with HIV/AIDS . . . sisters . . . people with AIDS (Focus Group – Teenagers, Frankfort).

They learn from the counsellor . . . From the clinic . . . I think the sisters and counsellors . . . I think it is the doctors and nurses . . . Even if is someone from the parliament who usually talk about HIV/AIDS . . . Winkie Direko . . . and Mr. Mandela (Focus Group –Ever married Females, Frankfort).

Summary

In the research sites, most respondents are aware of HIV/AIDS (98%). From the FGD and IDI data, it is clear that communities witness and feel the impact of HIV/AIDS on a daily basis.

Respondents have accurate knowledge about routes of transmission with 4% of respondents either with incorrect knowledge (2.8%) or unsure (1.2%). Vertical transmission is not a prominent feature of respondents' knowledge on HIV transmission with one respondent mentioning this route.

Accurate beliefs about HIV/AIDS, namely that a person can have HIV and still look healthy (90.2%) and that there is no cure (80.2%) are also high. However, almost 20 percent of respondents believe there is a cure for HIV/AIDS (11.6%) or are unsure (8.2%). Significantly more females believe there is a cure for HIV/AIDS than males, and more female teenagers are associated with the belief that there is a cure than other females.

Overall, respondents see health professionals and peer educators (including those living with HIV/AIDS) as preferred sources of information and primarily responsible for educating others about the disease. Study participants also emphasise multiple approaches to community education using as many formal/informal networks as possible.

3.1.3 Vertical HIV Transmission Knowledge

Overall, 73.9 percent of respondents know that babies can be infected with HIV/AIDS through breastfeeding, 12 percent disagreed and 14.1 percent were unsure. There were no significant differences by site or gender. When comparing older females and index female

type, teenagers were associated with being least likely to know (61%), followed by older females (67%), ever-married females (70.4%) and never married females (85.7%). Of respondents who knew that HIV/AIDS can be vertically transmitted to an infant, the most commonly mentioned "risk factors" for making breastfeeding a potential source of HIV transmission were: breast milk itself if the mother is HIV positive (63.3%), and sores on the breasts or nipples (7.6%). Overall, 76.3 percent of respondents gave correct information while 23.7 percent either did not know (23.1%) or gave incorrect answers. There were no significant differences by site or gender, but among index types, 89 percent of never married females gave correct answers, 68 percent of ever-married females and 53 percent of teenagers. Among teenagers, 42.6 percent did not know how HIV is transmitted through breastfeeding, 29.6 percent of ever-married females and 9.2 percent of never married females did not know (p = .000). Among older females (40+ years), 84 percent gave correct answers and 15 percent did not know.

Questions probing respondents' knowledge of preventing vertical transmission during birth show that 50 percent of all respondents are aware that mothers can take nevirapine or other anti-retroviral drugs. However, 37.3 percent were unsure or didn't know of ways to prevent transmission during birth and three percent said there was no way to prevent transmission. Overall 54 percent of respondents gave correct information but there was a significant difference by site, 46 percent giving correct information in Mangaung and 61.8 percent giving correct information in Frankfort (p = .000). Between males and females 41.4 percent and 57.3 percent respectively gave correct information on how to prevent transmission during birth (p = .005). Among females, correct knowledge of prevention during birth was highest among never married females (70.4%) followed by married females (61.2%), teenagers (52.1%) and then older females (40+ years) (43.4%). Of those females who had correct knowledge, most stated that a mother could take nevirapine.

To prevent transmission after birth, 44.9 percent of respondents suggested stopping breastfeeding while 29 percent did not know and the rest gave incorrect answers. There was a significant difference by site with Frankfort respondents (52.2%) giving correct information as compared to 37.4 percent in Mangaung (p = .000). Between males and females, males (61%) said stopping breastfeeding as compared with 40.8 percent of females. Again teenagers (35.1%) were least likely to have correct knowledge of prevention particular in Mangaung (26.7%) as compared with Frankfort (42.9%).

Under half of respondents (41.%) have heard of PMTCT services in the area in which they live. There was no significant difference between urban and rural sites with 38.8 percent having heard of PMTCT services in the urban site and 43.2 percent in the rural site. Females (43.8%) are significantly more likely to have heard of PMTCT services than males (30%) (p = .012). Across female index type and older females, Table 12 shows that female teenagers are least knowledgeable about PMTCT services in their area, while 61 percent of females (40+ years) know of PMTCT services.

Table 12: Knowledge of PMTCT services by index type and older female. Free State 2003 (N=400)

Females	Yes %
Teenagers (15-19 yrs)	22
Never Married Females (25-39 yrs)	49
Ever Married Females (25-39 yrs)	43
Females (40+ yrs)	61

Summary

Overall, almost three quarters of respondents know that babies can be infected with HIV through breastfeeding. Teenagers (61%) were least likely to know that HIV can be transmitted through breastfeeding and never married females (85.7%) most likely to know. Again, teenagers (42.6%) followed by ever-married females (29.6%) were least likely to know how HIV can be transmitted during breastfeeding.

Approximately half of respondents have correct knowledge on prevention of vertical transmission during and after birth. Males have more knowledge about preventing transmission after birth while females have more knowledge about prevention during birth. Overall, teenagers and older females (40+ years) were significantly less likely to give correct information on prevention.

Under half of respondents (41%) are aware of PMTCT services in their areas with males and female teenagers being significantly less likely to know about these services than females 25 years and above.

3.1.4 Infant Feeding Practices

The length of time infants are breastfed is two years taking the median of all respondents. This holds for both female (including all index types and older females) and male respondents and across both sites. Respondents report the median age at which infants start solid food is three months overall and this is the same across site and gender. Comparing female respondents, older females give a median age of six months, ever-married females three months, never married females 3.5 months and teenagers three months.

Overall 87.6 percent of respondents agree that babies are usually fed a mix of solids and liquids between birth and four months. There was a significant difference by site, with 79.6 percent of urban Mangaung respondents and 95.6 percent of Frankfort respondents agreeing that mixed is the norm in their communities ($p = .000$). Males (96%) were significantly more likely to think that mixed feeding was the norm than females (85.5%) (p

.004). Comparing females, 89 percent of married females, 96 percent of never married females and 98 percent of teenagers said that mixed feeding was the norm. In contrast, 59 percent of older females said mixed feeding was the norm between birth and four months.

When comparing overall infant feeding trends relating to exclusive breastfeeding, exclusive bottle feeding or mixed feeding (breast milk, formula milk, other liquids and solids), 80.6 percent of respondents said mixed feeding is the norm, 12.2 percent said exclusive breastfeeding and 7.2 percent chose exclusive formula feeding. There is a significant association between what people's perceptions are of the norm and site with 68.4 percent of respondents in Manguang claiming mixed feeding is the norm as compared to 92.8 percent of Frankfort respondents ($p = .000$). When comparing index type and older females, over 90 percent of index type respondents said mixed feeding is the norm while 58.4 percent of females over (40+ years).

Respondents were also asked if there are special herbs or traditional medicines that are given to babies orally during the first four months of life. Overall 46.2 percent of respondents stated there were special herbs designated for this purpose, 47.6 percent said there were none and 6.2 percent did not know or were unsure.[13] There was no significant difference by site on this practice. However, there was a significant difference between females (yes 55.3%) and males (yes 10%; no 81%; unsure 9%) on whether special herbs are given to babies orally or not ($p = .000$). Among females, 73 percent of teenagers, 70.3 percent of older females (40+ years), 50 percent of ever-married females, 27 percent of never married females said there were special herbs for infants up to four months.

Summary

The median age for the introduction of solids is three months. However, older females (40+ years) said it is six months.

The majority of respondents (80%) said mixed feeding is normal practice between birth and four months. More respondents in the rural site and more males than females said this is the norm. Although over 90 percent of females under 40 years of age said this is the norm, just under 60 percent of females (40+ years) said mixed feeding is the norm. Respondents were almost equally divided on whether traditional herbs are given to babies orally during the first four months of life.

3.1.5 Beliefs and Attitudes on Infant Feeding Practices

In the overall sample, 59.4 percent of respondents strongly agreed and 15.4 percent moderately agree that babies who cry do not receive sufficient nourishment from the breast and need additional food, while 19.6 percent disagreed. Males are significantly associated with this belief with 87 percent agreeing, while 71.8 percent of females agreed. Comparing index type and older females, Table 13 shows that older females (49.5%) and teenagers

[13] In the pilot we attempted to ask respondents to specify herb names, but most were unable to do this.

(69%) were less likely to agree with the belief that crying means breastfeeding is insufficient and the baby needs additional food than never married (89%) and ever-married females (80%).

Table 13: Belief that breast milk is inadequate by female type, Free State 2003 (N=400)

Females	Teenagers (15-19 yrs) %	Never Married Females (25-39 yrs) %	Ever-Married Females (25-39 yrs) %	Older Females (40+ yrs) %
Agree Strongly	66	48	57	47.0
Agree Moderately	3	41	23	2.0
Disagree	15	8	14	50.0
Unsure	16	3	6	1.0

That breast milk is inadequate and mixed feeding is therefore necessary in the first four months, 72.6 percent of respondents agreed either strongly or moderately. There was no difference in this belief by site, but by gender there was a significant difference (p = .000) with 67.3 percent of females and 90 percent of males agreeing with this statement. Between index type and older females (40+ years), there is a significant difference in their likelihood of agreeing with this statement with over 80 percent of index respondents agreeing while only 49.5 percent of older females (40+ years) agreeing.

Overall 58,6 percent of respondents believe that a woman who exclusively breastfeeds her baby between birth and four months is doing the natural thing and ensuring the child's health. However, 28.2 percent believe that a woman who does this is doing the wrong thing. The third most common opinion (6% of respondents) was that women do this because of poverty. Overall, one respondent (.2%) attributed this practice to a woman having HIV/AIDS. Similar trends occurred across both sites. However, there is a significant association between respondents' opinions and gender with 19% of males saying exclusive breastfeeding between birth and four months is natural and protective and 70 percent saying it is wrong as compared to females where 68.5 percent say is natural and protective and 17.8 percent say it is wrong (p .000). Table 14 shows differences among female index types with the majority of older females (40+ years) and never-married females giving the opinion that exclusive breastfeeding is natural and protective.

Table 14: Female opinions of a woman who exclusively breastfeeds her baby between birth and four months, Free State 2003 (N=400)

	Teenagers (15-19 yrs) %	Never Married (25-39 yrs) %	Ever-Married (25-39 yrs) %	Older Females (40+ yrs) %
Natural and Healthy	53	82	48	91
Because of Poverty	8	6	14	0
Wrong and Unhealthy	33	3	26	9
Other	6	9	12	0

In focus groups and interviews, a similar diversity of opinions emerges. Participants regard breastfeeding as vital for a baby's health and growth.

Breast milk is okay because the baby does not get other sicknesses and vitamins are there (Focus Group – Teenagers, Mangaung).

If you don't breastfeed your child you will find that after five years the child is suffering from kidneys and lack of eye sight (Focus Group – Older Females, Mangaung).

. . . and breast feeding makes babies strong and powerful (Focus Group – Older Females, Mangaung).

Some participants saw it as a healthier and less risky option than formula feeding.

Babies must be breastfed because some women do not thoroughly clean their bottles (Focus Group – Teenagers, Mangaung).

It was also associated with caring and good parenting.

Those who don't breastfeed are mothers who don't love their children (Focus Group – Older Females, Mangaung).

A woman who practices exclusive breastfeeding is a quality mother (Focus Group – Ever-married Females, Frankfort).

However, as reflected in questionnaire responses, communities do not necessarily think exclusive breastfeeding is ideal. In particular, participants suggested that it is not nutritionally adequate.

No, it is not acceptable to give the baby breast milk only, not to give water, no it is not acceptable . . . The baby has to have some proteins besides breast milk . . . no, she is lazy to cook . . (Focus Group – Never Married Females, Frankfort).

I breastfeed my babies and I also give them some water after a short while. They get breast milk and water only, it's okay (Focus Group – Older Females, Frankfort).

The elderly will say look we have raised your baby, giving her the water, we have raised you giving you the soft porridge, for two months, you are so healthy because of soft porridge, they don't have problems (Focus Group – Health Care Workers, Mangaung).

Breastfeeding also has connotations of poverty.

Most of the community breastfeed because of poverty (Focus Group – Community Social Leaders, Mangaung)

The most common opinion of women who do not breastfeed between birth and four months given by 52.6 percent of respondents is that the woman is not taking good care of the baby's health (31.8%) or good care of children (20.8%). This opinion is followed by the mother is ill (13.2%), there is not enough milk or the mother has breast problems (12.2%), the mother has a job (8.6%), she doesn't want to breastfeed (3.4%) and then the mother is avoiding breastfeeding because she has HIV/AIDS (2.2%). Only one respondent (.3%) suggested a woman was doing the right thing by not breastfeeding. Similar trends in opinion occur across both sites. However, there is a significant association ($p = .000$) between respondents opinions and gender with 69 percent of males and 48.5 percent of females saying the woman is not taking good care of the baby's health or good care of children, followed by 18 percent of males and 12 percent of females saying the mother is ill, and 4 percent of males and 14.3 percent of females saying the mother has breast problems and there is not enough milk. Only females (10.8%) suggest the mother has a job or the mother has HIV/AIDS (2.8%). Table 15 shows that female index type is also associated with opinion on this issue.

Table 15: Female opinions of a woman who does not breastfeed her baby between birth and 4 months, Free State 2003 (N=400)

	Teenagers (15-19 yrs) %	Never Married Females (25-39 yrs) %	Ever-Married Females (25-39 yrs) %	Older Females (40+ yrs) %
Does not care for the child or its health	69	22	34	69
Mother is ill	2	20	22	4
Problems with breasts or not enough milk	7	26	14	10
Mother has a job	4	19	11	9
Mother has HIV/AIDS	1	6	4	0
Other	7	7	15	8

Health and care are often given as reasons why people oppose EFF.

I did not breastfeed my older child, but if you can look at the younger one, his body was bigger than the older one. That means that there is a difference in EFF and EBF (Focus Group Ever-married Females, Mangaung).

Women are supposed to feed their babies with breast milk because some of them they don't know how to clean the bottles (Focus Group – Teenagers, Mangaung).

I see that there is a lot of problems with EFF, another woman came in here with an underweight baby, the nurses asked the grandmother why the baby was underweight because they had told them to do this and that. She told us that she was taking two teaspoons of formula to make a bottle. She said that she didn't hear. Grandmothers raise babies in ways that they, themselves have been raised. EFF is simple for youths but our mothers do not take care of babies as they should (Focus Group – Never Married Females, Mangaung).

Similarly with breastfeeding, exclusivity appears socially unacceptable.

It is not socially acceptable to only formula feed the child, an infant has to be fed breast milk (Focus Group –Ever- married Females, Frankfort).

It is acceptable that a mother can breastfeed and feed a baby with a bottle, it is acceptable . .. (Focus Group – Health Care Workers, Mangaung).

Participants in focus groups criticized teenagers for wanting to avoid breastfeeding and use formula because of vanity, laziness and not being sufficiently responsible, although 69 percent of teenagers said in the questionnaire not breastfeeding signaled the mother did not care for the health of the child.

Opinions of mixed feeding between birth and four months show that 60 percent of respondents said that a mother is doing a natural and traditional practice. However, 32 percent said she is doing the wrong thing not caring for the baby, while a further 6.2 percent said she is unable to breastfeed due to insufficient milk or other circumstances. Both urban and rural sites yielded similar results. There is again a significant association between gender and respondents' opinions with 98 percent of males who said it is a natural and traditional practice as compared to 50.6 percent of females, and 2 percent of males who said the practice is wrong indicating lack of care as compared to 39.6 percent of females. Table 16 again shows that female groups are also associated with differences in opinion. Females (40+ years) (93%) overwhelmingly believe that it indicates the mother does not care for the child. Never married females are the next most likely to have this opinion at 40 percent, while 87 percent of teenagers and 58 percent of ever-married females believe it is a natural and traditional practice.

Table 16: Female opinions of a woman who mix feeds her baby between birth and four months, Free State 2003 (N=400)

	Teenagers (15-19 yrs) %	Never Married Females (25-39 yrs)%	Ever-Married Females (25-39 yrs)%	Older Females (40+ yrs) %
Normal, natural or traditional practice	87	52	58	5
Wrong, not caring for child	12	40	13	93
Unable to breastfeed	0	5	25	1
Other	1	3	4	1

Summary

Almost three quarters of respondents think breast milk is inadequate during the first four months and therefore mixed feeding is necessary. More males (90%) believe this than females (67.3%) and four fifths of females under 40 years agree as compared to just under half of females 40 years and over. Almost two thirds of respondents believe mixed feeding is normal, however a third say mixed feeding indicates the mother does not care for the child properly. Almost all males think mixed feeding is normal practice in contrast to half of females. The majority of females (40+ years) believe that mixed feeding shows lack of care, while over half of married and never married females and over four fifths of teenagers believe it is normal practice.

Almost two thirds of respondents believe EBF is natural and ensures the baby's health, while almost a third believe that it is not correct to do so. Seventy percent of males believe it is wrong while almost the same percentage of females believes EBF is normal and protective. The majority of never married females and females 40 years and over think it is normal and protective while about half of ever-married females and teenagers think this way.

Over half of respondents believe that a woman is not taking good care of her baby if she does not breastfeed. Almost seventy percent of men and half of female respondents believe this. More older females (40+ years) and teenagers (69% for both) believe this than never married (22%) and ever-married females (34%).

3.1.6. Infant Feeding Information and Decision-making

Respondents' primary or most important sources of information on infant feeding are clinics and nurses (60.2%), followed by mothers (26.8%), elderly people (7.6%) and then by experience (3%). Sources of information are similar across sites and there is no significant difference between male and female. Between female index cases and older women (40+

years), 68.3 percent of index cases said the most important sources of information are clinics and nurses as compared to 35 percent of females (40+ years). Mothers are the most important source of information for 16 percent of female index cases as compared to 63 percent of females (40+ years) suggesting a trend towards professional sources of information among younger females supported by 74 percent of teenagers choosing clinics and nurses as compared to 67 percent of ever-married females and 64 percent of never married females.

Respondents' views of the role of fathers in infant feeding decisions show that in the overall sample 500 (59.2%) respondents felt that fathers are rarely or not involved in such decisions. However, 39 percent of respondents felt that fathers are involved. There was no difference by site. Across gender 59 percent of males and 59.3 percent of females felt that fathers are rarely or not involved and 35 percent of males and 40 percent of females felt they are involved. Table 17 shows that there is a significant association with female types and opinion on this issue (p = .000). Females (40+ years) (81%) and never married females (71%) are more likely to have the opinion that fathers are rarely or not involved. While 57 percent of ever-married females and 55 percent of teenagers feel fathers are involved.

Table 17: Female opinions of father involvement in infant feeding decisions, Free State 2003 (N=400)

	Teenagers (15-19 yrs) %	Never Married Females (25-39 yrs) %	Ever-Married Females (25-39 yrs) %	Older Females (40+ yrs) %
Involved at some level	55	29	57	19
Rarely or not involve	43	71	42	81
Unsure/ Do not know	2	0	1	0

Focus group and interview participants also speak of the role of fathers, but emphasise the role of mothers and grandmothers. However, their views also clearly demonstrate how decisions are part of broader social practice.

The sisters at the clinic would tell them . . . the neighbours . . . people in the household, who stay with her . . . the mother . . . Everyone controls how to feed her baby (Focus Group – Never Married Females, Frankfort).

It is the mother of the baby that has the influence . . . And the father of the baby, at most it is the mother . . . Again, most of the mothers are working, so the granny is the one who is looking after the child and she spends most of the time with the baby . . . Like me, my baby went to stay with my sister a at young age . . . anything the mother does, she does it through the phone (Focus Group – Ever married Females, Mangaung).

Mothers in law . . . Parents, all of them, mothers and fathers, but most it is the women (Focus Group – Health Care Workers, Mangaung).

I hear you saying it is the mothers who are taking the responsibility, I disagree with that thing usually it is culture. culture is orientating the person, it is true that when the family breastfeed you are also going to breastfeed whether you like to or not (Focus Group - Community Social Leaders, Mangaung)

Sister from the clinic . . . the mother . . . the mother-in-law . . . I say the father . . . the grandmothers (Focus Group – Ever-married Females, Frankfort).

Questionnaire results of the narrative vignettes also show that mothers, grandmothers and mothers-in-law play significant roles in decisions on infant feeding (See Section 3.3. Event 5)

Summary

Respondents' primary sources of information on infant feeding are nurses and clinics (60%), mothers (26.8%), older people (7.6%) and then experience (3%).

Almost two thirds of respondents believe that fathers are rarely or not involved. However, from focus group and interview participants, it is clear that infant feeding decisions involve a number of key players, usually mothers and mother-in-laws but also fathers, and take place within a broader social dynamic around cultural beliefs on best practice and who is empowered to make decisions.

3.1.7 HIV/AIDS Stigma

Although quantitative measures of stigma do not capture the full complexity of HIV/AIDS-related stigma, for comparative purposes some stigma related questions were included. Items were adapted from stigma studies undertaken under the HORIZONS PROGRAM of the Population Council and PATH. Several of the questions are designed to uncover gender-specific HIV/AIDS stigma.

The majority of respondents (95.4%) stated they would care for a female relative who was sick with HIV/AIDS in their household. This view differed significantly by site with 6.8% of respondents in the rural Frankfort site more likely to say no or be unsure as compared with 2.4% in the urban Mangaung site. There was no significant difference between males and females on this issue. Among female index types never married females were more likely to say they would care at 99 percent as compared with teenagers 90%, ever married females (93%) and females over forty (96%). Overall, 92.8 percent of respondents said they would care for a male relative who was sick with HIV/AIDS in their homes, 6.2 percent said no and one percent were unsure. There was no significant difference between sites. However, males (99%) were significantly more likely to say they would care for a male relative than females (91.3%) ($p = .007$). There was also a significant association across

female index types with teenagers (82%) and ever-married females (88%) less likely to say yes than never married females (99%) and older females (96%) (p .000).

Attitudes to HIV positive teachers, food sellers and medical personnel were also probed. Ninety per cent of respondents said a female HIV positive teacher should be allowed to continue working at school. However, there was a significant difference by site with 15.2 percent of respondents in Frankfort as compared with 4.8 percent in Mangaung saying a female teacher should not be allowed to continue teaching in school. There was no differences in opinion by gender or female index type. Similarly 89.6 percent of respondents felt that a male teacher should be allowed to continue teaching at school. Again there was a difference by site with 15.2 percent of Frankfort respondents saying a male teacher should not be allowed to continue teaching in school as compared with 5.6 percent in Mangaung. There were no differences by gender and female index type. Almost 70 percent of respondents said they would purchase food from a food seller who has HIV/AIDS. There were no differences by site, gender or female index type. Similarly, 70 percent of respondents said they would still want to be treated by a nurse or doctor who was HIV positive. Again there were no differences by site, gender or female index type.

The questionnaire also probed confidentiality and disclosure issues, as well as how PLWHA's are treated in the community. With disclosure of HIV status to others in their communities, 74 percent of respondents felt it was advisable to tell others about their status, 25.2 percent felt it was not and .8 percent was unsure. There was a significant difference by site with 78.8 percent of respondents saying it is advisable in the urban Mangaung site and 69.2 percent in the rural Frankfort site (p = .014). There was also a significant difference between males and females, with 92 percent of males and 69.5 percent of females saying it was advisable to disclose one's status to others in the community (p = .000). Among female index types there were no significant differences, however, six percent of females (40+ years) said it is advisable to disclose as compared to 92 percent of males and 90.7 percent of female index types (p = .000). The majority of females over 40 years (94%) said is not advisable to disclose.

Respondents give the following reasons for saying it is advisable or not advisable to disclose to other community members. Of those who said it was advisable, 64.1 percent gave the reason that people need to be open and break the silence about AIDS and 20.5 percent said they would be able to qualify for special grants and other services if they disclose. Between sites there was no significant differences. Males (46.7%) were more likely to cite special grants as a reason for disclosure than females (11.9%), while females (69.7%) were more likely to say being open and breaking the silence than males (47.8%). Although saying it is advisable to disclose, 11.6 percent of females felt they would get no help from others if they disclosed. Comparing female index types, 51.1 percent of teenagers cited openness and breaking the silence as compared to ever-married (83%) and never married (77.4%) females. Among teenagers, 28.9 percent felt they would get no help if they

disclosed despite being in favour of disclosure as compared to 4.5 percent of ever-married and 2.2 percent of never married females.

Of those who said it was not advisable to disclose, the three most common reasons were stigmatization and rejection (64.3%), shame (14.3%) and no help if they disclosed (11%). There was no difference across sites. Females revealed similar trends, but cannot be compared to males as there were only eight males who said it is not advisable to disclose. Similarly there are insufficient numbers to compare across female index types, but the majority who said it was not advisable to disclose gave the same reasons as above. Older females (40+ years), 94 percent who said it was not advisable to disclose also gave the same reasons with 66.3 percent citing stigmatization and rejection, 19.6 percent saying shame and 9.8 percent saying they would receive no help from others.

The most common descriptions of respondents on how community members treat those who disclose that they have HIV/AIDS are as follows: 36.5 percent of respondents said those who disclose are not accepted, but ridiculed and gossiped about, 35.9 percent said they are treated reasonably well by the community, 11 percent said they are treated like everyone else and 8.6 percent said the community would be shocked at first but would accept them. Comparing negative responses and positive responses, 56 percent of respondents gave positive responses from communities as opposed to 44 percent of respondents who gave negative community responses. By site, 60.6 percent of urban Mangaung respondents described positive responses and 39.4 percent negative ones as compared to 51.4 percent or rural Frankfort respondents who described positive community reactions to disclosure and 48.6 percent who gave negative ones ($p = .038$). There was a significant difference between males and females, with 50.5 percent of females describing negative community responses compared with 18 percent of males ($p = .000$). When comparing female index type, responses are the same with 45 percent overall suggesting negative community responses and 55 percent describing positive ones. Older females were significantly more likely to describe negative reactions (67%) than positive reactions (33%) when compared to other females ($p = .000$).

As to whether women who disclose are treated better, the same or worse than men, overall 52 percent said they were treated the same, 38.2 percent said they were treated worse and 9.6 percent said they were treated better than men. There was no difference on this issue by site. Again there was a significant difference between male and females with 46.9 percent of females and 73 percent of males saying women are treated the same, 41.8 percent of females and 24 percent of males saying they were treated worse, and 11.3 percent of females and three percent of males saying they were treated better by their community ($p = .000$). Comparing female index type and females 40 years and over, Table 18 shows that 21 percent of teenagers said that females are treated better than males as compared with 10 percent of ever-married and 12 percent of never married females. Nine percent of teenagers said women are treated worse as compared with 36 percent of never married and

24 percent of ever-married females, while 98 percent of older females (40+ years) say females are treated worse.

Table 18: Female opinions of community treatment of women who disclose HIV status, Free State 2003 (N=400)

	Teenagers (15-19 yrs) %	Never Married Females (25-39 yrs) %	Ever-Married Females (25-39 yrs)%	Older Females (40+ yrs) %
Better	21	12	10	2
Worse	9	36	24	98
Same	70	52	66	0

Most respondents (54.2%) felt that families of people with HIV/AIDS are treated worse than families without HIV/AIDS infected members, 33.6 percent said they are treated the same and 12.2 percent said they are treated better. There was a strong association with differences in opinion by site with 63.2 percent of respondents in rural Frankfort thinking that families are treated worse as compared with 45.2 percent in urban Mangaung. While a similar number of males and females said families are treated the same, 64 percent of males and 51.7 percent of females said families are treated worse and four percent of males and 14.2 percent of females say families with HIV positive members are treated better ($p = .010$). Table 19 shows the differences in opinion across female types. More teenagers thought families are treated the same, more never married and older females thought families are treated worse than other families.

Table 19: Female opinions of community treatment of families whose members disclose HIV status, Free State 2003 (N=400)

	Teenagers (15-19 yrs) %	Never Married Females (25-39 yrs)%	Ever-Married Females (25-39 yrs) %	Older Females (40+ yrs) %
Better	11	9	18	19
Worse	29	66	40	72
Same	60	25	42	9

Most respondents (71.4%) said they would not want to keep the fact that a member of their family was infected with AIDS a secret, 26.2 percent said they would and 2.4 percent were unsure. There was no difference by site or gender. Female index type and females (40+ years) are associated with differences in opinion on this issue. Teenagers (83%) and females (40+ years) (78%) said they would not want to keep a member of their family's HIV

positive status a secret as compared with 68 percent of ever-married females and 63 percent of never married females.

Table 20 gives the people to whom respondents felt most comfortable disclosing their HIV positive status by female index type, females (40+ years) and males.

Table 20: Persons to whom respondents feel most comfortable disclosing their HIV positive status, Free State 2003 (N=500)

	Teenagers (15-19 yrs) %	Never Married Females (25-39 yrs) %	Ever-Married Females (25-39 yrs) %	Older Females (40+ yrs) %	Males (25+ yrs)%
Spouse			51	27	44
No one	3		4	1	3
Mother	51	67	17	7	18
Close relative such as sibling	14	10	12	15	5
Close friend	4	8	2	4	2
Parents	18	9	4	2	7
Nurse	1		1	2	
Mother in law					
Pastor/priest			1	1	
Other		1	1	2	
Grown up children		2	2	32	2
Partner	8	3	1		17
Neighbour			4	7	2

Participants in focus group interviews emphasised the stigma attached to being infected by HIV/AIDS particularly when a child is infected as well as levels of denial.

People they gossip even when you pass them, they gossip things . . . People tell themselves that if a baby of that house is HIV so is everyone else in the house . . . They are treated worse cause people don't accept that this person has got AIDS, so they treat them badly (Focus Group – Teenagers, Mangaung).

It is because we are afraid, people will say eish what are people going to say? (Focus Group – Ever-married Females, Mangaung).

Most people do not talk because of stigma, others end up infecting their mothers because they don't talk to their parents at home, at the end mothers are left with grand children and within a short space of time they die too (Focus Group – Health Care Workers, Frankfort).

Some they don't treat them alright but some they treat them okay, you find that people who have AIDS their families leave them to smell bad when they have bad sores. It is when they mess themselves that they take them to the hospital, when they are asked questions at the hospital they act as if they didn't see anything (Focus Group – Males, Mangaung).

I think it is still the fact that people, they still go to traditional healers . . . They won't tell you . . . They'll tell you that you've got diabetes or you have kidney problems, they won't tell you straight that you have HIV . . . they fear that stigma . . . I think stigma is very high (Focus Group – Health Care Workers, Mangaung).

Some are afraid because of stigma and some are gossiped about (Focus Group – Teenagers, Mangaung).

Summary

The majority of respondents said that they would care for an infected individual in their homes.

Ninety percent of respondents said both male and female teachers who are infected should be allowed to continue teaching. However, rural respondents were significantly less likely to agree with this than urban respondents. Over two thirds of respondents said they would buy food from an infected person and be treated by a nurse or doctor who was infected.

Almost three quarters of respondents felt it was advisable to disclose if one is HIV positive. Urban respondents and males were significantly more likely to support disclosure than rural respondents and females particularly older females (40+ years). Breaking the silence around HIV/AIDS and getting grants were the main reasons respondents gave for disclosure. Stigmatization, rejection and shame were the main reasons for non-disclosure. Never married females and teenagers were most likely to disclose to their mothers, while ever-married females and males are most likely to disclose to their partners.

Just over a third of respondents said infected individuals are rejected and ridiculed, while almost half of respondents said they are treated reasonably well or like everyone else. Urban respondents and males are significantly more likely than rural respondents, females and particular older females (40+ years) to say that a person who discloses will receive a positive response. If a woman discloses, half of respondents felt she would be treated the same as a man who discloses, but male respondents were significantly more likely to think this than females where just over 40 percent said she will be treated worse than a man. Just over half of respondents thought a family with a family member who is HIV positive will be treated worse than other families. Rural respondents and females are again significantly more likely to think they are treated worse than other families. Despite these responses, almost three quarters of respondents said they would not want to keep the fact that a family member was HIV positive a secret. However, focus group and interview participants overwhelming emphasized the stigma associated with being HIV positive.

3.2 KEY INFORMANT WORKSHOP FINDINGS

3.2.1. The Mangaung Narrative Workshop

The Mangaung narrative workshop was held at the clinic site of the Mangaung University Community Partnership Programme (MUCPP) and attended by twelve participants: one doctor, four nurses and three counsellors involved in the PMTCT programme, a mother who had been through the PMTCT programme and three support workers from community based HIV/AIDS organizations in the surrounding area. Two participants were male and the rest female.

The workshop began with a review of how the PMTCT programme is carried out at MUCPP and infant feeding practices in local communities. At MUCPP, when a pregnant woman comes in for her first visit she gets a group introduction to the antenatal programme including information about HIV and the counseling service. She then has an option of seeing one of the lay councillors in an individual session. During the session the woman gets further information about HIV and pre-test counseling. Should the woman feel that she wants to be tested, she is given three choices, she can either test now and get the results now, she can test now and get results later, or she can test later if she decides to go home and think about her choices. If she chooses to test, she will be given her results in a post-test counseling session. If she tests positive, she will be advised on nevaripine for herself during labour and for her child within 72 hours after birth as well as feeding regimens: exclusive breast feeding or exclusive formula feeding. In the pilot sites and according to the PMTCT protocol, if a woman chooses to exclusively formula feeding, she will get free formula for six months. However, at MUCPP free formula is not offered. The mother ideally brings the infant for regular check-ups, vaccinations and at 18 months for an HIV test.

Workshop participants say that breastfeeding is the norm in local communities but solids are introduced very early sometimes in the first month. Consequently mixed feeding is a common practice. If a woman exclusively breastfeeds, families and communities perceive this to be against cultural practice. Community members often hold the belief that breast milk is insufficient for the child. If a woman exclusively formula feeds, communities also perceive this to be against culture and a sign that the mother does not care for the child or has the means to afford formula feeding. However, formula feeding because of certain circumstances is acceptable. If mothers have to return to work, infants may receive a combination of formula, breast milk and solids. Participants also suggested that due to media campaigns, communities are beginning to associate exclusive breastfeeding and exclusive formula feeding particularly certain brands with being HIV positive. Overall, if a mother does not mix feed, communities see her as doing something outside of normal practice. Moreover, it is common practice to give newborn infants sugar water and other traditional herbs. Failure to do so is also seen as incorrect culturally.

For the narrative, workshop participants first created a character for the narrative. They chose a never married woman index type around which to design the narrative. During the workshop they discussed whether her narrative would be different if she were married or a teenager. Table 21 gives a description of the character and the people in her lives.

Table 21: Main characters for the narrative workshop, Mangaung, Free State 2003

Case Study Type	Main Characters
Single/Never married female	**Lerato** 22 years old Lives at home with parents and 2 brothers and 1 sister 2nd year at teachers college Has a steady boyfriend of 2 years First pregnancy **George** Lerato's boyfriend of 2 years 25 years old 4th year engineering student at technicon **Lerato's mother** Runs a tuckshop Passed Std 8 (Grade 10) **Lerato's father** Miner in Welkom Comes home once a month Passed Std 4 **Mimi** Lerato's best friend 22 years old Has one child No boyfriend, left her when she got pregnant **Masentle** HIV counsellor at the clinic **Dinco** Nurse who does the HIV test and the nevaripine and infant feeding counselling

The story surrounds Lerato a 22-year-old single female with a steady boyfriend, George, of two years. She is in her second year of teacher training and lives at home with her parents and siblings (The narrative stories are shown in an organogram in Appendices A and B). She misses her period and doesn't feel well. She goes to the clinic at about eight weeks and has a pregnancy test that confirms she is pregnant. She then books for her first antenatal

visit at 16 to 20 weeks. She is afraid to tell her mother but eventually she does so. She tells George first. He is not happy and wants an abortion. If Lerato were a teenager, participants felt she would most likely tell a friend that she was pregnant being afraid to tell her mother at first.

Lerato does not want to have an abortion and goes for her first antenatal visit, where Masentle, the counselor, gives them basic information on HIV, the importance of testing during pregnancy and the availability of nevirapine. Lerato is then offered a one-on-one session with a counsellor to which she agrees. During the session, Lerato decides that she will first ask George before taking an HIV test. George does not want Lerato to take a test and does not want to take a test himself. He is not keen on the pregnancy and believes, since they are both healthy, it is unnecessary.

Lerato decides she will have an HIV test and does so at 24 weeks. Since the clinic does a rapid test and then a confirmation test if the rapid test is positive, Lerato can get her results immediately. The nurse does the test and the counsellor gives her the results. In role plays and discussions, participants said that Lerato might not want to get her results despite taking the test. For the sake of exploring the PMTCT process, the narrative dictates that Lerato tests positive. She is in a state of shock and gets post-test counselling. (During role plays of this event, issues of whether the test is correct and refusal to accept the result, who gave her HIV and the reactions of others arose.) She will then return at 32 weeks for counselling on nevirapine and infant feeding options.

Lerato wants someone to confide in. She tells her best friend Mimi that she is pregnant and also discloses her HIV status. (If Lerato was a teenager, participants felt she would tell a sister rather than a friend, boyfriend or mother. She would be worried her boyfriend would leave her.) She wants to tell her mother, but finds it difficult and doesn't want to hurt her. She does tell her George and he won't believe her. She accuses George of giving her the virus as she has not had another boyfriend. George in turn accuses her. (During the role plays, denial and blame were major aspects of the disclosure scene.) George says he will go for a test. He doesn't go but tells Lerato he has been to another clinic and has tested negative. Lerato is confused and goes back to Masentle at the clinic and gets very angry. Masentle persuades Lerato to bring George for a test. George comes, but says they should test elsewhere as everyone who comes to this clinic tests positive. George avoids being tested, and denies he is HIV positive. However, he continues to support Lerato although their relationship is now strained. Lerato is still confused about how she could have become infected but realizes George is lying. (In the case of the married Lerato, participants felt that she would disclose to her husband but he might abandon her.)

At 32 weeks, Lerato meets with Sister Dineo who explains how the nevirapine will work and when to take it and discusses infant feeding choices. She tells her the advantages and disadvantages of exclusive breastfeeding and exclusive formula feeding. She establishes who will look after Lerato immediately after the birth of her baby and whether they are

aware of her status. She goes over the importance of not administering traditional herbs if Lerato wants to breastfeed and whether she can economically sustain formula feeding if that is her choice. At MUCPP they encourage exclusive breastfeeding for four months because solids are introduced about this time and they are concerned that mixed feeding with breast milk may occur if they stipulate six months. Lerato chooses exclusive breastfeeding and Sister Dineo reminds her that since her mother does not know her status she may not understand this choice. Lerato says she will tell her mother her status, but does not do so at this stage. Only after the birth, when her mother pressurizes her to give the baby sugar water does Lerato disclose to her mother. (Participants felt that if Lerato were a teenager she might initially choose exclusive formula feeding but might change her choice to exclusive breastfeeding when she realizes she does not have the economic resources to do so.)

When in labour the nursing staff will see on her card that she needs nevirapine. However, if she forgets her card, participants thought she would disclose to the necessary clinic staff in order to get nevirapine. Lerato delivers and she and her baby get nevirapine at the appropriate times.

Her parents bring her home from the hospital. Lerato is breastfeeding her baby. Her mother wants to give the baby sugar water, but Lerato tells her the clinic said she shouldn't do this. Lerato's mother does not understand. Lerato is upset and discloses to her mother who then understands and is supportive. The father does not become involved in the issue of what the baby is fed or he may criticize exclusive breastfeeding but he is not told about Lerato's status. Role-playing this scene, reveals that Lerato's mother exerts considerable pressure on Lerato to give sugar water and other herbs to the baby. The pressure forces Lerato to disclose, but there is still pressure because of the mother's sincere belief that such practices are in the best interests of the child despite hearing from Lerato that doing this would be detrimental. Nevertheless, Lerato is able to persuade her mother not to introduce any other liquids at that moment, but cannot explain to her mother why such practices are dangerous. In some cases, participants said her mother might end up persuading Lerato that it will be more detrimental not to introduce other liquids. Lerato has to persuade her mother to accompany her to the clinic to find out why in order to gain her compliance. However, her mother's beliefs are still likely to lead to the introduction of other substances if for example the baby has colic later on. (A married Lerato might be able to keep to her choice if she has the strength, but participants felt she would be forced to obey her mother-in-law on infant feeding and that her husband would influence her to listen to his mother. Again because of strong cultural beliefs on what is best practice, participants felt that these beliefs would ultimately hold sway.)

Since the PMTCT programme at MUCPP was only six months old at the time of the workshop, participants were unsure as to whether Lerato would return at 18 months for the baby's HIV test. They were already having problems with follow up after birth and

they predicted that only 15 to 20 percent would come for follow up visits on the basis of the current uptake. Also of concern is that mothers do not know what to do after four months when the baby still needs milk and there is no formula available, but they have to stop breastfeeding if they introduce solids at that time.

Finally, when Lerato resumes sex, participants felt she would most likely use a condom.

Throughout the narrative workshop, stigma was a key influence on decision-making and participants explicitly confirmed that it was the key problem for PMTCT.

3.2.2. The Frankfort Narrative Workshop

The Frankfort narrative workshop was held at the public library in Frankfort and attended by eight participants: three nurses and three counselors involved in the PMTCT programme and one peer educator/support worker. Three participants were male and the rest female.

The workshop began with a review of how the PMTCT programme is carried out in Frankfort. In almost all aspects it was similar to the programme at MUCPP except that free formula milk was available from hospitals and clinics and testing of babies took place at one year and at 18 months, although the programme was not yet a year old.

For the narrative, workshop participants created three characters, one for each index type. Table 22 gives a description of the three characters and the people in their lives.

Table 22: Main characters for the narrative workshop, Mangaung, Free State 2003

Case Study Type	Main Characters
Teenager	**Karabo** 16 years old Grade 10 at school Lives with her grandmother in an informal settlement Her three sisters who are between 25 and 30 years, have children but are not married, also live with her Her mother works in Johannesburg. The father is not around **Thabo** Karabo's boyfriend 40 years old Married Businessman Lives in another town
Single/Never married female	**Maki** 32 years old Has three children (7, 12, and 17 years). This is her fourth pregnancy Lives in a new section of a Frankfort township Originally from the farms Does not live with her partner who is the father of the 7 year old and fourth child **Simon** Maki's partner 52 years old Driver working for a company in another town
Ever married female	**Thandi** 29 years old Has one child of 5 years This is her second pregnancy Lives in a small village about 50 km from Frankfort Lives with her husband **Vusi** Thandi's partner 36 years old Policeman

Participants chose to focus on Karabo, the teenage index type. She is taken to the clinic by her sister because she is complaining of nausea. The nursing sister confirms she is about 13 weeks pregnant. She is then booked for her first antenatal visit the following week. Karabo attends the group information session on HIV/AIDS and then a one-on-one session with the counsellor. As the counsellor stresses the effectiveness of nevirapine, Karabo decides to

test now and get the results now. Karabo tests positive and is given post-test counselling. At this point the counsellor asks to whom she might disclose and Karabo chooses her grandmother. However, participants say she doesn't disclose to anyone at this stage. During the role plays, Karabo is unable to disclose to Thabo, her boyfriend, but is able to disclose to her grandmother who admonishes her for her promiscuity but grudgingly and tacitly agrees to support her when the child arrives.

With Thandi, the married index type, participants felt she would agree to test because she believes HIV doesn't affect her as a married woman. Others felt she might also agree to test if she thought her husband was a philanderer. However, because she lives in a small community, participants also felt she might worry about confidentiality and this might discourage her from testing. In the case of Maki, participants felt she would not test because she is afraid. She knows she has had a number of partners with whom she has had unprotected sex.

Returning to Karabo, we find that she tells Thabo she is pregnant but not HIV positive. Thabo runs away because he already knows or suspects he has HIV. During her 32 week counselling session, Karabo decides to exclusively formula feed. After delivery, when Karabo returns home and mixes formula, her grandmother questions why she is not breastfeeding. In this even participants chose that Karabo had not disclosed to anyone. Karabo comes under intense pressure to breastfeed from her grandmother, mother and sisters and ends up mix feeding with breast and formula milk. Participants felt she would be unlikely to disclose because they would blame her behaviour for having got herself into this predicament. In the role-play, Karabo does not disclose, but makes excuses about having a problem with her breasts. The grandmother maintains that breastfeeding is best for the health and growth of the child, while Karabo's sisters say they suspect something. Participants had mentioned that the sisters would be aware of the link between formula feeding and HIV. However, Karabo's sisters also accuse her of wanting to go off and play and not taking responsibility for her baby by formula feeding. Karabo maintains that there is a problem with her breasts throughout the role-play and says that since she is a child herself, they also give free formula to children under such circumstances. Ultimately Karabo is able to maintain her choice.

With Thandi, the married female, participants felt she would not disclose to her husband because he might react violently or abandon her. They felt she would most likely disclose to her mother and perhaps go to her mothers and stay there after delivery and not have to disclose to the husband. Thandi chooses exclusive breastfeeding as participants felt formula feeding is stigmatized. However, they thought Thandi may opt for formula after four months and no longer give the child the breast. Thandi is likely to come under pressure from the mother-in-law to introduce solids earlier than four months so there may be an overlap and mixed feeding results. If Thandi can maintain breastfeeding, participants

said she will still follow the cultural norms, often with pressure from the husband, to give the baby traditional herbs in the first few months.

Although participants felt Maki would not take an HIV test, if she had taken one, they also felt she would not disclose to anyone, not even her partner. In terms of feeding choices, they felt that Maki would be able to maintain her chosen regime because her partner would not have the same control over her since they were not married.

3.2.3 Conclusions

From the case studies developed during these workshops, three major issues emerge. The first is that a combination of factors influence the choice whether to test for HIV or not. Women may decide to consult their partners first and depending on the partner and the woman's concern about how likely she is to have the disease as well as concern for the baby's health, she decides whether to have a test. In smaller rural communities, fears that confidentiality may be compromised, also influence decisions to test.

The second theme and possibly the key issue is disclosure of HIV status. Disclosure to partners is particularly difficult because of blame, fear of abuse and abandonment. Women, if they disclose are likely to disclose to someone other than their partner. Whether a woman discloses also impacts on other aspects of PMTCT particularly the infant's risk of contracting the disease through unsafe feeding practices. Disclosure may occur at the point where the infant's protection from HIV is about to be compromised by another caregiver within the household.

The third issue is carrying out safe feeding choices. Cultural beliefs about what is best practice may mean the introduction of other liquids, traditional herbs and solids. Considerable pressure is put on mothers who do not conform to expected practice particularly with married women where power dynamics between the husband, mother-in-law and mother come into play. Married women may compromise safe feeding practices especially if they feel they cannot disclose. Single women may be able to adhere to safe practices more easily while teenagers may be able to adhere if they can disclose. Even with disclosure, cultural beliefs about what is nutritionally best for the child may still result in the introduction of other foods.

3.3 Narrative story questionnaire results

The narrative story component of the questionnaire was based on the key informant workshops. Key episodes of the stories developed during the key informant workshop were then transformed into narrative vignette items in the questionnaire. Only female index types, that is, teenager (15-19 years), never married females (25-39 years) and ever-married females (25-39 years) answered the narrative vignette questions. The story itself was introduced to the questionnaire respondent and some background on the storyline provided before introducing the questions. Note that the case studies as they appear in the questionnaire format may differ slightly from the workshops depending on factors such as limitations in questionnaire length and results of the pilot. For purposes of the questionnaire, the case studies were amalgamated into a single storyline: a composite of the single never married female, teenager and the ever-married female.

Event 1: The Initial Counselling Experience

Event 1 was designed to explore the initial experiences of Lerato, the pregnant antenatal clinic attender, with PMTCT. At 28-30 weeks Lerato books at ANC for her first antenatal visit. At this point she is given the group introduction to PMTCT services by the clinic's AIDS counsellor (lay counsellor) and then has an individual counselling session to discuss her test decision. The majority of women (89.9%) in both study sites (94.6% in Mangaung and 86% in Frankfort) thought Lerato would have a positive interaction with the AIDS counsellor. In Frankfort, 19 percent of teenagers felt that the AIDS counsellor would not treat Lerato well as compared with three percent of never married females and seven percent of ever-married females ($p = .000$) Nearly all participants (90% overall) felt she would be made comfortable enough by the AIDS counselor to ask questions and get all the relevant information she needs about HIV and PMTCT. There were no differences by site, but again 21 percent of teenagers did not think Lerato would be made comfortable enough to ask for all the information she needs as compared with two percent of never married females and seven percent of ever-married females ($p = .000$).

When asked how the counselor's attitude toward Lerato will affect her decision to have an HIV test, most women (88%) felt that the counsellor's (supportive) attitude would give her the courage to seek an HIV test. Similar results occurred across sites. However, there were significant differences by index type. While nearly all ever-married (92%) and never married (95%) females felt the counsellor's attitude would encourage her to test, almost a quarter (23%) of teenagers felt that it would not.

We also asked how a counselling session would differ if a nurse, not a lay counsellor, undertook the initial counslling session with Lerato. Sixty-five per cent of all respondents felt that the nurse would treat Lerato well (66% ever-married, 72% never married, 56% teenagers).

Although 89.9 percent of females felt Lerato would have a positive experience with the lay counselor and 65% felt she would have a positive response with a nurse doing counselling, the majority (60.3%) felt that the most appropriate person to counsel was a nurse, followed by 22.7 percent who felt a lay counsellor was most appropriate, 8.7 percent who thought a doctor, 5.7 percent who felt someone living with AIDS would be most appropriate, and 2.3% percent chose a social worker. Responses differed significantly by site but not by index type. In Frankfort, 70.7 percent felt a nurse was the most appropriate counsellor as compared with 50 percent in Mangaung. In Mangaung, 15.3 percent chose a doctor and 10.7 percent someone living with AIDS, whereas only two percent and .seven percent chose these options in Frankfort. The number of respondents choosing a lay counsellor was 20.7 percent in Mangaung and 24.7 percent in Frankfort.

As to whether Lerato would prefer someone with her during the counselling session for support or not, 48.7 percent of respondents felt she would prefer someone to support her and 51.3 percent felt she would rather be alone. This issue differed significantly by site. In Mangaung 63 percent of respondents felt she would rather be alone while in Frankfort 91 percent of respondents felt she would rather be alone ($p = .001$). Teenagers (56%) felt Lerato would want a person to support her as opposed to 41 percent of never married females and 49 percent of ever-married females, but this difference was not significant.

Among those who stated Lerato would want a support person, respondents were asked to specify whom she would want to accompany her. Among ever-married females, 71.4 percent said her husband, followed by 14.2 percent choosing her mother. Among never married females, 59.5 percent chose the mother followed by 23.8 percent who said she would want the partner or boyfriend. Sixty per cent of teenagers said the mother followed by her boyfriend (32.7%).

Event 2: The HIV Testing Experience

If Lerato were going to have an HIV test, respondents were asked if she would prefer to be tested alone or along with her steady partner/spouse. Respondents were almost equally divided with 53.7 percent saying she would want to be tested alone and 45.3 percent saying she would want to be tested together with her partner. (1% were unsure). Sixty per cent of ever-married females thought Lerato would prefer to do so with her husband/partner as compared with 41 percent of never married females and 35 percent of teenagers.

In terms of testing options, overall 42 percent felt that Lerato would choose the test now - results now option, followed by 32.3 percent who thought she would test now and have the results later, 20.3 percent who stated she would test later and 4.3% percent who said she would decide not to have a test. While 49 percent of ever-married females and 46 percent of never married females chose the test now – results now option for Lerato, 31 percent of teenagers chose this option. Similar percentages of index types (32%) choose test

now – results later, but 29 percent of teenagers chose the test later option as compared to 11 percent of ever-married and 21 percent of never married females ($p = .016$). Across sites, 22 percent of teenagers in Mangaung chose the test now – results now option and 42 percent the test now – results later option while in Frankfort 40% chose the test now – results now and 22 percent test now – results later.

One issue probed with regard to HIV testing was the likelihood of attrition if choosing an option other than test now-results now. There was between a 41 and 44 percent chance across index type and site that Lerato would NOT come back to have a test if she did not test immediately. If Lerato chose test now – results later there was between a 23 and 31 percent chance that she would not return for her results depending on index type with more teenagers (76%) saying Lerato would return than ever-married (66%) and never married (43%) females. Participants were asked why Lerato would not return for her results or to have a test at all. In both cases, women stated that Lerato would likely be afraid to face the truth that she is infected with HIV/AIDS or does not want to be discouraged or stressed by getting a positive result; and thus would rather either not fetch her test result or not have a test at all.

If Lerato takes an HIV test and she is positive, most participants (44.3%) felt Lerato would tell her mother, followed by a boyfriend or partner (36.3%), her parents (8.3%) and then no one (6%). However among ever-married females, 77 percent said Lerato would tell her husband/partner, 10 percent her mother and five percent would tell no one. Among never married females 71 percent said Lerato would tell her mother, followed by her partner (11%) and then no one (8%). Seventy-one per cent of teenagers said Lerato would tell her mother or parents, 21 percent said her partner and five percent no one. If Lerato did not disclose her status to anyone, 85 percent of respondents felt this would be because she would be too afraid of victimization or stigmatization.

For those women who said she would disclose, they were asked to speculate on how the confidante would treat Lerato from that point onward. Most (80%) chose an option that indicated the confidante would accept and support her. However, 20 percent chose an option that suggested a negative reaction and possibly rejection. However, ever-married females were significantly more likely to chose a negative option (44.2%) than never married women (5.4%) and teenagers (8.4%). In terms of keeping Lerato's confidence, 55.3% of participants stated that her confidante would keep her secret safe. However, there were significant differences by index type with 60 percent of ever-married females saying the person to whom Lerato discloses will not keep her confidence as compared with 25.3 percent of never married females and 47.4 percent of teenagers. Particularly in the rural Frankfort site, married females did not think Lerato's confidence would be kept. Finally, women were asked to speculate on how Lerato's husband or main partner would react to the news. Respondents (67.4%) said he would not accept the situation, accuse her of infidelity and reject or abandon her while 24.1% said he would accept her. By index type,

49 percent of ever-married females said her husband would not accept the situation and reject her while 40 percent said he would accept the situation. Of never married women, 78 percent chose a rejection scenario for Lerato and 13 percent acceptance of some form, while among teenagers, 68 percent chose possibilities that meant rejection and 15 percent acceptance for Lerato.

Event 3: Initial Infant Feeding Decisions

In Event 3, participants were asked to assume that Lerato has received an HIV positive test result and must now consider how she will feed her baby once it is born. The counsellor discusses the options with her and the risks and benefits of each possible feeding type (i.e. exclusive breast feeding (EBF), exclusive formula feeding (EFF), or traditional mixed feeding). Taking her lifestyle and home situation factors into consideration, participants were then asked to speculate on Lerato's most likely feeding option choice. Overall, most women felt she would opt for EFF (75.7%), followed by EBF (14.7%) and then traditional mixed feeding (9.7%). When data were analyzed by site and index type, both differences were significant. In Frankfort, 81.3 percent of respondents said Lerato would choose EFF, 13.3 percent chose EBF and 5.3 percent chose mixed feeding as compared with 70 percent in Mangaung who chose EFF, 16 percent who chose EBF and 14 percent who chose mixed feeding. Among index types, 80 percent of ever-married and never married females thought Lerato would choose EFF while 67 percent of teenagers thought so. Teenagers (23%) were also more likely to think Lerato would choose mixed feeding while not one never married female chose the mixed feeding option.

When participants were asked why Lerato would choose this feeding method, 80 percent said she felt this was the safest means to ensure the child's health, eight percent said she chose a particular feeding method to avoid disclosing her status and 5.7 percent said her chosen method was the most natural way to feed a baby.

Event 4: Labor and Delivery

Overall, most women (58.7%) felt Lerato would not disclose to the staff while giving birth. Among ever-married females 42 percent said Lerato would not disclose, 76 percent of never married females said she would not disclose and 58 percent of teenagers felt the same way. Among those participants who felt she would not disclose, opinions as to why ranged from fears that the staff would not keep her confidence (43.7%), treat her badly if they knew she was HIV positive (35.3%) and general stigma fears (14.3%).

Event 5: Infant Feeding at Home

In Event 5, respondents were asked to imagine that Lerato has delivered normally and is now at home with her newborn infant. Respondents were reminded of her feeding options and ultimate choice made during counselling prior to delivery. Respondents were also

asked to assume no one at home knows about Lerato's HIV status. A prominent theme in this part of the storyline (and questionnaire) was household decision making power dynamics surrounding infant feeding.

Respondents were asked who in the household besides Lerato would be involved in deciding how the baby would be fed. Sixty-four per cent of respondents said the mother, 29 percent the mother-in-law and four percent the husband. Other options were grandmother (.7%), sister (0.7%) boyfriend (1%) and no one else besides Lerato (0.7%). In the urban Mangaung site more respondents (32%) said the mother-in-law would be involved than in the rural Frankfort site (26%). While in the rural site, more respondents (7.3%) said the husband would be involved in deciding how the baby would be fed (urban respondents .6%). There was a significant association between index type and who would be involved in infant feeding decisions. While the majority of never married females and teenagers (95%) said their mother would be involved, among ever-married females, 86 percent said their mother-in-law and 12 percent their husband would be involved ($p = .000$).

Participants were then asked what this individual would think is the best way to feed a small baby. In both sites, the majority (51.2%) felt that the person involved in infant feeding decisions would prefer exclusive breastfeeding, followed by mixed feeding (25.1%) and then exclusive formula feeding (23.7%). There was no significant difference by site. However, there was a significant association with infant feeding choice and female index type. Ever-married females (55%) said the decision maker would choose mixed feeding while only eight percent of never married females and 12 percent of teenagers felt this way. The majority of never married women (89%) said the decision maker would choose exclusive breastfeeding and only three percent said the person would choose exclusive formula feeding. Teenagers (51%) said the person would choose formula feeding and 36 percent said breastfeeding ($p = .000$).

If Lerato had chosen EBF for the baby, 58.2 percent of respondents said the decision maker would support her choice, 17.7 percent said they would fight over how to feed the baby, 13.7 percent said they would persuade her to mix feed, 7.4 percent said the person would be suspicious and question her choice and 1.7 percent said the decision maker would secretly feed the baby inspite of what Lerato wants. In other words 40.5 percent would take some form of opposition to EBF. Similar results occurred across sites, however there was a significant association between respondents' views and index type. Among never married females, 92 percent said that the decision maker would support Lerato's decision while among ever-married females and teenagers, 63 percent and 54 percent respectively said their would be some kind opposition to EBF ($p = .000$). If Lerato had chosen EBF, 42.3 percent of respondents felt that ultimately Lerato would be able to continue with this choice at home and 40.3 percent said she would end up mix feeding. The remaining respondents (17.3%) said Lerato would switch to EFF. Although not significantly different

more respondents (47.3%) in rural Frankfort thought Lerato would be able to realize her choice to EBF than in Mangaung (37.3%). Again, across index types, 75 percent of never married females as compared with 26 percent of ever-married females and teenagers felt Lerato would be able to EBF. The majority of ever-married females (58%) and teenagers (61%) said she would end up mixed feeding. More never married females (23%) said she would end up EFF than ever-married females (16%) and teenagers (13%).

If Lerato had chosen EFF for the baby, how would the decision-maker react? Overall, 27.4 percent of respondents said the other decision maker in the household would support an EFF choice. However, 77.6 percent said there would be some form of opposition with similar reasons given for opposing EBF. By site, there were similar results, but with index cases, 91 percent of never married females said there would be some form of opposition while 68 percent of ever-married women and 57 percent of teenagers felt this way ($p = .000$). If Lerato had chosen EFF, 48 percent of respondents thought she would be able to continue with this choice, 42.3 percent said she would end up mixed feeding and 9.7 percent said she would EBF. There was a significant association with ultimate practice and site with 56.7 percent of respondents in Frankfort saying Lerato would be able to EFF, 36,7 percent saying she would mix feed and 6,7 percent saying she would EBF as compared with 39.3 percent saying she would EFF in Mangaung, 48 percent saying she would mix feed and 12.7 percent saying she would ultimately EBF ($p = .008$). When analyzed by index type and stratified by site, there was also a significant association. In Frankfort, 96 percent of never married females said Lerato would EFF and 70 percent in Mangaung. Most ever-married females (60%) in both sites said she would mix feed and only 33 percent said she would stick with EFF. Among teenagers, 63 percent said she would end up mix feeding but with 78 percent of those in Mangaung saying this would be the case as compared to 48 percent in Frankfort. Eighteen percent of teenagers in Mangaung said Lerato would be able to stick with EFF and 38 percent in Frankfort ($p = .000$).

Another issue explored in this section of the story was potential stigma associated with collection of tinned formula from the clinic for EFF. Participants were asked if Lerato chose EFF, would she feel self-conscious having to get formula tins from the clinic. Overall, 46 percent said yes, 51.7 percent said no and 2.3 percent were unsure. When analyzed by site, 40 percent of Mangaung respondents and over half (52%) of Frankfort respondents replied in the affirmative ($p = .037$). When data were stratified by site and index type there was also a significant association. Overall, teenagers (61%) were more likely to say yes and ever-married female (69%) more likely to say no, while there were almost equal numbers of never married females who said yes and no across site. The opinions of teenagers on this matter differed be site with 48 percent saying Lerato would feel self conscious in Mangaung and 74 percent saying so in Frankfort. Those who thought she would be uncomfortable were asked why she would feel this way. Most women (82.3%) stated that people would start asking questions.

Respondents were asked if having to go to the clinic to fetch formula would ultimately be a deterrent or obstacle to Lerato's choosing formula feeding. Just over half (51.3%) said yes. There was no significant difference across sites. However, 30 percent of ever-married females, 54 percent of never married females and 70 percent of teenagers felt it would be an obstacle to Lerato ($p = .000$). Female respondents were asked what kind of support Lerato would need to be able to successfully enforce her feeding regimen. Nearly half (45.3%) stated she would need someone to collect the formula milk on her behalf and 27.3 percent said she would need continuous counseling.

The section ended with a question about disclosure. Female respondents were asked if during this initial period at home, Lerato would disclose her status to anyone. Overall 60 percent said she would not reveal her status during this period in the story. There was a significant difference by site with 47.3 percent in Mangaung saying she would not as compared with 76.7 percent in Frankfort ($p = .000$). Most teenagers (77%) said Lerato would not disclose, followed by 62 percent of never married and 41 percent of ever-married females ($p = .000$). More respondents across all index types in Frankfort said she would not disclose particularly teenagers where 94 percent said she would not do so.

Event 6: Resuming Sex

The final segments of the story dealt with events in the post-partum period. Event 6 addressed resumption of sexual intercourse. At some point during the first six months to a year after the baby is born Lerato meets a man (if a single adult or teenager case study) who becomes her boyfriend. Their relationship becomes close and the issue of starting a sexual relationship arises. The man does not know Lerato is infected with HIV/AIDS. If the person being interviewed was a married woman, a slightly different rendition of the story was given, in which Lerato's husband – without knowing her HIV status – wishes to resume sexual relations with her.

Among never married females and teenagers, overall 54 percent said Lerato would not reveal her HIV positive status to her new boyfriend when the issue of a sexual relationship arose. However, 23 percent said she would at the point they were ready to have sex, 11 percent said early in the relationship and eight percent after having started sex. There was a significant difference by site with 64.9 percent of respondents saying Lerato would not reveal her status in Mangaung and 46.4 percent in Frankfort ($p = .009$). Sixty percent of never married females said Lerato would not disclose as compared to 48 percent of teenagers. Almost twice the percentage of teenage respondents (62%) in Mangaung said Lerato would not disclose than in Frankfort (34%).

For ever-married females, 14 percent stated she would not tell her husband about her status before they resumed sex, 33 percent said Lerato would tell her husband early on and 28 percent said at the point they were ready to resume sex. Fifteen percent said Lerato would her tell her husband when her body showed signs of illness and three percent at

some point after having resumed sex. Comparison across sites showed that six percent of ever-married female respondents in Mangaung and 22 percent in Frankfort said Lerato would not reveal her status. In Mangaung, 38 percent said she would tell her husband early on as compared to 28 percent in Frankfort and 42 percent in Frankfort said she would disclose when they were resuming sex as compared to 14 percent in Mangaung. Twenty-eight percent of Mangaung respondents said she would disclose when she became ill while only two percent said she would do so in Frankfort.

Index participants were also asked to speculate on whether Lerato discusses condom use with her partner or husband. Most never married females felt she would discuss condom use (83.5%) and there was no difference by site or between teenagers and never married females between 25 and 39 years. Among ever-married women overall 85 percent felt she would discuss condoms with her husband before first sex. By site, 92 percent of Mangaung ever-married females and 78 percent of Frankfort women said they felt she would discuss use of condoms ($p = .05$).

Among never married females and teenagers, 76.5 percent thought that Lerato and her partner would use a condom. Among ever-married females overall 84 percent felt Lerato would use a condom when they resumed sex.

Finally, females were asked whether condom use would be sustained. The question was, if the couple starts using a condom early in the relationship, will they continue using it once they have started having sex regularly. The majority of never married females and teenagers (69.5%) felt they would continue using a condom. For ever-married women 75 percent felt they would maintain condom use once they started having sex again regularly.

Event 7: 12 Month HIV Test

Respondents were asked whether Lerato would bring her baby back to the clinic for the required HIV test at 12 months. Overall 69.7 percent said yes. By site there was no difference but among index cases there was a significant association with 86t percent of ever-married females, 51 percent of never married females and 72 percent of teenagers saying Lera o would do so. More never married females said no or were unsure whether Lerato would do or not than other index types ($p = .000$). More never married females in the Frankfort site (62%) said Lerato would return than in Mangaung (40%). The most common reasons for not returning were that she would be afraid to know the babies status (39%) as she knows her status and assumes the baby is the same (39.7%). Other reasons were she fears the communities reaction (9%) and her partner might find out her status (5%). Similar reasons were stated across site but in Manaung 48 percent said she would be afraid and 33 percent said she would assume her baby would also have HIV while in Frankfort 30 percent said she would be afraid and 46 percent said she would assume the same status for her baby.

If the baby tested positive, most respondents said Lerato would disclose to her mother (52%), followed by her husband or partner (36%), five percent said parents, four percent said no one and 2.7 percent said her mother-in-law. There was a significant association in responses by index type 93 percent of never married women saying she would tell her mother and no one saying she would tell her partner in contrast to ever-married females, where 91 percent said she would tell her partner and two percent her mother and five percent her mother-in-law. Among teenagers, 61 percent said Lerato would tell her mother, 13 percent a parent and 17 percent a partner (p = .000).

Event 8: Life Beyond Twelve Months

The final parts of the narrative assume that both Lerato and her baby are infected. The main source of care for Lerato and her baby would be her mother according to 67.3 percent of respondents, followed by her mother-in-law (20.3%) and then her husband (4.3%). Again ever-married females differed from other index types with 61 percent naming the mother-in-law, 16 percent the mother and 13 percent the husband as the primary source of care while for 96 percent of never married females and 90 percent of teenagers, the mother would be the primary care source. The major difference between sites is that in the Frankfort site 80 percent of ever-married respondents said the mother-in-law would care for Lerato and her baby in contrast to Mangaung where 42 percent said this would be the case and 30 percent the mother (p = .000).

Overall, 92.7 percent of respondents said being sick will make it more likely that Lerato will disclose her status. Most respondents (69.7%) say Lerato would disclose to her mother followed by 9.7 percent saying she would disclose to the mother-in-law, and 8.3 percent the husband. Again this choice differs by index type with ever-married females (29%) saying she would disclose to her mother-in-law, 25 percent to her husband and 20 percent to her mother. Among never married females and teenagers 96 percent and 93 percent respectively said Lerato would tell her mother (p = .000). Again ever-married females in Frankfort were more likely to choose disclosure to the mother-in-law (36%) than the mother (4%) and in Mangaung ever-married females were more likely to say she would disclose to the mother (36%) than the mother-in-law (22%).

Most respondents (92%) said that if Lerato's family knew her status they would accept it and care for her. When given a choice between care or abandon her, 96.7 percent said the family would care for her and 3.3 percent said the family would abandon her.

4

CONCLUSION

The aims of this study were to collect data on the socio-cultural and contextual factors affecting PMTCT in two disparate environments, rural and urban, within Free State province. The findings of this study are in many respects similar to the previous studies done in Limpopo and KwaZulu-Natal provinces.

Overall, in all sites across the three provinces HIV/AIDS awareness and knowledge on modes of transmission is high. However, knowledge of how HIV is transmitted vertically from mother to child and awareness of PMTCT services is much lower.

In all three sites, mixed feeding is the norm between birth and four months with breastfeeding seen as a valuable part of infant feeding practice. Formula feeding is generally less acceptable particularly when it is seen to replace breastfeeding. In most sites, at least some people administer herbs and other traditional medicines to babies although this practice is by no means universal. In contrast to the Limpopo and KwaZulu-Natal sites where older females encourage mixed feeding, in Free State province, we found that older females were significantly more likely to introduce solids later and support exclusive breastfeeding.

Infant decision making in all three provincial sites was clearly not an individual decision by the mother, but influenced by senior female family members. In all sites, married females and to some extent teenagers were the least empowered to make their own decisions about infant feeding with married females more likely to be unable to maintain infant feeding decisions that would protect the baby from getting vertical transmission.

Overall, case studies in all three sites show that disclosure and support are key aspects in preventing mother-to-child transmission. However, stigma is high and impacts on people's willingness to disclose which in turn can compromise the health and well-being of the child as well as the mother.

As recommended in the KwaZulu-Natal report, community focused education on PMTCT is vital. Clinic-based counselling needs to take place in the context of wider educational campaigns that also target key role-players such as males and older females. PMTCT programmes need to broaden their focus to include partners and other key family members if PMTCT is to be maximally effective.

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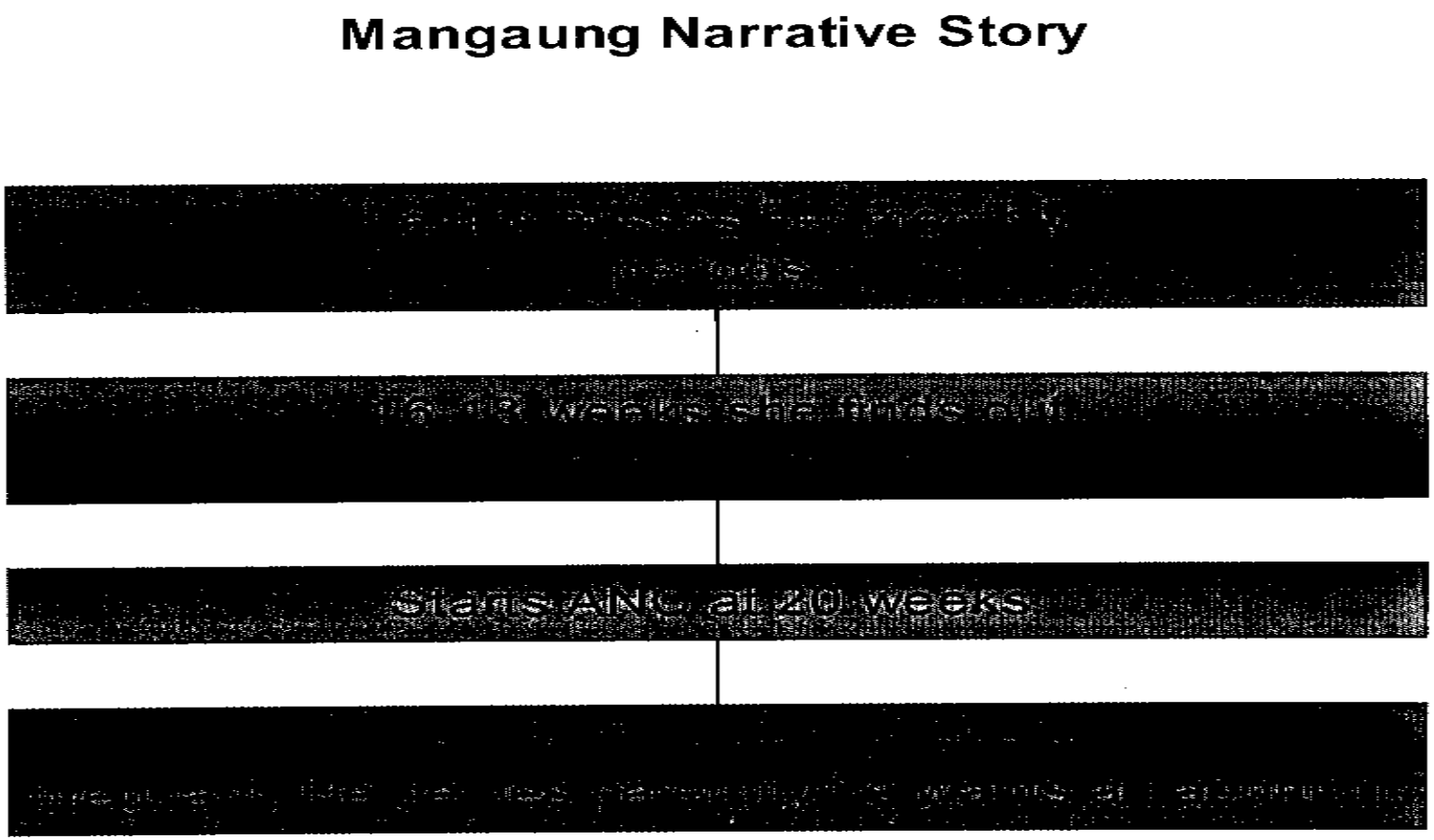
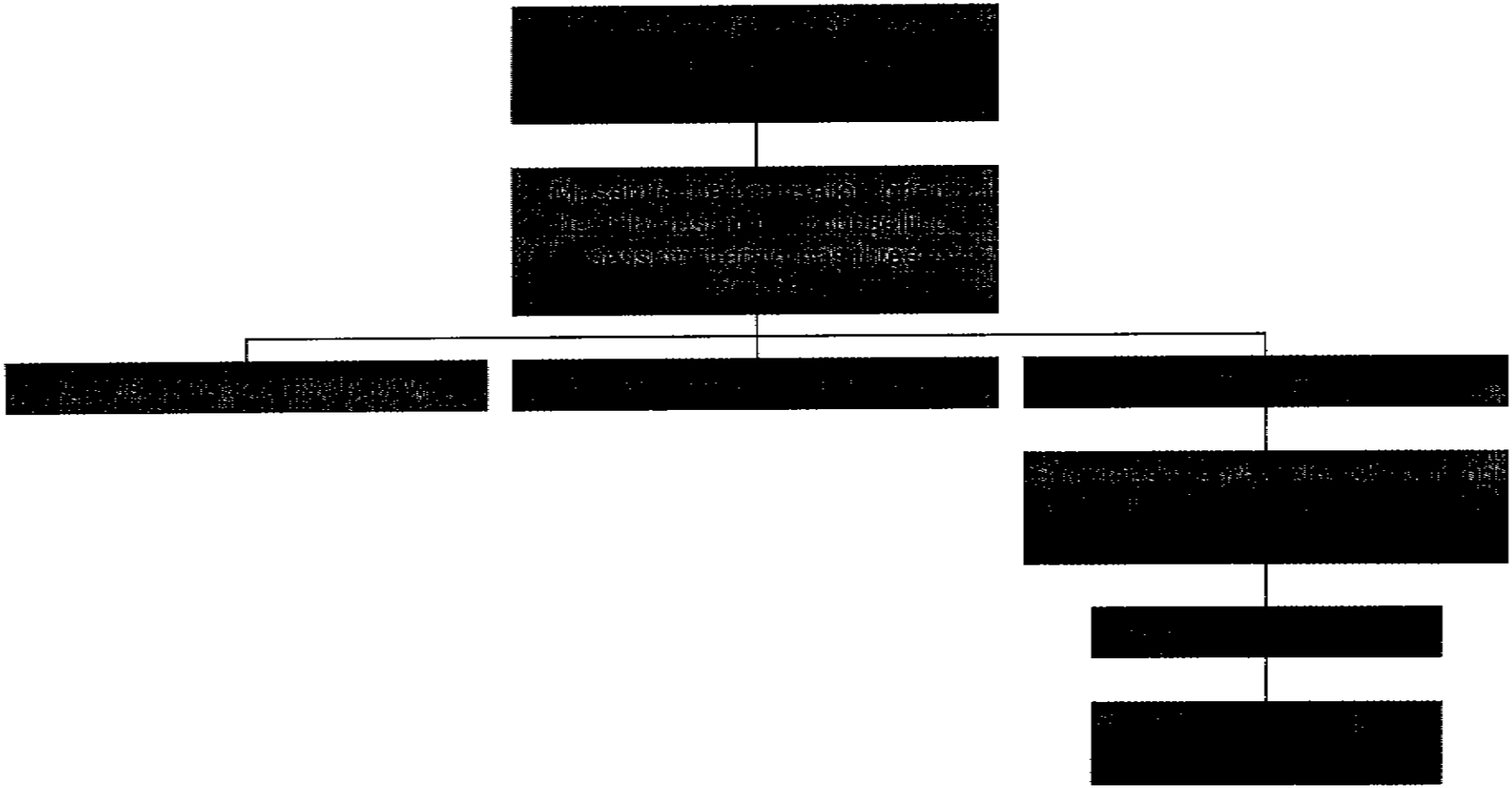
PPENDICES

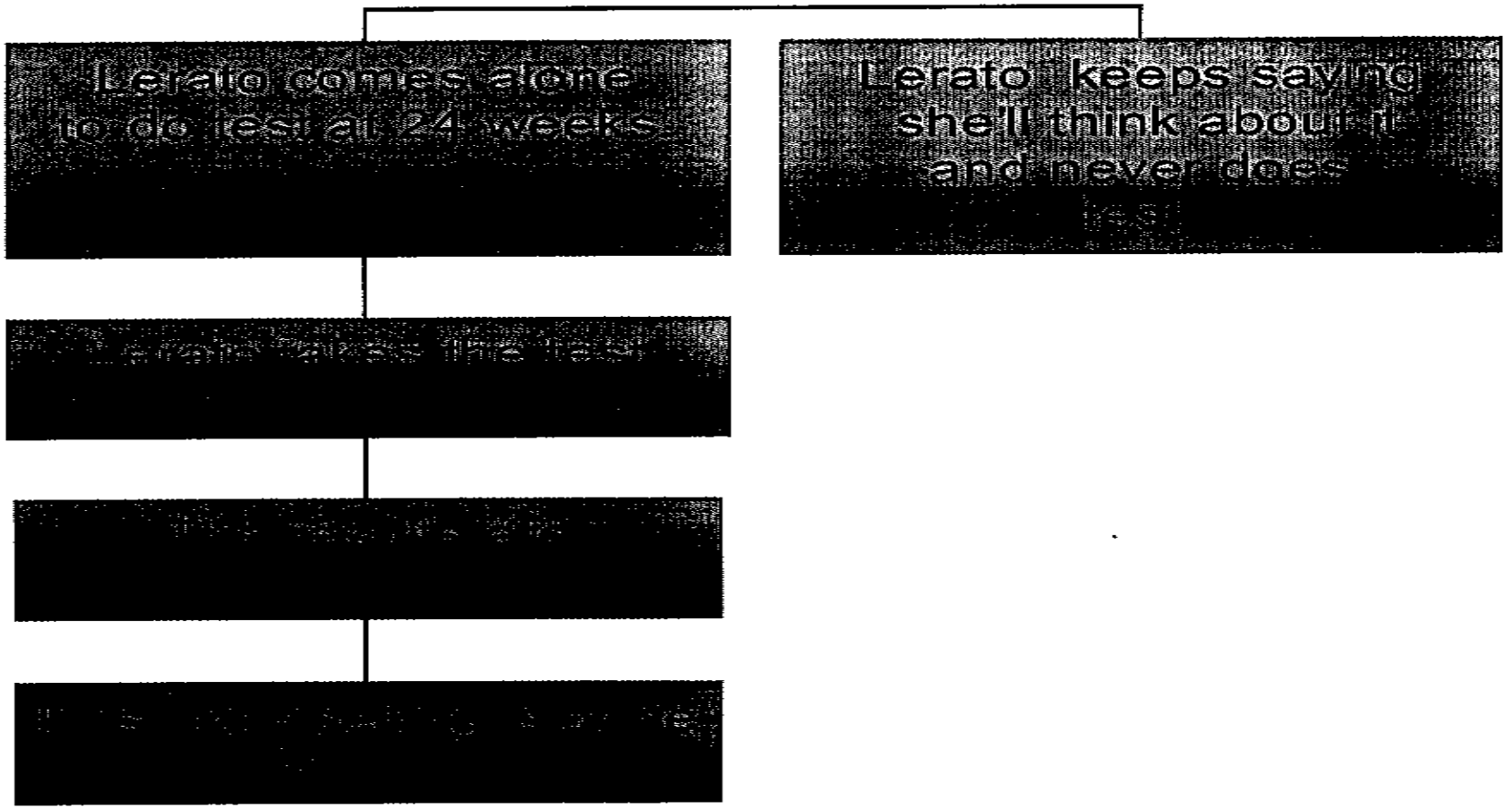
APPENDIX A: MANGAUNG NARRATIVE STORY



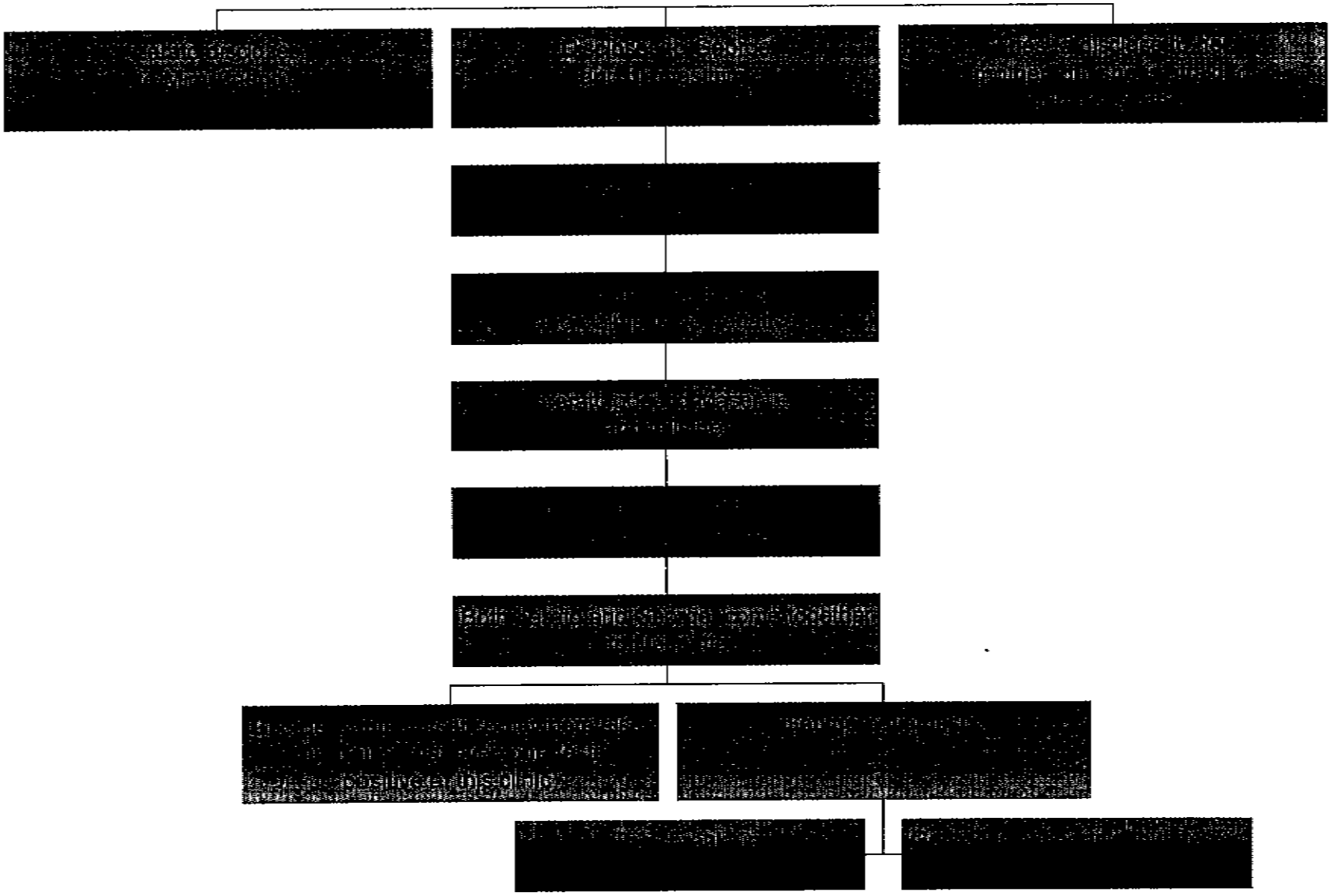
Counselling Experience



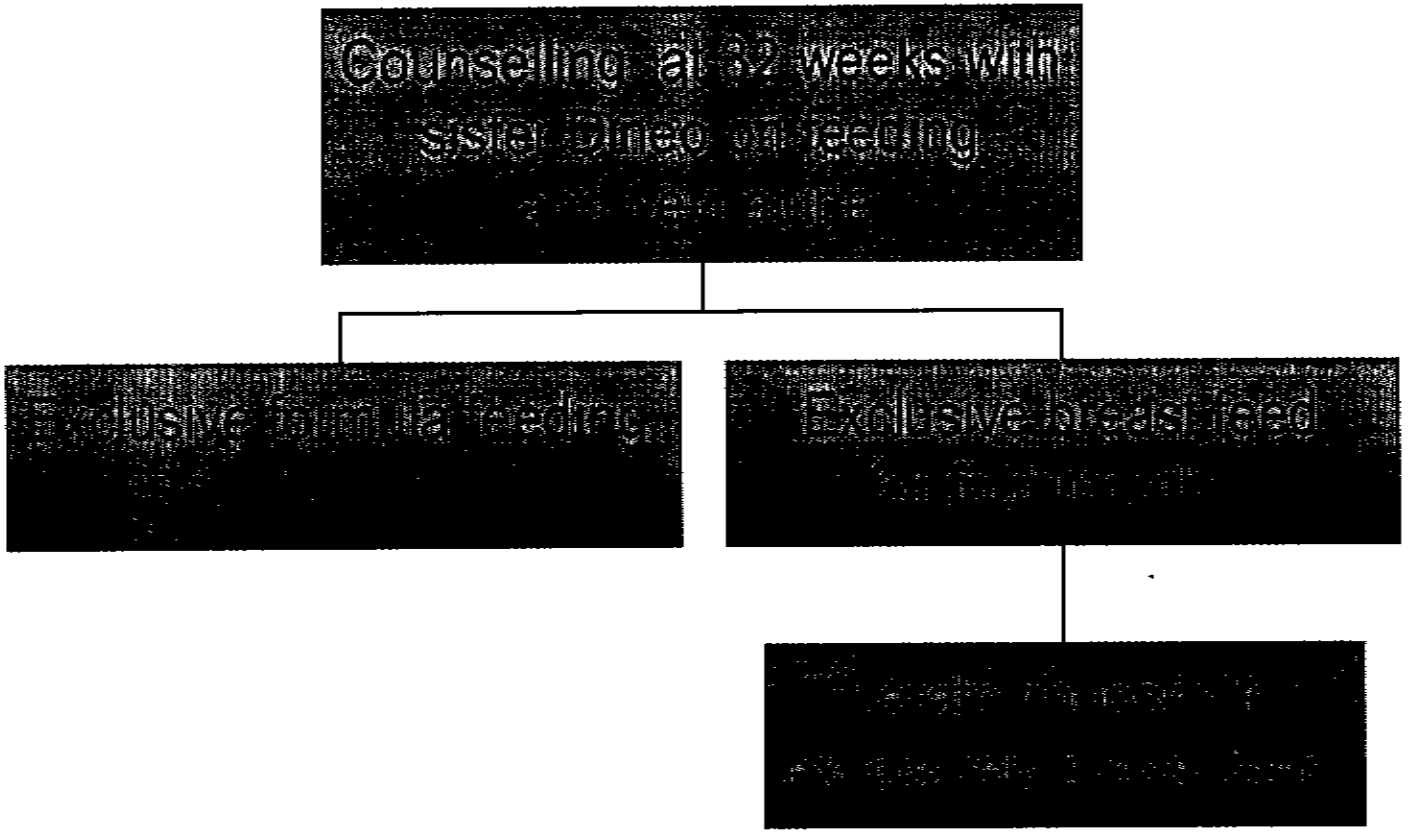
HIV Testing Experience



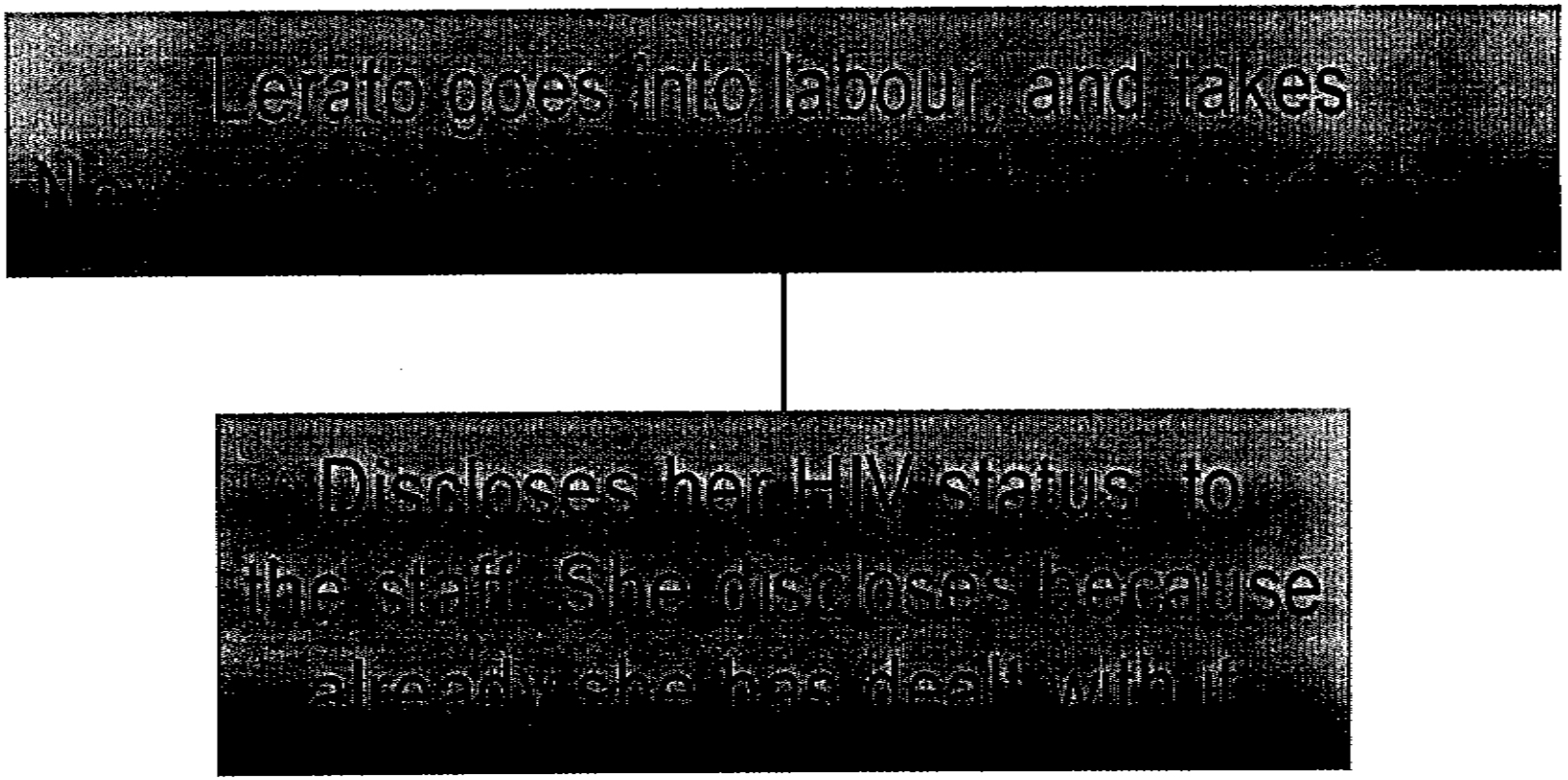
Disclosure



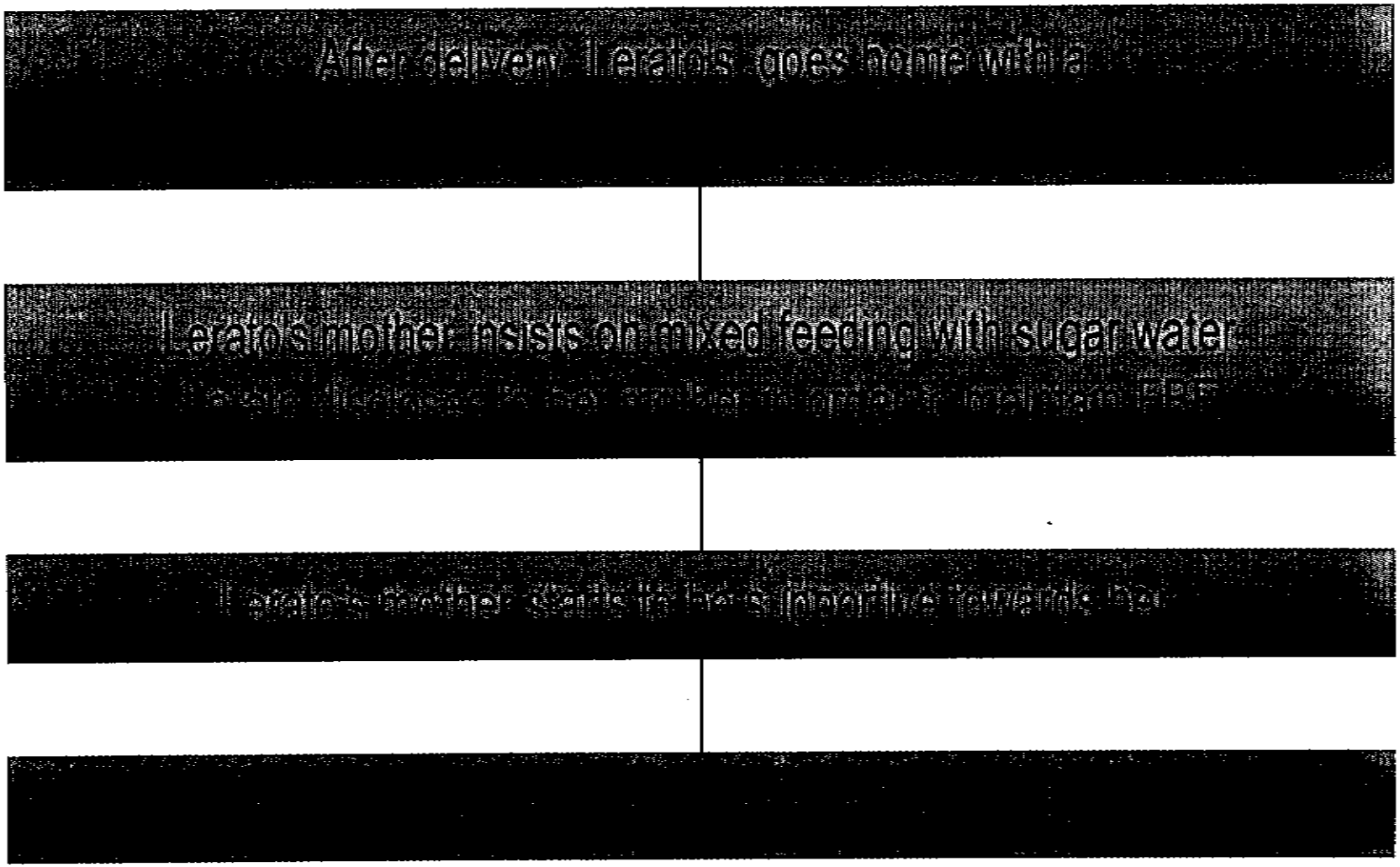
Infant Feeding Decisions at the Clinic (Antenatal)



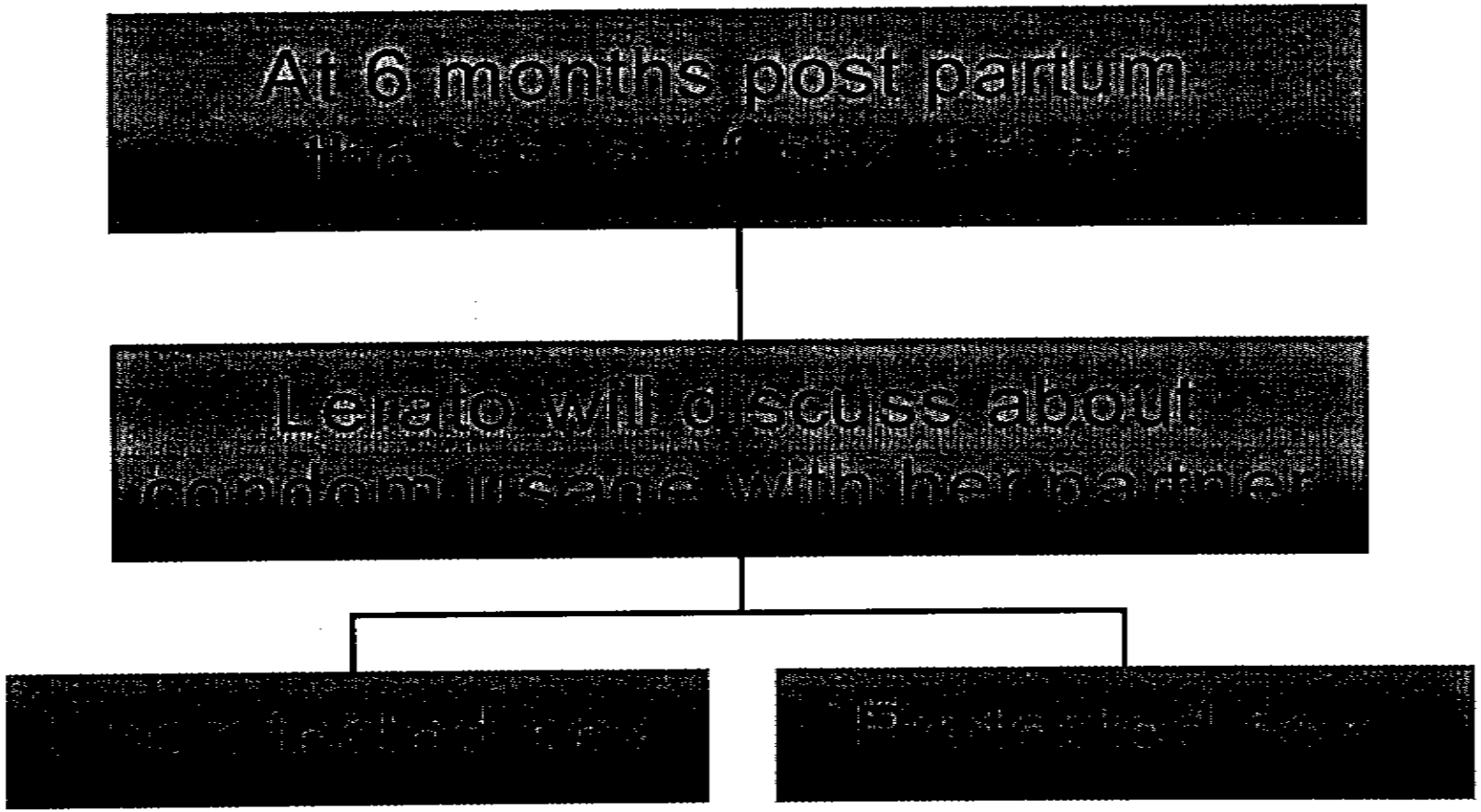
Labour and Delivery



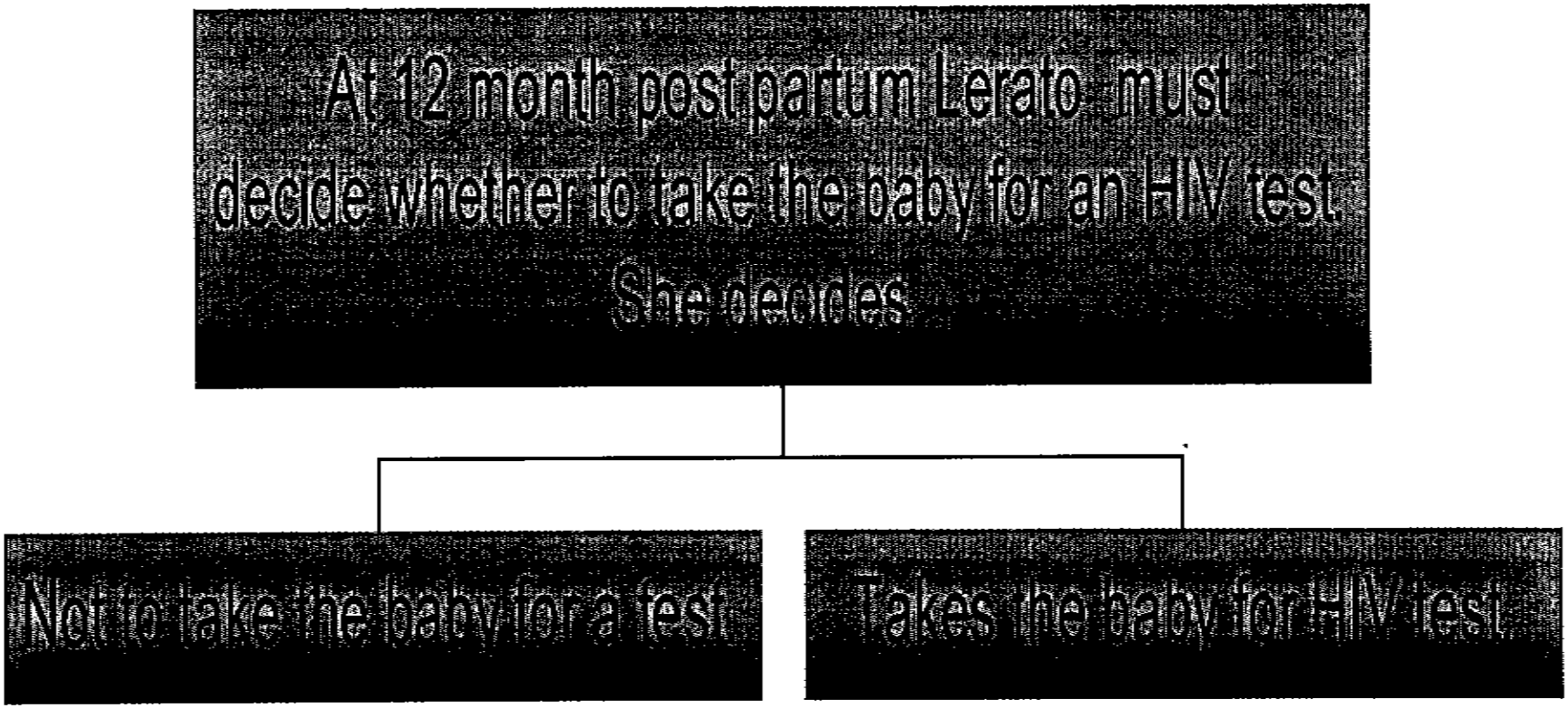
Infant Feeding After Delivery.



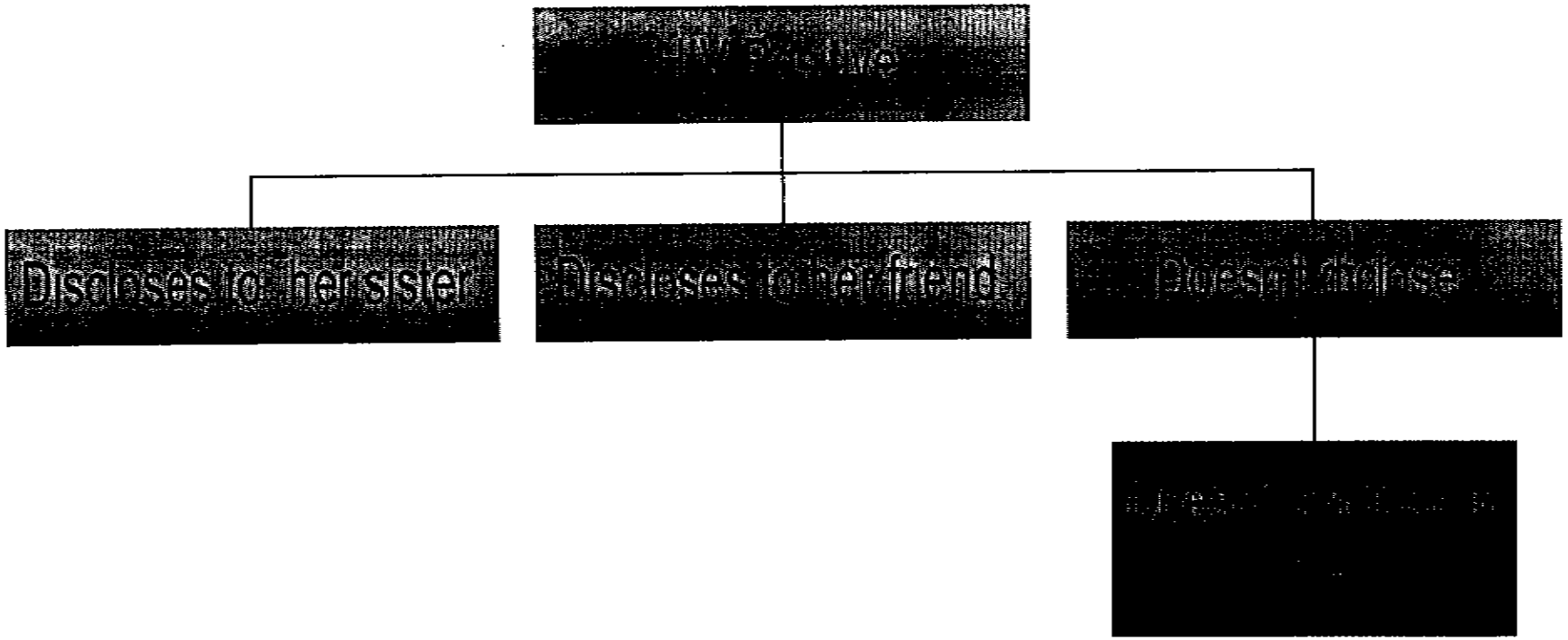
6 Months Post Partum...



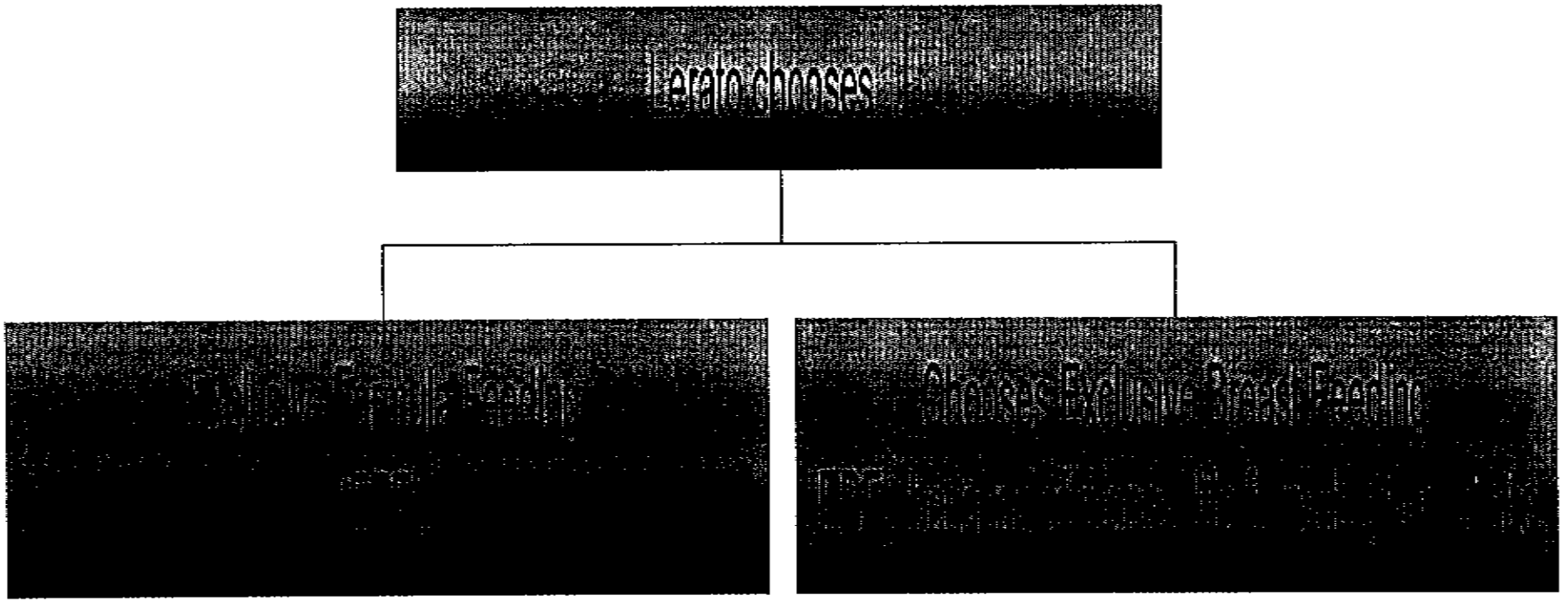
12 Month HIV Test



If Lerato is a teenager...
Disclosure

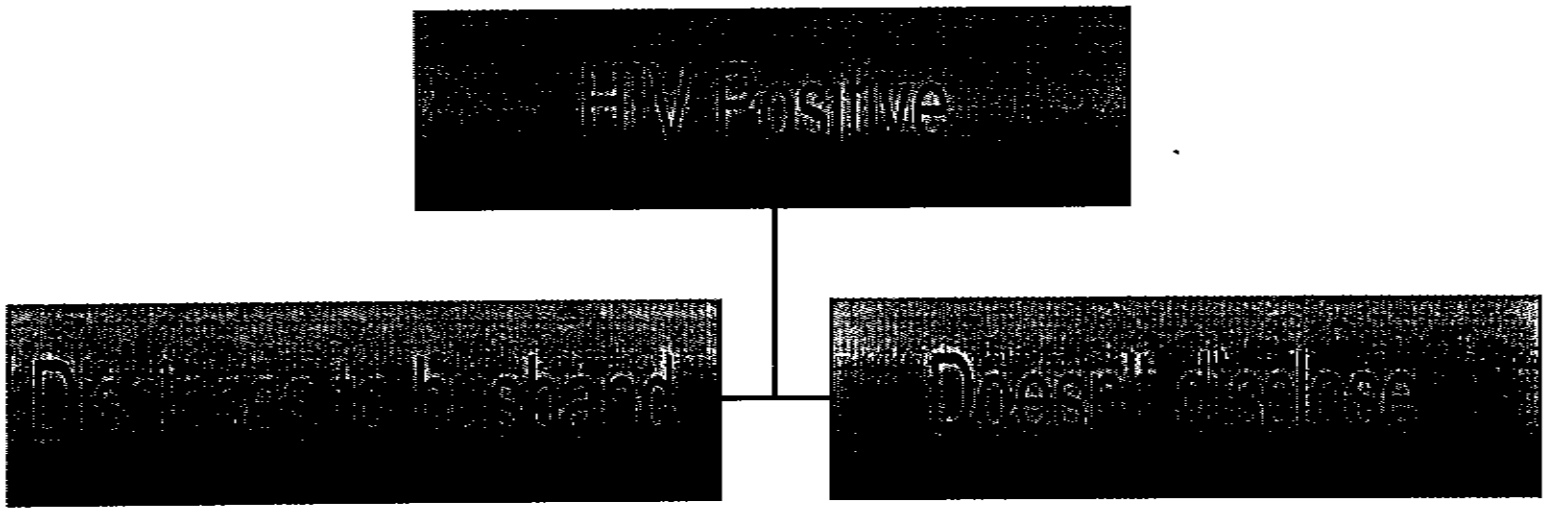


Feeding Options

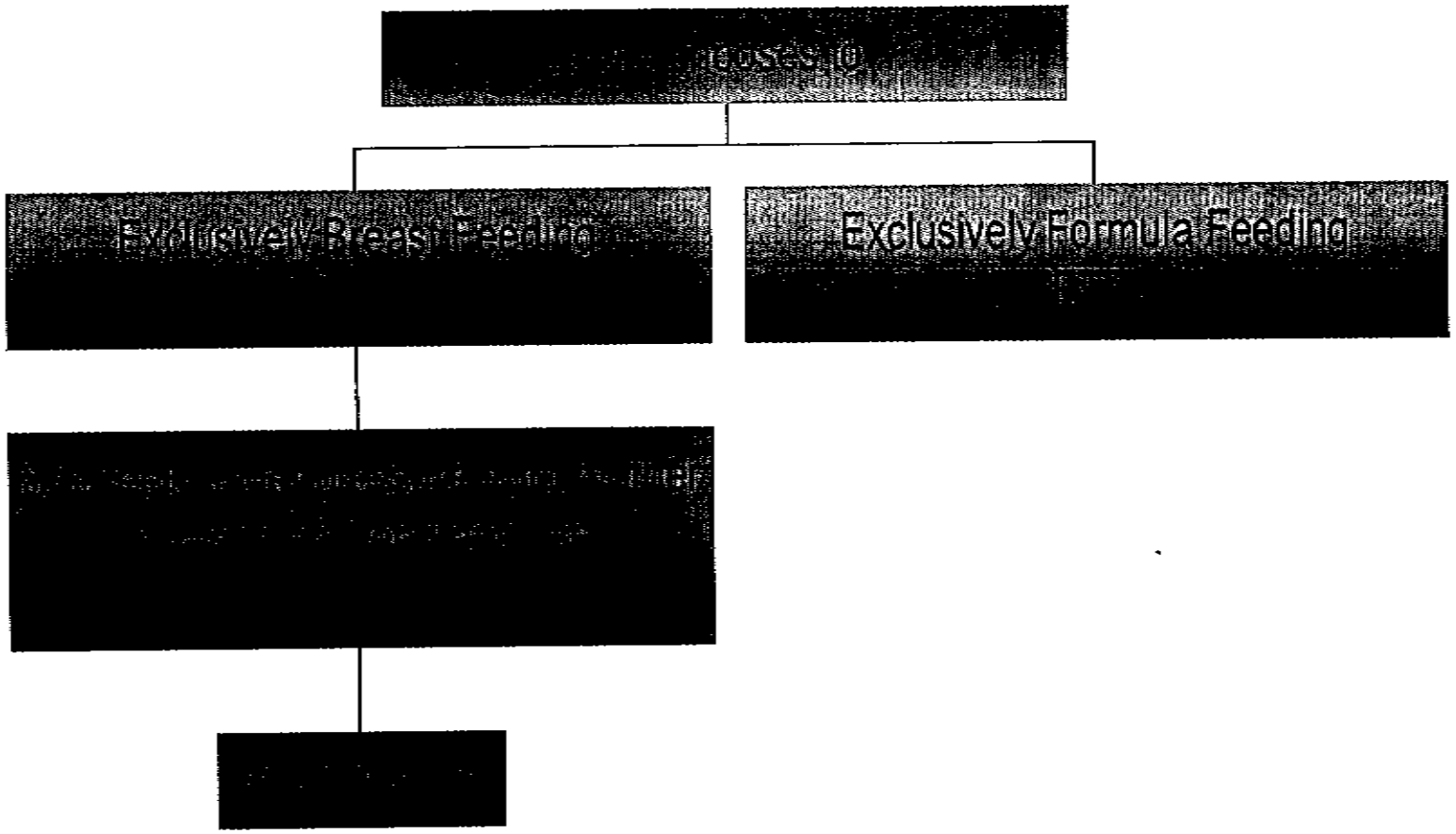


If Lerato is married to George...

Disclosure

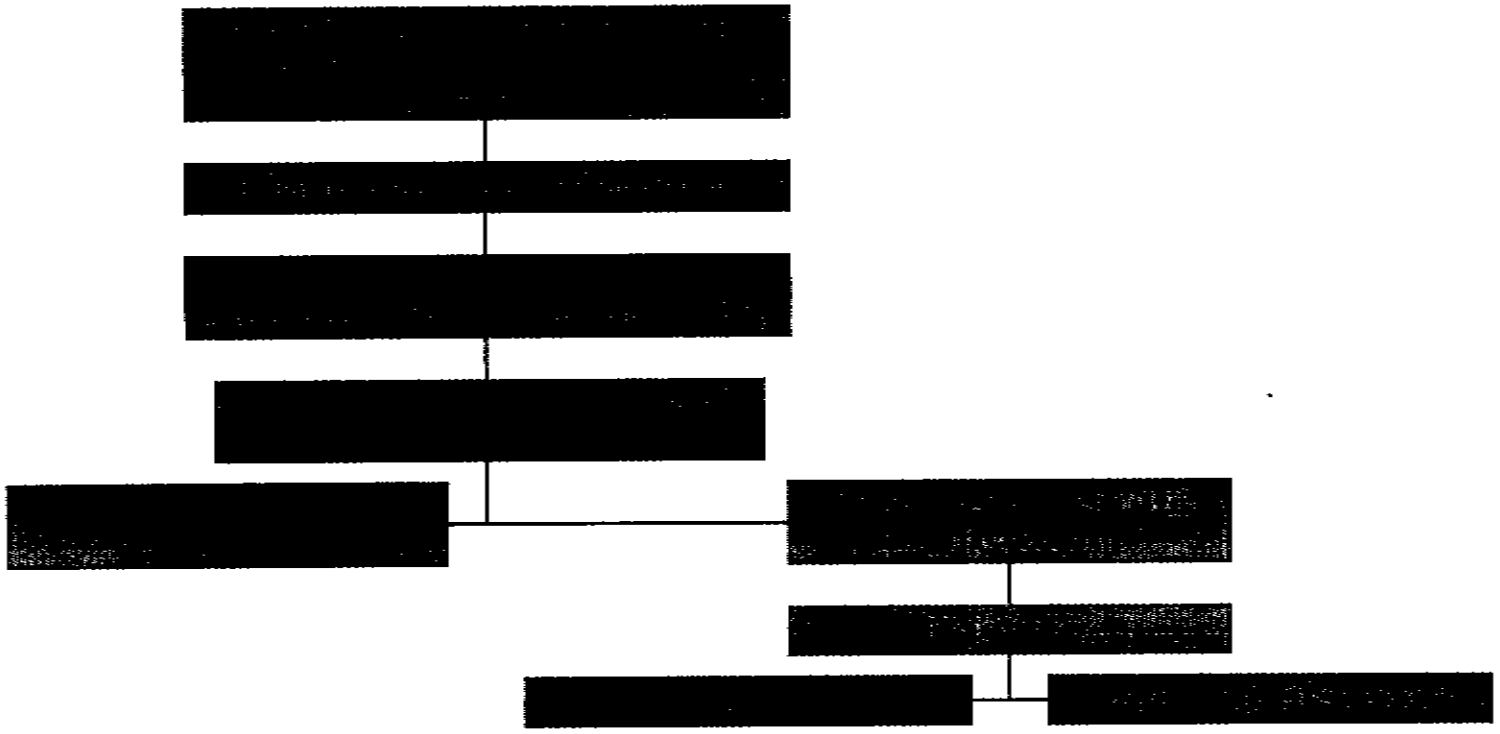


Feeding Options

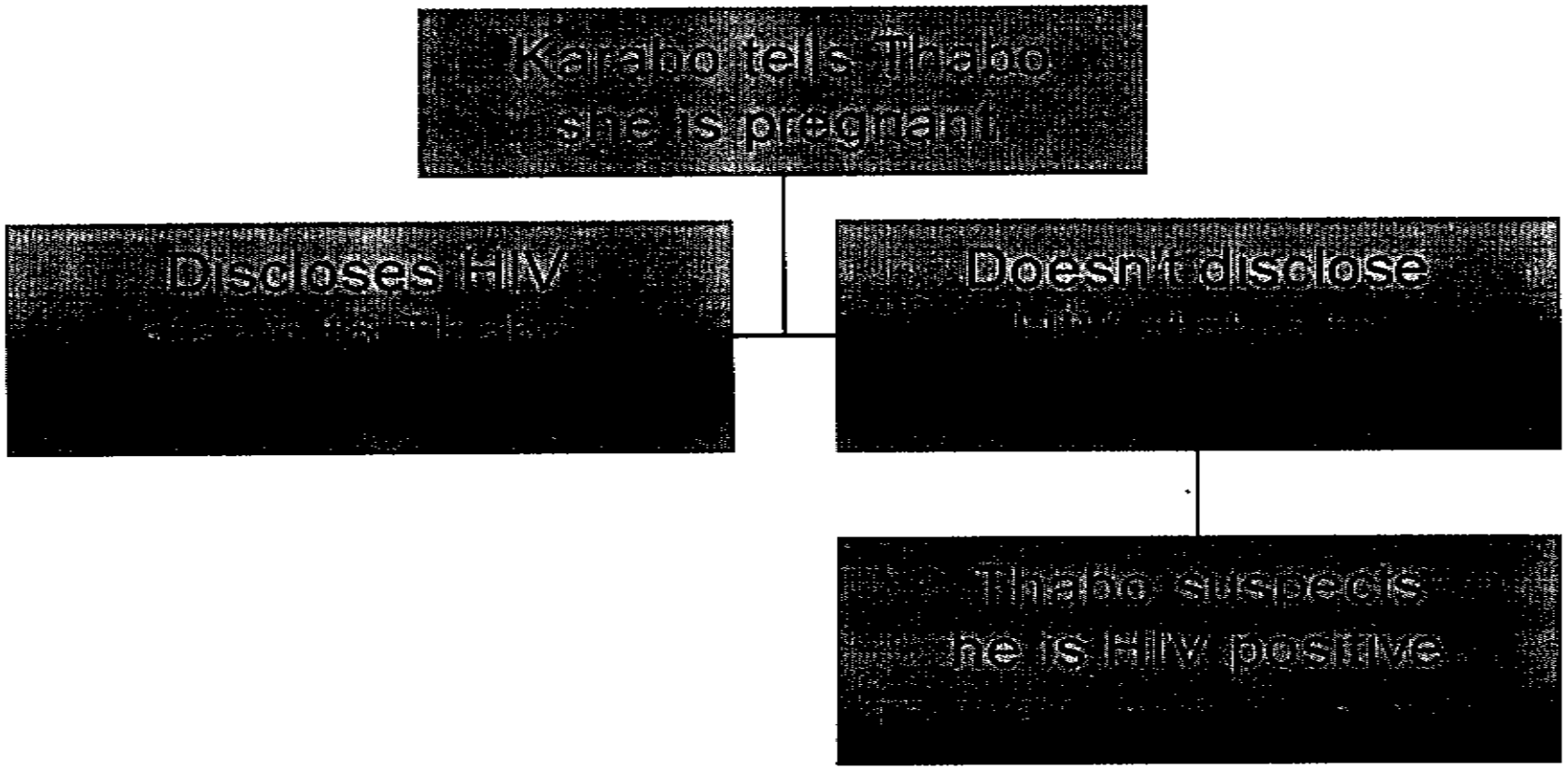


APPENDIX B: FRANKFORT NARRATIVE STORY

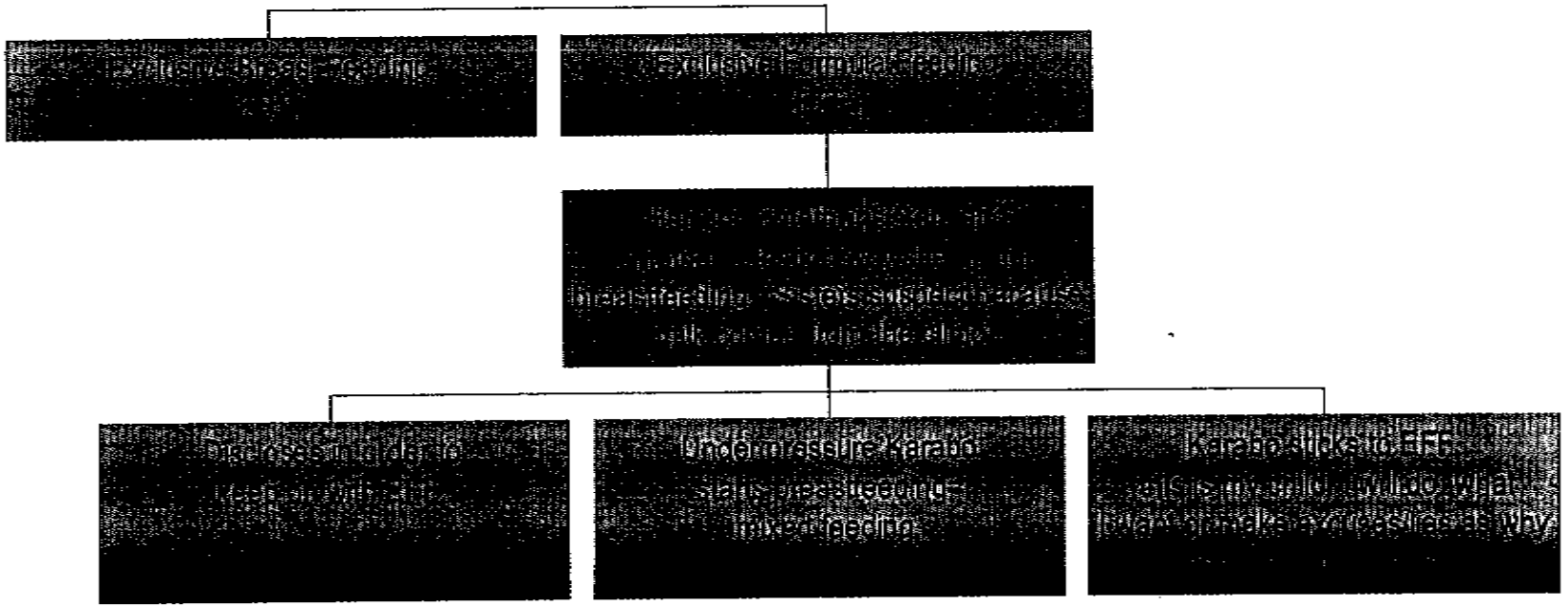
Counselling Experience
Karabo - Teenager



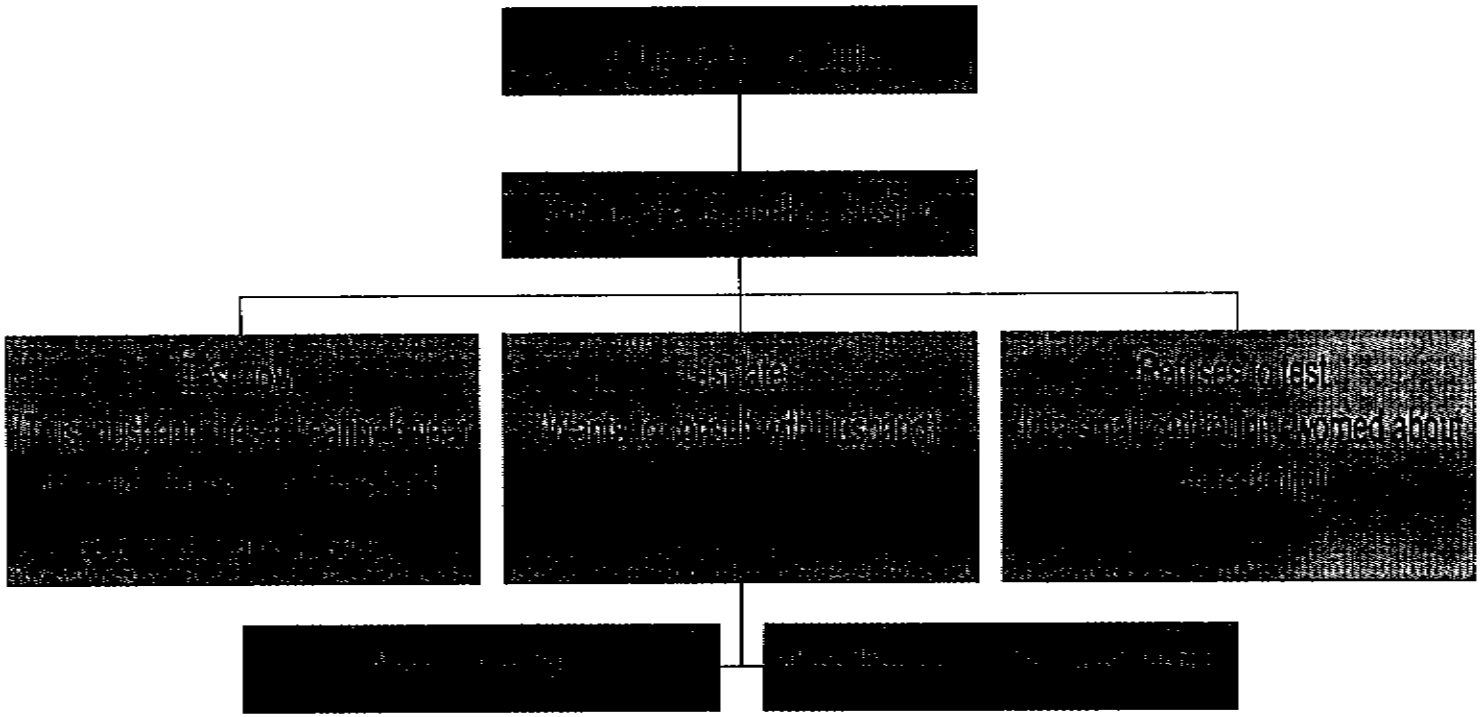
Disclosure
Karabo



Infant Feeding After Delivery
Karabo

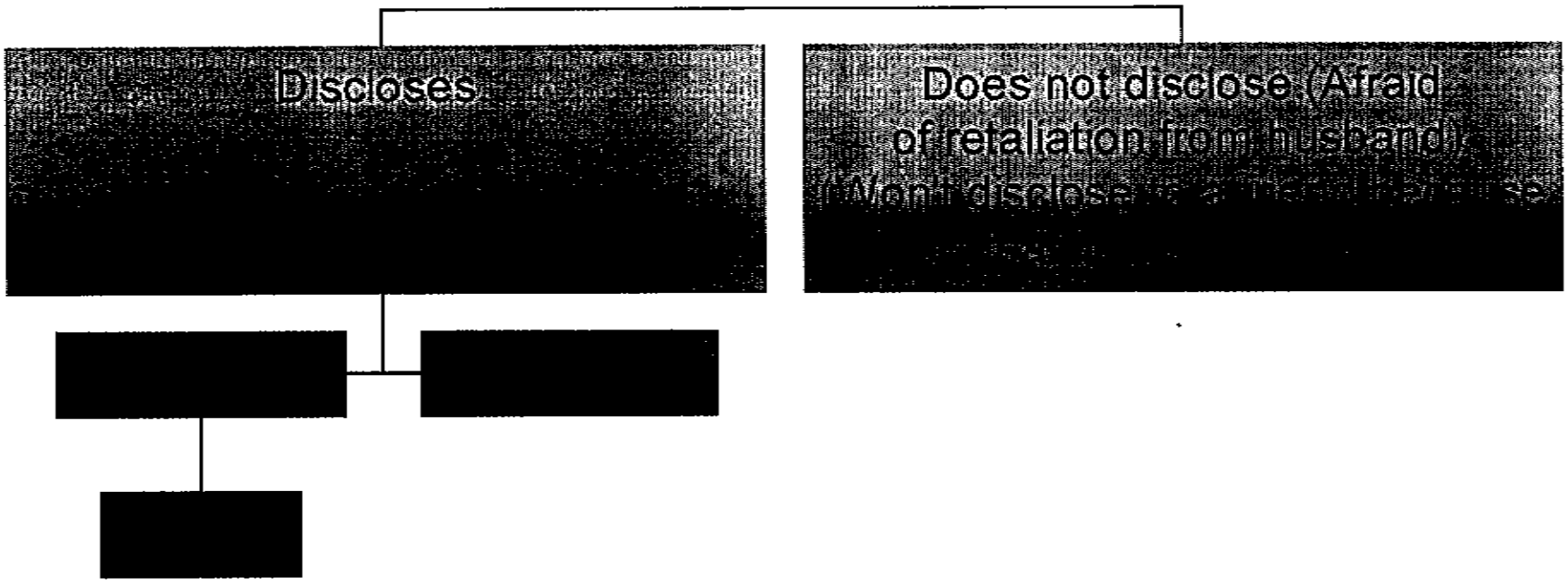


Counselling Experience
Thandi - Married



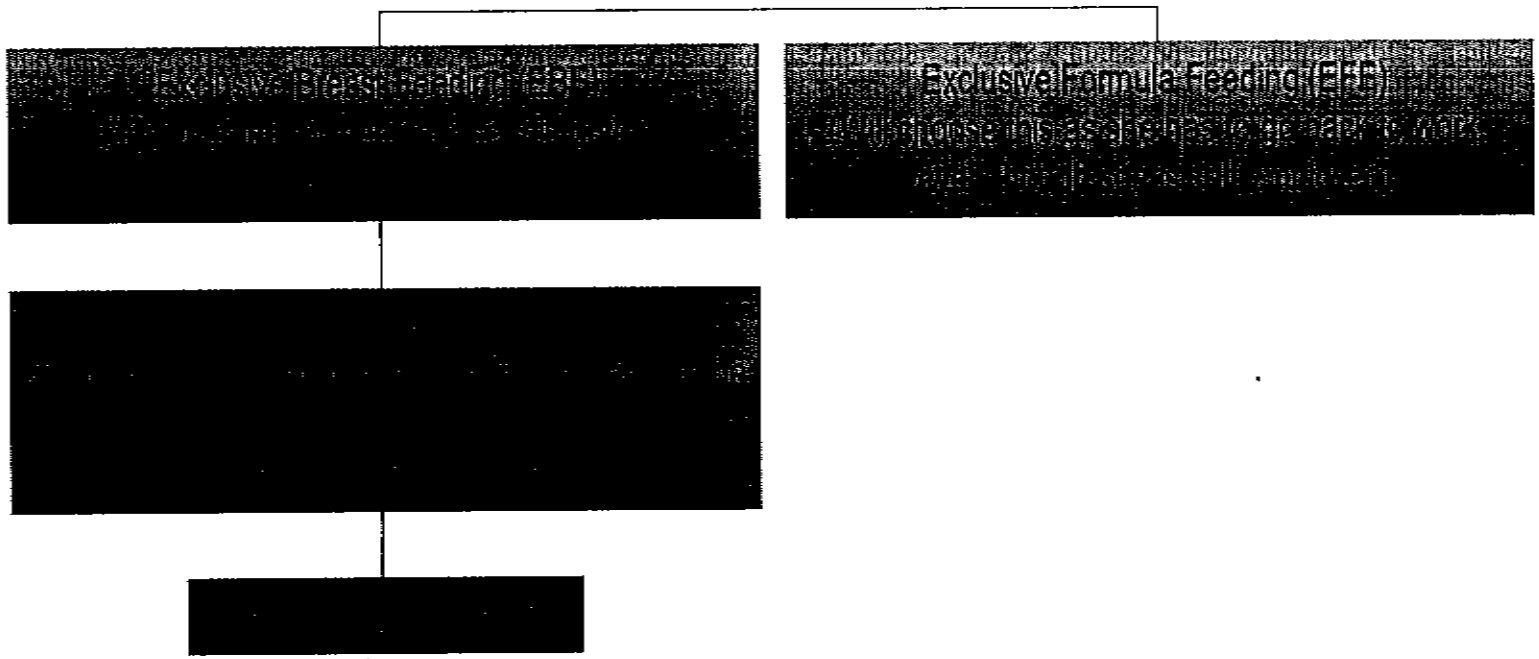
Disclosure

Thandi



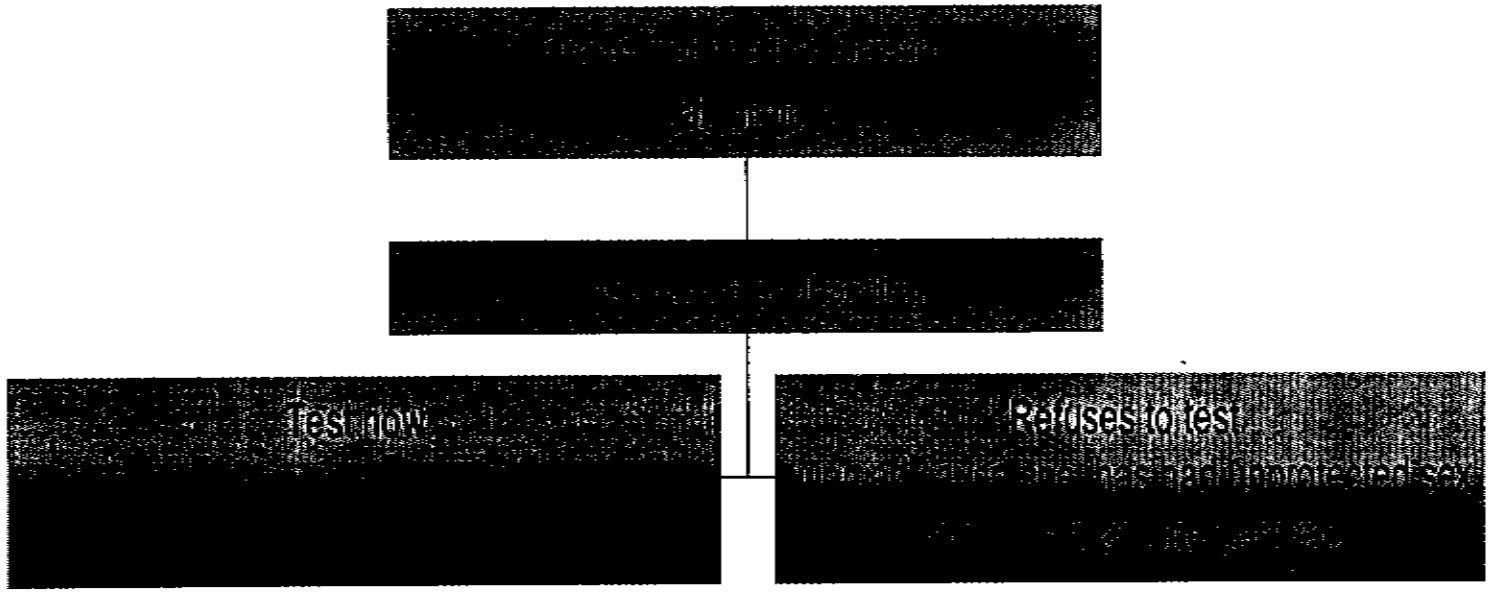
Feeding Options

Thandi



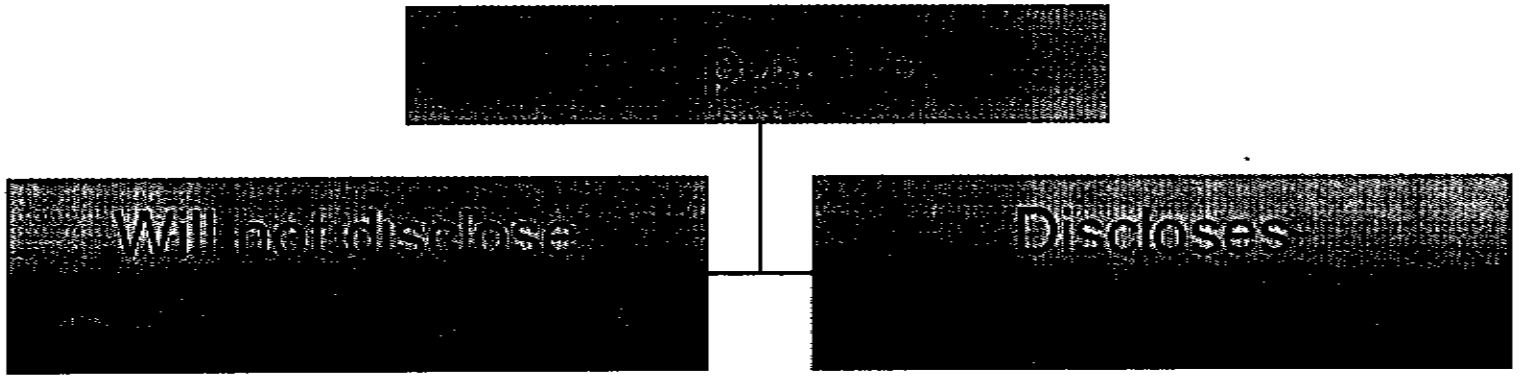
Counselling Experience

Maki - Single



Disclosure

Maki



Feeding Options

Maki