

## **CHAPTER 3 - SCOPE OF RESEARCH AND HYPOTHESIS/PROBLEM STATEMENT**

### **3.1. INTRODUCTION**

Maternal nutritional status during pregnancy is an important predictor of birth weight and intrauterine growth retardation, independent of clinical HIV disease progression.<sup>156,157</sup> On account of this, there is a growing body of literature from Africa that examines these relations in the presence of HIV infection. It is also known that HIV infection increases micro- and macronutrient requirements as part of the body's immune response, making women who are both pregnant and HIV-positive more likely to be at an additional health and nutrition risk. The direct and indirect causes of maternal morbidity and mortality may be more severe or debilitating in HIV-positive women, especially those with symptomatic HIV disease or AIDS.<sup>158</sup>

There is limited data from Africa on the effect of HIV on body composition (anthropometry) during pregnancy and even postpartum. However, it is well documented that both pregnancy and lactation are periods of rapid changes in the body composition of women. Research from Zimbabwe<sup>80</sup> indicates that, independent of CD4 counts, weight loss is a common manifestation of HIV infection and that it is strongly correlated with predicting survival. It is for this reason that the nutrition component of the Serithi study sets out to examine the interaction between psychosocial factors and maternal nutrition on disease progression, infant feeding and growth of the HIV-exposed baby over two years.

The concern over maternal health and nutritional status, especially during the postpartum period, has been particularly driven by the findings of Nairobi-based researchers.<sup>23</sup> The findings of this study indicated that HIV-positive mothers had higher mortality rates if they breastfed their infants. Interestingly, in this study

mothers did not self-select the infant feeding option but were being randomised into either feeding arm. It was also found that maternal death was associated with subsequent infant death and this effect was even stronger after controlling for infant HIV-1 infection status. The Nairobi study findings were in total contrast to those from Durban, South Africa<sup>49</sup>, which included an analysis of morbidity and mortality in mothers enrolled in a randomised study of Vitamin A supplementation. Neither of these studies provided detailed information on the mode, duration and quantity of breastfeeding and the associated mortality risks. In addition, the two groups of women enrolled in the trials are not directly comparable. Despite the limitations in these studies, they did highlight the need to monitor nutritional status of women who are HIV positive, regardless of their infant feeding choice.

Documentation from studies that have followed both mothers and their infants and the separate assessment of the benefit of HIV prevention interventions to one or the other is limited.<sup>158</sup> This has often been cited as one of the major flaws of prevention of mother-to-child-transmission of HIV (PMTCT) programmes, which seem to focus only on ensuring infant survival but seldom assess the health outcomes for the HIV-infected mother. This thesis will report on the impact of HIV infection among mothers on the childhood outcomes over a two year follow-up period.

Whilst the effect of HIV on micronutrient status is known, there is limited data on the relative importance of the effect over time. One review<sup>100</sup> mentions that micronutrient deficiencies, whether existing before HIV infection or directly resulting from HIV, may affect the transmission and progression of HIV. The most challenging aspect of the importance of micronutrients is the need to establish which micronutrients would be likely to have a positive effect in slowing HIV disease progression and the conditions under which this occurs. Further it is also important to understand the contextual issues such as the predominant

dietary practices and diets including the intakes of inhibitors of micronutrient absorption and the impact of seasonality on diets as they may all contribute to the outcomes of nutritional interventions.

### **3.2. SCOPE OF RESEARCH**

Maternal nutritional status is an acknowledged risk factor for pregnancy outcome. The additional influence of socio-economic and psychological factors associated with HIV disease progression, mothering capability and infant outcomes have not been extensively studied on mothers in the African context. Given that the PMTCT programme in SA provides for two options of infant feeding, it was of interest to assess what the feeding intent and actual practices would be. This research provides information on factors associated with the selection of either of the two choices on infant feeding in a peri-urban setting and adherence to the prenatal infant feeding choices of HIV-infected women in comparison to actual infant feeding practice after delivery.

This thesis describes associations between nutritional status, as assessed through anthropometric measurements and micronutrient levels in the blood, and HIV disease progression among women enrolled in a prevention of mother-to-child-transmission of HIV-1 programme. It also explores how far psychosocial factors were related to infant feeding practices and outcomes. This thesis will also document whether those mothers who chose to breastfeed were of better or poorer nutritional and immuno-status (determined through CRP, ferritin and CD4 counts) than those mothers who selected to formula-feed and to assess what the trends in nutritional status and CD4 counts were over a 24 month follow-up period.

Concern over the nutritional status of HIV-infected mothers is growing<sup>81</sup>, primarily due to the realisation that maintaining good health and nutritional status of mothers post-delivery is one of the key contributors to reversing the trends in maternal orphanhood in the HIV context. Within South Africa there is, as yet, no study that has systematically documented, over a two year period, trends in body composition, micronutrient status and CD4 counts and early infant feeding practices in a peri-urban setting.

The value of the study being reported on in this thesis is that it measures long - term changes up to 24 months post-delivery among a cohort of HIV-infected women living in peri-urban and urban settings, using non-invasive methods. Further, this study provides a unique opportunity to link anthropometric measurement changes with disease progression, which is measured through CD4 count determinations at intervals of six weeks and 6, 12, 18 and 24 months, as well as psychosocial variables of wellbeing. This study includes an assessment of whether in the first three postnatal months there are significant anthropometric measurement changes by infant feeding method of the mothers. Based on the findings from research, such as that conducted in KwaZulu-Natal<sup>8,160</sup> in a predominantly rural setting, it might be expected that the trends in nutritional status in an urban setting among HIV-infected women would be different i.e. that the women would be better off from a nutritional point of view. The value of this research in this thesis is that it assesses the trends in anthropometry (body composition) using simple measurements that can be applied in the normal delivery of health services in South Africa.

There is extensive documentation on psychosocial variables impacting on HIV disease<sup>10, 11,12,160-163</sup>. This thesis is unique in the South African context in that it determines the levels of psychosocial wellbeing and trends over time and relates this to infant feeding choices and practices. This thesis will assess the

relationship between HIV disease progression (measured by CD4 cell count) as well as the caring capacity of the mothers (manifesting as optimal infant growth).

### **3.3. RESEARCH QUESTIONS**

In summary, the following questions were posed in the research to be described in the subsequent chapters of this thesis:

- a. What were the prenatal feeding choices and postnatal infant feeding practices of HIV-infected women in Tshwane and what factors including nutritional status of the mother determined their selection?
- b. What were the infant feeding practices of postnatal HIV-uninfected women and how do they compare to those of the HIV-infected women?
- c. What were the longitudinal changes in body composition and determinants thereof amongst a cohort of HIV-infected women from six weeks postpartum until 24 months?
- d. Were there any differences in the first six weeks post-delivery between the anthropometric and biomarker status of breastfeeding and non-breastfeeding HIV-infected mothers?
- e. What were the psychosocial determinants of well-being and stigma over time among HIV infected mothers?
- f. What was the HIV transmission rate among children born to HIV-infected mothers over a two-year period?

g. What was the outcome for mothers and babies and how was this linked to maternal health factors and infant feeding practices of the HIV – infected mothers?

## **CHAPTER 4 - PARTICIPANTS AND METHODS**

### **4.1. INTRODUCTION**

This was a prospective, longitudinal, descriptive study in which pregnant women (aged 14 years and above) were enrolled within an average time of four weeks after testing positive for HIV-1. Women participated in interviews at the time of study enrolment along with additional interviews up to 24 months post-delivery. The eligible women were generally at 28 weeks of gestation at recruitment between June 2003 and June 2005 and were from four antenatal clinics in townships serving two large, demographically similar communities in Tshwane (Pretoria), South Africa. The clinics provided health services to a primarily black, low to middle socio-economic class, urban population and were thus representative of a large portion of the urban community in South Africa.

Trained HIV counsellors, employed by the clinics, provided post-test counselling using standard PMTCT procedures and referred women to the research project. All study participants provided written, informed consent. A separate appointment was made for the first study interview to clearly separate the study from the service. In the recruitment interview at around 28 weeks of pregnancy information was gathered on age, education, socio-economic and marital status and obstetric history, and the psychosocial status of each participant was assessed.

Selection of study participants was based on the assumption that HIV infected women who self selected for enrollment into the study would not differ in characteristics from other HIV infected women who choose not to be included in this study.

#### ***Inclusion criteria:***

- Sero-positive women, who have undergone voluntary counseling and testing and are aware of their HIV status. The women were expected to be residing in Pretoria.

***Exclusion criteria:***

- Women with an AIDS defining illness. Women who are not permanently resident in Pretoria and women who will not be staying with their infants for the first 6 months post delivery.

This study is an exploratory, descriptive study aimed at seeing which of a number of nutritional status variables predict HIV progression. An attempt was made to recruit sufficient subjects so that multiple regression models can be fitted to examine the relationship between the explanatory variables and disease progression as defined by the decline in CD 4 counts. The study population of the Serithi project was therefore estimated to comprise of approximately 800 women recruited at the 4 clinics, however for the nutrition related study, a subset of 150 to 200 of these subjects were to be included. The final numbers of women recruited was 317.

Interviews were conducted in the subjects' home language, either Sepedi, isiZulu or Setswana, which are the most common languages spoken in the areas served by the clinics.

The follow-up interviews for the nutrition component of the study were conducted at three days, six weeks, three months, six months, 12 months, 18 months and 24 months post-delivery. See Table 4.1 for an outline of the assessments conducted at each of these visits. All the questionnaires administered at each of the visits are appended to this thesis in Annexure 1. At these follow-up visits a physical examination was conducted, anthropometric measurements were taken and blood samples were collected and a detailed

infant feeding questionnaire was administered up to three months postpartum. At every visit women were also asked to indicate if they had had any illnesses in between the visits.

A subset of 53 confirmed HIV-negative mothers was recruited from the same four clinics where the main cohort of mothers came from. The comparison mothers had undergone routine voluntary counselling and testing at the clinics and were thus assumed not to differ from the study mothers in all other respects. This was to form a comparison group for feeding practices and for the assessment of biomarker levels. The HIV-negative women were interviewed only at six weeks postpartum.

The Serithi Study consisted of a variable number of between 10 and 12 field workers or research assistants who were responsible for the collection of data. There were four supervisors of whom three were retired nurse midwives and one a medical doctor. Training was conducted periodically on the questionnaires, on blood collection techniques and on ethics and ethical considerations pertaining to confidentiality of the data and patients' rights. Questionnaires were divided into those that focused on psychosocial data and those that were medical/of nutritional content. Actual field work in Serithi commenced after the pilot study in June 2003.

Once enrolled into the study the mothers and babies were expected to attend all scheduled visits. In addition, there was a request for mothers to bring the antenatal card to the first and second visit, and the infant's "road-to-health" card to all visits after birth. If the baby was cared for by another person, then that person was expected to bring the baby for visits. If a baby died at any time during the follow-up period, the mother was expected to continue her scheduled visits. The details of the assessments at each visit are contained in Table 4.1.

In order to minimise loss-to-follow-up, the Serithi Project applied an active system to trace the missing participants. Household visits were undertaken to the community by a dedicated research assistant every Tuesday and Wednesday in an attempt to trace those mothers who had not been coming for regular visits.

## 4.2. METHODS

**Table 4.1: Assessments undertaken at scheduled visits**

<b>Time of visit</b>	<b>Tasks performed</b>
28 weeks pregnancy ( recruitment interview)	28-week questionnaire
3 days after birth of infant (early infant feeding data)	PCR heelprick to infant. Birth infant feeding questionnaire
6 weeks (nutrition study baseline values for biomarkers)	6-week infant feeding and growth questionnaire. PCR heelprick to infant. Blood from mother and maternal anthropometry
3 months	3-month psychosocial questionnaire. Heelprick to infant Infant feeding questionnaire
6 months	6-month questionnaire. Bloods from mother and maternal anthropometry If the baby was ever breastfed, repeat heel prick
12 months	12-month questionnaire. Bloods from mother and maternal anthropometry.
18 months	18-month questionnaire and blood from the mother. Infant growth and health assessment. Psychosocial assessment.
24 months (final interview)	Nutritional and medical questionnaire and bloods from the mother. Infant growth and health assessment.

### 4.2.1. Socio-demographic information

Socio-demographic information included questions concerning the woman’s age, marital status, level of schooling, employment status, type of house, whether running water was available inside the house, a flushing toilet, electricity and a refrigerator. As a measure of socio-economic status a “housing score” of zero to five was developed by assigning one point to each of the following, if available: if

the home was constructed of brick or concrete, had running water, a flushing toilet, electricity and a refrigerator.

In order to assess the changes in the socio-economic and living circumstances, questions were included at the three month visit. This included questions on whether the participant lived with her partner and was receiving financial support from him.

#### **4.2.2. Anthropometric measurements**

Anthropometric measurements were taken of both the mothers and children over the post-delivery two-year period. For the mothers, weight was measured in light clothing, to the nearest 100g using an electronic digital scale (Scales 2000, Durban, South Africa), whilst height was taken without shoes to the nearest 0.1cm using a stadiometer (Scales 2000, Durban, South Africa). Validation of equipment was performed every 2 months using standard weights to ensure correct calibration of the weighing equipment. Further the researcher and the medical doctors on the team re-assessed the weighing and measuring techniques of the research assistants at all 4 clinics every other week.

A non-stretchable tape measure was used to take the mid-upper arm circumference measurement (MUAC). MUAC is the circumference of the left upper arm measured at the mid-point between the tip of the shoulder and the tip of the elbow (olecranon process and the acromium). These measurements were taken at six weeks as well as at six, 12, 18 and 24 months (see Table 4.1).

Weight and height measurements were later computed into Body Mass Index (BMI). BMI is a ratio of weight in kilograms divided by height in meters squared

and is a measure of current nutritional status and is not age dependent.<sup>62</sup> Table 4.2 indicates the classification of BMI.

**Table 4.2: Classification of BMI**

<b>Classification</b>	<b>BMI category</b>
Underweight	<18.5
Normal weight	18.5-24.9
Overweight	25.0-29.9
Obese class 1	30.0-34.9

Adapted from: Gibney, MJ, Ljungqvist, O and Dowsett, J (2005)<sup>62</sup>

Mid upper arm circumference was used as a measurement of body composition. Cut-off points for MUAC as an indicator of undernutrition are indicated in Table 4.3.

**Table 4.3: Classification of Mid-Upper Arm Circumference**

<b>Level of undernutrition</b>	<b>Mid-upper arm circumference</b>
Moderate	18.5 cm
Severe	16.0 cm
Normal	>18.5cm

Adapted from: <http://www.unsystem.org/SCN/archives/adults/ch06.htm> accessed May 02, 2008

For the children, weight was measured to the nearest 0.1kg using an electronic scale (Durban Scales, 2000) in 100g increments. To measure the height of the children who could not yet stand unassisted, supine length measurements (using non-stretchable tapes affixed to the bed) were taken, with the child lying on an examination bed. For those children who could stand unassisted, height was measured in a standing position. The height measurements were taken to the nearest 0.1cm with a tape measure affixed to the wall.

Nutritional status was assessed using algorithms developed by the WHO and CDC's anthropometrical programme (Nutrstat). The raw anthropometric data were transformed into Z-scores and the data was evaluated using the National Centre for Health Statistics/WHO reference data. These anthropometric

measurements were used to compute weight-for-height (w/ht), weight-for-age (w/a) and height-for-age (ht/a). Table 4.4 indicates the interpretation of each of the Z-scores.

**Table 4.4: Interpretation of Anthropometric Z-scores**

<b>Z-score</b>	<b>Interpretation</b>
Low weight-for-height Z-score (WHZ)	A WHZ score below -2SD is wasting, an indicator of acute, severe weight loss
Low height-for-age Z-score (HAZ)	A HAZ below -2SD indicates stunted growth, and reflects chronic malnutrition
Low weight – for – age Z score (WAZ)	A WAZ score below -2SD is reflective of underweight

WHO ([http://www.int/nut-growthdb/intro\\_text.htm](http://www.int/nut-growthdb/intro_text.htm) (accessed May 02, 2008)).

### **4.2.3. Infant feeding assessment**

In accordance with the National PMTCT protocol, trained HIV counsellors, employed by the clinics, provided post-test counselling using standard procedures and referred women to the research project. The post-test counselling provided women with information on the two infant feeding options available in the SA PMTCT programme, namely exclusive breastfeeding, followed by early, abrupt cessation or exclusive formula-feeding for six months. In the routine PMTCT counselling sessions women were informed of the availability of free infant formula if this was the method of feeding that they opted for.

During the first Serithi Study interview during pregnancy, women would then, on the basis of information imparted during the PMTCT counselling session, inform the counsellor which feeding option they intended to feed their baby with. All women participating in this research received routine antenatal care and were offered a single dose of nevirapine, which they were instructed to take during labour to reduce mother to child transmission. Upon delivery, their newborn infants were also to be offered a single dose of nevirapine within 72 hours.

At each of the subsequent study interviews mothers were also asked to indicate which additional foods (liquids and semi-solids) they were feeding their infants to supplement breastmilk or formula milk. At every visit, HIV-infected mothers who selected to breastfeed their infants were requested to indicate the age of the infant, when they stopped, and the process they followed in ceasing to breastfeed. Mothers who breastfed at any time during the follow-up were classified as breastfeeders and those who never breastfed were classified as formula-feeders.

#### **4.2.4. Clinical assessment**

Clinical medical assessments were conducted on the women and a medical history on illnesses since the last visit was collected through a standardised questionnaire.

#### **4.2.5. Nutritional biomarkers and immunological assessment**

A non-fasting venous blood sample was collected from the mothers by venipuncture during the regularly scheduled participant visits, as tabulated in Table 4.1. All clinics used as study sites were provided with the same blood collection and processing tubes from the Ampath Central Laboratory in Pretoria by Ampath Clinical Trials. Details of the lab collection flow chart are contained in Figure 2. Blood samples were protected from bright- and direct light and immediately placed into a cooler box prior to collection by laboratory personnel.

Blood specimens collected at six weeks (baseline), six months, 12 months, 18 months and 24 months were used to examine haemoglobin, T-lymphocyte count, and serum concentration of select nutrients. Table 4.5 shows the measurements,

instruments used and the methods for assessing each blood specimen as well as the cut-off points for the normal ranges of each biomarker.

**Table 4.5: Methodologies for Micronutrient, biomarker and immunological parameter assessment (Ampath Clinical Trials, Pretoria)**

TEST	INSTRUMENT	PRINCIPLE OF THE METHOD	REFERENCE RANGE
<b>CRP</b>	DADE BEHRING BNII (before 5/6/2006)	Nephelometry	0.00 - 5.00
	Roche Modular P800 (from 5/6/2006)	Immunoturbometric	0.0 – 4.9
<b>Vitamin A</b>	Waters 2690 HPLC	High performance Liquid Chromatography	260 - 720 µg/L 300 – 800 mg/L
<b>Vitamin E</b>	Waters 2690 HPLC	High performance Liquid Chromatography	6 - 10 µmol/L 5 – 18 µmol/L
<b>Iron</b>	Roche Modular P800	Electrochemiluminescence	9 – 30µmol/L
<b>Transferrin</b>	Roche Modular P800	Electrochemiluminescence	2 - 3.6 g/L
<b>%Saturation</b>	Manual	Calculation	15 – 50%
<b>Ferritin</b>	Roche Modular E170	Electro-chemi iluminescence Immunoassay	13 – 150ng/mL
<b>Vitamin B12</b>	Roche Modular E170	Electrochemiluminescence Immunoassay	145 – 637pmol/L
<b>Red cell folate</b>	Roche Modular E170	Electrochemiluminescence Immunoassay	597 – 2334nmol/L
<b>Selenium</b>	ICPMS (before Jan 2006)	Inductive Coupled Plasma Mass Spectrometry	46 – 143 µg/L
	Agilent 7500 ce (since Jan 2006)	Inductive Coupled Plasma Mass Spectrometry	70 – 130 µg/L
<b>Haemoglobin</b>	Beckman Coulter HmX	VCS Flow Cytometry	12 – 16g/dL
<b>CD4 lymphocytes</b>	FACS caliber	Flow Cytometry	500 – 2010cells/µL
<b>Iron</b>	Roche Modular P800	Electrochemiluminescence	6.6 – 26

At subsequent visits to the Serithi Project, the women were asked if they had commenced HAART and, if so, the date of commencement and whether they were continuing to take the medication as prescribed. Records at the Immunology clinic at Kalafong Hospital were reviewed to verify the information supplied on HAART by the mothers.

#### **4.2.6. HIV transmission assessment**

Within a period of three days postpartum, HIV-1 infection status of the children was determined by collecting heel prick blood and using a nested HIV-1 DNA PCR assay performed on filter paper (Roche Amplicor version 1.5 HIV DNA PCR; Roche molecular systems, Basel, Switzerland). Tests were repeated at three days postpartum, 6 weeks, and 3 months of age. Subsequent PCR testing was performed on breast fed infants, until 3 months after cessation of breastfeeding. The blood specimen was collected on absorbent filter paper and kept in the Project offices for collection every fortnight. Sufficient blood to saturate at least three of the five circles with blood collected from an infants heel prick was collected. The DBS were collected fortnightly by the National Institutes of Communicable Diseases personnel. Each sample, upon drying, was placed in an individual, sealed envelope to avoid contamination with other samples.

#### **4.2.7. Measures of Psychosocial well-being**

Table 4.6 describes all the constructs of psychological well-being that were applied to the study participants.

##### *4.2.7.1. Disclosure*

At both the 28 week and three month Serithi interviews, data were gathered on whether women had disclosed their HIV status and to whom and reasons for disclosure or non-disclosure. Early disclosure refers to disclosure during the pregnancy but before the baseline interview and late disclosure refers to disclosure subsequent to the baseline interview up to the interview performed three months postpartum. Disclosure was reported on as a percentage.

#### *4.2.7.2. Stigma*

Two scales were used to assess stigma: personal or internalised stigma, which refers to the person's experience of or fear of being stigmatised (12 items  $\alpha = 0,72$ ) and perceived community stigma, which is a person's perception of the stigmatising attitudes existing in the community (12 item  $\alpha = 0,75$ ). The stigma scales were adapted from research conducted in the United States<sup>163</sup> and pre-tested in a community sample of 1077 subjects in Tshwane. The scales were adapted in such a way as to make them more culturally acceptable to our population. Stigma was reported on as a score.

#### *4.2.7.3. Depression*

The Center for Epidemiologic Studies Depression scale<sup>164</sup> consists of 20 items designed to measure depressive symptoms experienced during the previous week. The measurement excluded somatic items, which are confounded by medical symptoms, as recommended by others (15 items  $\alpha = 0.88$ ).<sup>162</sup>

#### *4.2.7.4. Coping*

Active and negative coping styles were assessed using an adapted version of the Brief Cope Scale<sup>165</sup>, based on a model of coping behaviour.<sup>166</sup> Positive or active coping is regarded as constructive ways of coping, such as acceptance and positive reframing (13 items  $\alpha = 0.75$ ). Avoidant or Negative coping involves avoidance, denial, self-distraction and substance use (8 items  $\alpha = 0.54$ ). Table 4.6 summarises these psychosocial measures.

### **4.3. STATISTICAL ANALYSES**

The statistical evaluation was performed with the help of a biostatistician from the Medical Research Council of South Africa and from a data manager from the University of Pretoria. Descriptive statistics and chi-square tests were conducted. Bivariate and multivariate logistic regression models were also undertaken. In addition, analysis of co-variance was undertaken to assess differences in micronutrient levels while controlling for the CD4 count. Detailed methods of analysis are presented in the individual component chapters of this thesis.

Baseline demographic and nutritional status variables between HIV-infected and HIV-uninfected mothers were tested for significance using the Chi-square test for categorical variables and the Student t-test for continuous variables.

To analyse the factors associated with weight changes for the HIV-infected mothers over time, stepwise regression analyses using the following independent variables were performed: CRP, CD4+cell count, changes in CD4+cell count, nutritional biomarkers.

Feeding practices amongst women were assessed as early as three days after delivery and at this time we found that there were 21 mothers who only breastfed for between one and seven days. These mothers were categorised as neonatal breastfeeders. These 21 women were eventually re-categorised into their infant feeding practice that prevailed after this neonatal period. Detailed methods of analysis are presented in the individual component chapters in this thesis.

Maternal baseline characteristics were summarised using means for continuous variables and proportions for categorical variables. Continuous variables were

compared using Student t-tests for means and categorical variables were compared using Chi-square tests.

In the analysis of absolute CD4 cells, counts for the study participants were stratified in accordance with the CDC Prevention Criteria for HIV/AIDS classification namely (>500, 201-499 and <200 cells/mm<sup>3</sup>)

Adjustments were made for CD4 cell counts, CRP and serum ferritin as a means of controlling for the confounding effect of the acute phase response in multivariate analysis.

#### **4.4. ETHICAL CONSIDERATIONS**

Institutional review board approval for this study was obtained from the Faculty of Health Sciences' Research Ethics Committee at the University of Pretoria, South Africa (Number 209a) and the Human Investigation Committee of Yale University School of Medicine, USA (Number 2235). All study participants provided written informed consent and were provided with a travel allowance of ZAR30.00 per interview.

To comply with internationally accepted ethical standards, researchers undertook the following measures:

- Names of participants and their offspring were recorded on questionnaires or blood specimens only once prior to recording this information in the data base. Thereafter unique patient identification numbers were assigned and used for labelling of samples.
- Whenever CD4 counts and other biomarker data were received from Ampath or NICD, the unique patient identification number was utilised.

- Participants who requested to know the HIV status of their children were individually issued with the result sheet as received from the NICD.
- During analysis the results were reviewed only from the participant number and not by the clinic name.
- Enrolled participants continued to receive care from the clinics and hospitals to treat any opportunistic or other illnesses that might have occurred during the follow-up period.

After April 2004, when HAART became available in the public health sector in SA, study participants found to have severe immuno-suppression (CD4 cell count < 200cells/ $\mu$ L) were referred to the immunology clinic at Kalafong Hospital, a referral hospital serving the clinics included in the study, for continued care.

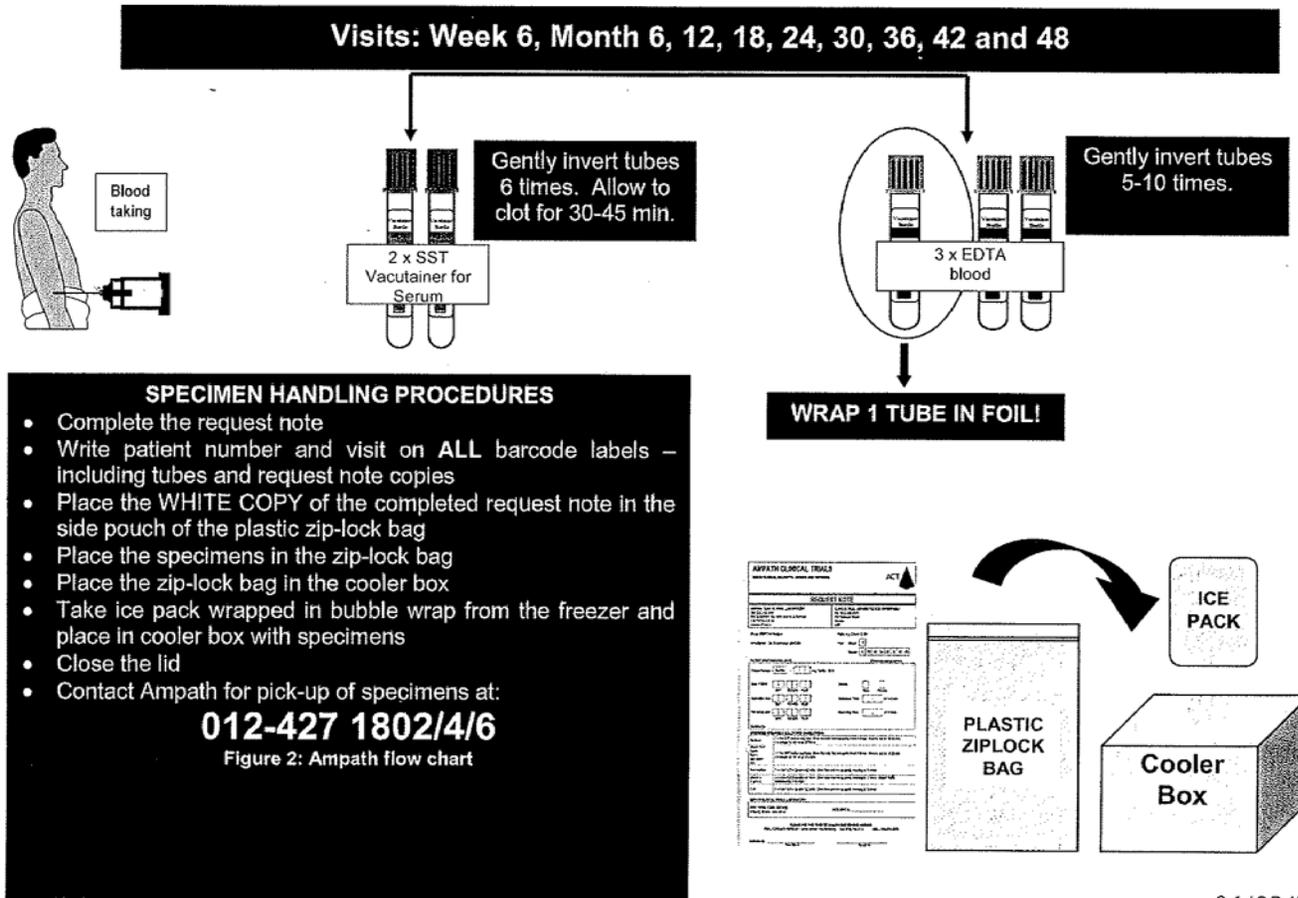
Prior to the conducting of the study, letters of request were sent to the Tshwane Municipal Government, the Gauteng Department of Health (Superintendent), Clinic managers and senior officials at clinic level in all the four clinics. The letters served to inform the recipients about the Serithi study protocol and to seek permission for the conduct of the survey in Tshwane.

**Table 4.6 Constructs of Psychosocial Wellbeing applied**

Construct	Scale	Comments	No. of items	Cronbach alpha (present study)
<b>Internal stigma</b>	Perceived stigma of HIV/AIDS: Personal view	Adapted from scales developed by Westbrook and Bauman <sup>28</sup> [Visser, Kershaw, Forsyth & Makin, Development of an HIV Scale –in press]	12	0.75
<b>Support</b>	Multidimensional Social Support Inventory (MSSI) <sup>29</sup>	Two aspects positive and negative		
<b>Positive</b>		Scale created using “practical, affirmational and emotional support”	9	0.87
<b>Negative</b>		Excluded one item	3	0.56



<b>Self-esteem</b>	Rosenberg Self-Esteem Scale <sup>30</sup>	Minor changes in wording for cultural appropriateness	10	0.75
<b>Depression</b>	Center for Epidemiologic Studies Depression (CESD) <sup>31</sup> .	Excluded somatic items which are confounded by medical symptoms as recommended by Kalichman, Rompa & Cage <sup>32</sup>	15	0.88
<b>Coping</b>	Brief Cope <sup>33</sup>	Fifteen items from original scale included with minor wording changes. 9 items added to make the measure more HIV-specific. An exploratory factor analysis identified two factors - positive and avoidant Two separate scales then created		
<b>Positive</b>			13	0.75
<b>Avoidant</b>			8	0.54
<b>Power Scale</b>		This is a scale that has been developed by the Serithi group to measure the degree of autonomy a woman has within her household.	7	0.60
<b>Knowledge score</b>		This scale includes questions on various aspects of HIV/AIDS and was developed by the Serithi group to assess a woman's knowledge about her disease	15	0.64



## **CHAPTER 5 - FACTORS AFFECTING HIV-INFECTED WOMEN'S ANTENATAL CHOICE AND POSTNATAL PRACTICE OF INFANT FEEDING IN TSHWANE**

### **5.1. OBJECTIVES**

1. To describe prenatal infant feeding choices and actual feeding practices of HIV-positive women up to three months post-delivery and to establish the psychosocial and economic determinants thereof.
2. To describe the infant feeding patterns from birth to 6 weeks of HIV-negative mothers and to establish the social and economic determinants thereof.

### **5.2. SUBJECTS AND METHODS**

The Serithi research project was conducted in the Mamelodi and Atteridgeville communities in Tshwane, the administrative capital of South Africa. These are both historically disadvantaged communities with a mainly African population and a large number of people living in informal housing. Mamelodi is a township situated on the eastern side of Tshwane, whilst Atteridgeville is on the western side. All sites chosen for inclusion in the Serithi Project were fully implementing PMTCT services when the study commenced in July 2003. The clinics selected included Mamelodi West Clinic, Saulsville Clinic, Phomolong Clinic and Pretoria West Clinics.

In a sub-component of this study, 53 HIV-negative women were interviewed on infant feeding practices between birth and 6 weeks postnatally, and the nutritional status of the mothers was assessed for comparison with the larger cohort.

Continuous and categorical variables that have been included as possible determinants of infant feeding choices and practices in this Chapter are tabulated in Table 5.1, highlighted with an asterisk. These include socio-demographic and psychosocial indicators. Personal variables such as parity, age, self-esteem, disclosure and other psychological measures of well-being were included as was water source, electricity and availability of a refrigerator - these three items being considered necessities that women would require to prepare safe infant formula.

### **5.3. STATISTICAL ANALYSIS**

Data from the study were entered into a MS Access 2000 database (Microsoft ® Corp., Redmond, WA, USA) and analysis was performed using SPSS for Windows version 13.0 (SPSS Inc, Chicago, IL, USA).

Associations between independent variables change from formula-feeding intent to actual breastfeeding practice were examined using the Chi-squared test for categorical data and the Student t-test for continuous data. Factors associated with feeding intent that had a  $p$ -value of less than 0.25 were subsequently entered into a logistic regression (enter method) to determine which factors were independently associated with breastfeeding intent and practice and with a change from initial feeding intent. A  $p$ -value less than 0.05 was considered statistically significant.

A second analysis was undertaken, making use of similar variables but having the outcome variable as breastfeeding practice. In a third analysis, to determine factors associated with a change from formula-feeding intent to breastfeeding practice, the association between variables at the recruitment interview with the subsequent change in feeding was examined. Regarding the individuals that

changed to breastfeeding practice from an original formula-feeding intent, it was hypothesised that socio-economic factors, especially the availability of a refrigerator, piped water in the house and electricity, as well as disclosure and stigma levels would be independently associated with breastfeeding practice. As with the previous two analyses (Chi-squared test and T-test), factors with a  $p$  value of  $<0.2$  were entered into a logistic regression model to establish the factors that were associated with the change.

**Table 5.1: Variables included in the analysis of factors associated with prenatal feeding intent.**

<b>Variable</b>	<b>Postulated direction</b>
<b>Continuous variables</b>	
Parity	Increased parity may lead to increased breastfeeding
SE status (housing score)* <ul style="list-style-type: none"> <li>• Formula-feeding score</li> </ul>	Low socio-economic score may result in more breastfeeding
Age	Increasing age, more experience with breastfeeding, therefore increasing breastfeeding
Per capita income (rands)* <sup>4</sup>	More finances in house, more likely to formula-feed
Household decision-making power score	Participants with more power in the household are less likely to breastfeed
Support score (positive)	Participants with less support more likely to breastfeed
Support score(negative)	More negative support or domineering support to participants is likely to lead to more breastfeeding
Knowledge* <sup>2</sup> score	Low knowledge score on modes of transmission, less breastfeeding
Self-esteem score	Low self-esteem may lead to less breastfeeding
Depression	High depression may lead to more breastfeeding
Active coping	Low active coping may lead to more breastfeeding
Avoidant coping	High avoidant coping may lead to more breastfeeding
Weeks from diagnosis to first interview	Less time interval between diagnosis and interview may lead to more breastfeeding
Personal stigma	Higher personal stigma, higher breastfeeding
Community stigma	Higher community stigma, higher breastfeeding

\* Individual items making up se score shown in table below

\*<sup>2</sup>Knowledge question specifically related to breastfeeding transmission shown in table below



<b>Categorical variables</b>	<b>Postulated direction</b>
Marital status <ul style="list-style-type: none"> <li>• Single with partner</li> <li>• Married</li> <li>• No Partner</li> </ul>	Single = more breastfeeding
Maternal education <ul style="list-style-type: none"> <li>• Primary and below</li> <li>• Secondary</li> <li>• Tertiary</li> </ul>	Those with lower level of education more likely to breastfeed
*Brick house	More formal housing, more resources, less likely to breastfeed
*Flushing toilet	Access to resources, less likely to breastfeed
*Piped water inside house	Access to resources, more likely to formula-feed
*Electricity	Access to resources, more likely to formula-feed
*Fridge	Access to resources, more likely to formula-feed
Living with Partner (does not include those without partners)	If no disclosure less likely to breastfeed
Living with relatives	More pressure from relatives, more likely to breastfeed
Living with others, not related	More pressure, more likely to breastfeed
Maternal regular income	More access to resources, less likely to breastfeed
Partner regular income (does not include those without partners)	More access to resources, less likely to breastfeed
Partner providing support (does not include those without partners)	More supportive environment, less likely to breastfeed
Partner education <ul style="list-style-type: none"> <li>• Primary and below</li> <li>• Secondary</li> <li>• Tertiary</li> </ul> (does not include those without partners or those who did not know their partner's education level)	Higher partner education, less likely to breastfeed
Time from diagnosis Categorized <ul style="list-style-type: none"> <li>• &lt; 1 week</li> <li>• 1-4 weeks</li> <li>• &gt;4weeks</li> </ul>	More time to think about risks of breastfeeding, less likely to breastfeed
Know someone with HIV <ul style="list-style-type: none"> <li>• Family</li> <li>• Frequent</li> </ul>	Knowing a person living with HIV, less likely to breastfeed



contact	
Disclosure <ul style="list-style-type: none"><li>• Disclosure to partner</li><li>• Disclosure to others</li></ul>	More disclosure, less likely to breastfeed
Knowledge specific to transmission via breastfeeding. This is assessed by answering true or false to the statement "all babies born to HIV-infected mothers if breastfed will get HIV"	Increased belief that all babies born to HIV-infected women, if breastfed, will get HIV is likely to result in increased formula-feeding.
Per capita income <ul style="list-style-type: none"><li>• &lt; 320</li><li>• &gt;=320</li></ul>	More income, less likely to breastfeed.

## **5.4. RESULTS**

### **5.4.1. Description of the Study Population**

Three hundred and seventeen (317) pregnant women were recruited between July 2003 and May 2005. Preliminary analysis of the data indicated that there were 24 study participants who had positive HIV results prior to testing for enrolment into the Serithi Study. Given that the 24 women could be classified as “experienced” with living with HIV, they were excluded from the analysis.

Table 5.2 depicts the socio-demographic characteristics of the 293 women who were included in the study. The average age of the women was 26.4 years (range 16-32). Most (89.1%) of the women had attended school, with the majority (75%) having some form of secondary schooling. Eighty percent of the study participants used electricity for cooking, 62.8% had a refrigerator, 67.2% had a flushing toilet in the yard but only 30% had direct access to piped water for cooking purposes in their homes. The median per capita monthly income in the households was R320.00 and the Inter-quartile Range (IQR) was R345.97. There were 185 (63%) participants whose per capita income was below R431.00, the national poverty line in 2006. The median time from HIV diagnosis to the recruitment interview was one week. The majority of women (68.3%) were not married and almost half (47%) were living with their husband or partner.

At the time of the recruitment interview, 173 (59%) of the women had disclosed their HIV status to others. Of those who disclosed, only 124 had disclosed to their partners, whilst 49 had disclosed to others. One hundred and five (36%) subjects reported knowing someone who was HIV-positive.

**Table 5.2: Baseline Characteristics of Study Participants (N=293)**

<b>A. CONTINUOUS VARIABLES</b>	
<b>Socio- demographics:</b>	
<b>Age in years:</b> [mean (SD)]	26.5 (5.1)
<b>Marital status:</b>	
Single, with partner	68.3%
Married	20.5%
No partner	11.2%
<b>Housing</b>	
Electricity	80.0%
Flushing Toilet	67.2%
Fridge	62.8%
Brick or concrete house	30.4%
Running water indoors	30.4%
Socio-economic score [mean (SD)]	2.9 (1.76)
<b>Household Income</b>	
Per Capita income (rands)	441.8 (458.1) Median 320 Range (0-3600)
Subject has regular income	24.2%
Partner has regular income	77.7%
Partner provides money	82.3%
<b>Psychosocial Measures</b>	
Power score	4.4 (1.8)
Support score (positive)	18.8 (6.3)
Support score (negative)	2.0 (2.3) Median 2.0 Range (0-9)
Self-esteem score	31.7 (4.0)
Depression level	11.8(8.5)
Active coping	31.1 (4.3)
Avoidant coping	16.2 (2.7)
Personal stigma	4.6 (2.7)
Community stigma	9.8 (2.4)
Knowledge Score related to breastfeeding transmission	10.1 (2.5)
<b>Interval since HIV diagnosis and first interview</b>	
Mean interval in weeks (SD)	4.1 (6.2)
Median interval in weeks	1.0
Range in weeks	0-36



<b>B. CATEGORICAL VARIABLES</b>	<b>N (%)</b>
<b>Marital status</b>	
Single with partner *	200(68.3)
Married	33(11.2)
No Partner	60 (20.5)
<b>Maternal Educational level</b>	
Primary and below	32 (10.9)
Secondary	221(75.4)
Tertiary	40 (13.7)
<b>Partner Educational level</b>	
Primary and below	25(10.5)
Secondary	169 (71.3)
Tertiary	43 (18.2)
<b>Living conditions</b>	
Brick house	157 (53.6)
Flushing toilet	197 (67.2)
Piped water inside house	89 (30.4)
Electricity	234 (79.9)
Fridge	184 (62.8)
Living with Partner (excludes those without partners)	138 (53.1)
Living with relatives	229 (78.2)
Living with others (non-relatives)	8 (2.7)
Maternal regular income	71(24.2)
Partner regular income (excludes those without partners)	202 (77.7)
Partner providing support (excludes those without partners)	214 (82.3)
<b>Time from HIV diagnosis to first interview</b>	<b>N (%)</b>
< 1 week	78 (26.6)
1-4 weeks	138 (47.1)
> 4 weeks	77 (26.3)
<b>Know someone with HIV</b>	105(35.8)
Family member with HIV	49 (16.7)
Someone participant has frequent contact with	76 (25.9)
<b>Disclosure</b>	173(59)
Disclosure to partner	129(44)
Disclosure to others	89(30.4)
<b>Knowledge specific to transmission of HIV via Breast-feeding</b>	83 (28.3)
<b>Per capita income (monthly)</b>	
Median per capita income (rands)	320
<320 (rands)	141(49.3)
>=320 rands	145(50.7)
Interquartile Range ( rands)	345.97

#### **5.4.2. Prenatal infant feeding intent**

Of the 293 study participants, 218 (74%) stated that they were planning to formula-feed, while 75 (26%) planned to breastfeed or mixed feed. Seventy-nine percent of the women choosing formula had already disclosed to their partners and other persons by the time of recruitment. The most commonly cited reasons for formula-feeding intent included: best for baby's health - 161 (74%), the need to return to work or school, poor maternal health or breast health problems collectively cited by 43 (20%) women and 14 (6%) found breastfeeding to be "too complicated".

Most of the mothers planning to breastfeed (71%) felt it was best for the baby's health. Twelve percent had breastfed before and another 12% felt it was the most affordable option. In 5% of cases the stated reasons included "did not know how to measure formula", "I want my baby to feel my love for it", "advised by others to breastfeed" and "I am working and do not want to mix feed".

In order to assess a woman's ability to make decisions on infant feeding, we asked who in the household made decisions on the feeding method for the baby. Two hundred and ninety one women responded to this question and of them 78% (229) stated that they made the decision, but this was not the case for the remaining 62 women (22%). Twelve women (4%) stated that the partner decided on infant feeding and 6.4% (19) said they made the decision jointly and the remaining 10.6% (31) named a caregiver and other relatives besides herself or her partner.

#### **5.4.3. Factors associated with prenatal feeding intent**

The factors associated with the pre-natal intended feeding choices appear in Table 5.3 ( $p < 0.25$ ). Only “knowledge” and “actively coping” were significantly different between the two groups. Logistic regression analysis was undertaken to further explore the factors associated with breastfeeding intent.

**Table 5.3: Factors associated with prenatal infant feeding choice (Formula-feeding or Breastfeeding)**

<b>Variable</b>	<b>Formula (218)</b>	<b>Breast ( 75)</b>	<b>P value</b>
<b><i>Continuous variables</i></b>	<b>Mean (SD)</b>	<b>Mean (SD)</b>	
Depression	12.2(8.7)	10.8(8.1)	0.24
Active coping	31.7(3.9)	29.5(5.1)	<b>&lt;0.01*</b>
<b><i>Categorical variables</i></b>	<b>Number (percentage)</b>	<b>Number (percentage)</b>	
Marital status	40(18.3)	20(27)	0.12
Mother tertiary education	34 (15.6)	6(8.0)	0.10
Time from diagnosis to interview >4wks	53(24.3)	24(32.0)	0.19
Know someone with HIV	85(38.9)	20(26.7)	0.06
Disclosure to partner	103(47.2)	26(34.7)	0.06
Disclosure to others	71(32.6)	18(24.0)	0.16
Knowledge about HIV transmission via breast milk	54(25.0)	29(38.7)	<b>0.02*</b>

\* Denotes those variables for which  $P < 0.05$ .

Table 5.4 indicates those factors that were independently associated with breastfeeding intent. Women who intended to breastfeed tended to have lower active coping scores, were twice more likely to be married and were less likely to have disclosed their HIV status to their partners than those intending to formula-feed. Women intending to breastfeed were twice as likely to have the correct knowledge regarding HIV transmission than those women planning to formula-feed. This implies that mothers planning to formula-feed were more likely to

believe that “all babies who are breastfed” by an HIV-infected mother will themselves be infected

**Table 5.4: Logistic regression to identify factors associated with breastfeeding intent.**

Variable	Adjusted Odds Ratio (CI)	P value
Active coping	0.88 (0.82,0.94)	0.01
Marital status	2.06 (1.03, 4.12)	0.04
Disclosure to partner	0.54 (0.30, 0.99)	0.04
Knowledge on HIV transmission through breastfeeding as assessed by the statement “all babies who are breastfed by an HIV infected mother will get HIV”	2.11 (1.14, 3.90)	0.02

### 5.4.5. Postnatal infant feeding practices

#### 5.4.5.1. Neonatal breastfeeders

Feeding practices amongst women were assessed as early as three days after delivery and at this time we found that there were 21 mothers who only breastfed for between one and seven days. These mothers were categorised as neonatal breastfeeders. These 21 women were eventually re-categorised into their infant feeding practice that prevailed after this neonatal period. There were four mothers who had antenatally planned to breastfeed, and did breastfeed but only in the neonatal period, and they were re-categorised into formula-feeders, as this was the predominant feeding option eventually. There were also 17 mothers who had antenatally planned to formula-feed, but breastfed only in the neonatal period and eventually formula-fed as the predominant form of feeding. Table 5.5 indicates the reasons why the early neonatal breastfeeders opted for this feeding practice.

**Table 5.5: Reasons for Breastfeeding in the Early Neonatal Period ( $\leq 7$ days)**

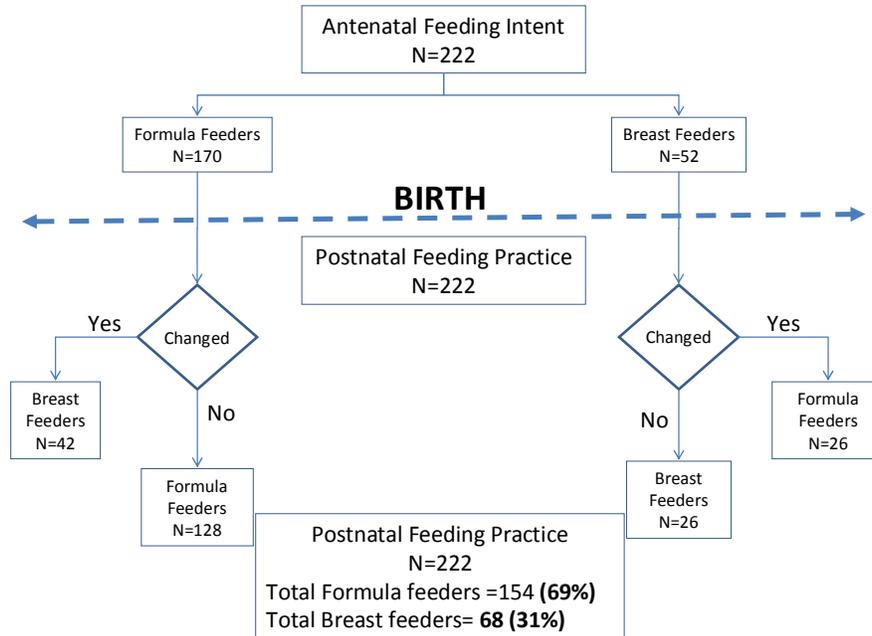
Reason	Number (%)
Forced in hospital: non-disclosure or no formula available in hospital	9 (42.9)
Breastfeeding is healthier, cultural norm, and easier to cope with, and it is affordable	7 (33.3)
Unaware of HIV transmission risk	2 (9.52)
Baby premature or got ill from Nan Pelargon	2 (9.52)
Forced at home by family members	1 (4.76)
<b>Total</b>	<b>21 (100)</b>

#### **5.4.6. Comparison of antenatal infant feeding choices and postnatal feeding practices.**

In assessing postnatal infant feeding practices, 71 cases from the 293 subjects had to be excluded due to incomplete infant feeding data, allowing analysis of 222 subjects for infant feeding practices. These women differed from those with complete information in terms of the following, measured at the first interview: They were more likely to indicate they were going to stay with someone else after the birth of the infant (34% vs 44 20%,  $p=0.001$ ). Their housing score was 2.1 vs 3.2 ( $p= 001$ ) and they were less likely to have disclosed (47% vs 63%,  $p=0.013$ ). They did not differ in terms of feeding intent as 68% vs 77% intended to formula-feed ( $p=0.13$ ).

The comparison of feeding practices shows that the vast majority (94%) of HIV-uninfected mothers were breastfeeding their babies at age 6 weeks, while 69% of study mothers were formula-feeding. Five (7.4%) of the HIV-infected mothers claimed to be exclusively breastfeeding by 6 weeks, whilst among the HIV-negative mothers 14% had already introduced solids or semi-solid food by 6 weeks. Only 1 HIV-infected mother had stopped breastfeeding by 6 weeks as she stated that she had to return to work.

Of the 222 women, 170 (74%) intended to formula-feed but 25% changed their mind and breastfed, while 50% of 52 women planning to breastfeed switched to formula-feeds. This left 154 formula-feeders (69%) and 68 breastfeeders (31%) (see Figure 5.1).



**Figure 5.1: Comparison between prenatal infant feeding intent and postnatal feeding practice**

#### 5.4.7. Reasons for the change from formula-feeding intent to breastfeeding practice

We determined those factors that were associated with this change and these are presented in Table 5.6. Logistic regression analysis (see Table 5.7) showed mothers that did not adhere to their original formula-feeding intention were significantly younger than those who remained with their original choice, were more likely to have received negative or domineering support, and shared their home with somebody else other than a partner.

**Table 5.6: Determinants of change from antenatal formula-feeding intention to breastfeeding practice**

Variable	FF** choice to FF practice(N=128)	FF choice antenatally to BF*** practice (N=42)	P-value
<b>Continuous variables</b>	<b>Mean(SD)</b>		
Age mean (SD)	26.5(4.9)	24.7(4.7)	<b>0.03</b>
Negative Support Mean (SD)	2.2(2.3)	1.4(2.1)	0.07
Active coping Mean (SD)	31.5(3.6)	32.4(4.1))	0.17
<b>Categorical variables</b>	<b>Number(percentage)</b>		
Disclosure to others other than partner	51(39.8)	10(23.8)	0.06
Partner providing support	86(67.7)	35(83.3)	<b>0.05</b>
Share home with anybody except partner	108 (84.4)	30 (71.4)	0.06
Partner schooling (tertiary or not)	22(17.2)	2(4.8)	<b>0.05</b>
Maternal schooling (tertiary or not)	26(20.3)	3(7.1)	<b>0.05</b>

\*Highlighted p-value indicates variables with  $p \leq 0.05$  \*\* FF – formula feeding \*\*\* BF – breast feeding

**Table 5.7: Logistic regression on factors associated with change from formula-feeding intent to breastfeeding practice among HIV-infected mothers.**

Variable	AOR (CI)	P-value
Age	0.89 (0.82, 0.97)	0.01
Negative support	0.80 (0.65, 0.98)	0.03
Staying with someone other than partner	0.38 (0.14, 0.97)	0.04
Partner schooling (tertiary or not)	0.16 (0.03, 0.81)	0.02

In an attempt to gain greater understanding as to what motivated the 42 (25%) mothers to change from their original intention of formula-feeding to practicing breastfeeding, 16 (38%) of respondents stated that were forced to breastfeed in hospital, six (14.3%) for comforting a crying baby and four (10%) were forced by family members. We were unable to identify any factors that were independently associated with a change from breastfeeding intention to formula-feeding practice, due to the small number of mothers that fell into this category.

There was no significant association found between disclosure or measures of stigma at recruitment and change from formula-feeding intention to breast practice (Table 5.8). However, the majority of women who formula-fed stated that they felt it necessary to give an excuse when asked by others why they were not breastfeeding. At six weeks postnatally, 69 of 154 formula-feeding mothers responded to a question about people asking why they were not breastfeeding. Only eight of 69 (11%) admitted to being HIV-positive rather than giving reasons like ill health (including breast cancer, TB, sore or itchy breasts), work, school, breast refusal or personal choice.

Table 5.8 shows that of the 26 women who remained with their original breastfeeding intent, 56% of them had disclosed at the recruitment visit and these women had a personal stigma score of 4.31 and a community stigma score of 9.98. Of the 128 women that had planned to formula-feed and actually formula-fed postnatally, 67% had disclosed at recruitment and the personal stigma score for these women was 4.48 whilst the community stigma score was 9.86. More formula-feeders than breastfeeders had disclosed at the recruitment visit. It was found that of the 26 women that had planned to breastfeed but later actually formula-fed, fewer (39%) had disclosed in pregnancy, whilst for those 42 women that had intended to formula-feed but actually breastfed, 63% had disclosed their HIV status and these women had a mean personal stigma score of 4.47 and a community stigma score of 9.56. Statistically there were no

significant differences according to the psychological measures between the groups of women.

**Table 5.8: Comparison between stigma and disclosure levels at recruitment by infant feeding intent and practice.**

<b>Feeding intent to Feeding practice</b>	<b>Disclosure level (% at recruitment)</b>	<b>Personal stigma score</b>	<b>Community stigma score</b>
Breastfeeding intent to Breastfeeding practice (n=26)	55.6	4.32	9.99
Breastfeeding intent to Formula-feeding practice (n=26)	60.9	4.89	9.91
Formula-feeding intent to Formula-feeding practice (n=128)	67	4.48	9.86
Formula-feeding intent to Breastfeeding practice (n=42)	62.8	4.47	9.56

#### **5.4.8. Supply of infant formula**

Respondents who selected to formula-feed their infants were asked whether they had ever run out of infant formula and, if so, the reasons. By six weeks postnatally, 32 (20.8%) of 154 formula-feeding mothers stated that they had run out of formula milk supply. The main reasons for running out of supply were: insufficient formula supply from the clinic and “baby eats a lot more than is supplied” - 25 (78%), four (13%) mothers said they did not know they could collect milk before the replenishment date, and three (9%) had run out of supplies over the weekend or before their scheduled visit and were thus unable to access the health facility for replenishment.

Mothers were also asked what they fed their infants during the period when they ran out of formula. Infants were most commonly offered formula milk, 16 (51%), with some mothers specifically mentioning that they bought “Nan”, “Lactogen” or “S26” and not “Pelargon” as it was “expensive” in the shop. One mother mentioned that she had “borrowed Pelargon” from another mother who she

knew was on the PMTCT programme. Eleven mothers fed glucose water, water or rooibos tea. Two mothers fed “cream of maize” or porridge. Four mothers stated that they breastfed their infants as an alternative to the formula milk and five mothers said they collected formula from the clinic.

Amongst the HIV-negative mothers who had selected to breastfeed, only one had stopped breastfeeding by 6 weeks as she stated that she had to return to work.

We included questions for the HIV-negative mothers which would provide an indication of the quality of counselling provided during Voluntary Counselling and Testing (VCT), especially as it pertains to infant feeding (Annexure 1). We established that 20 (37.7%) of the HIV-negative controls had been counselled on the benefits of breastfeeding whilst two (3.77%) had been counselled on safe formula-feeding. There were 36 (67.9%) women who stated that the counsellor had recommended that they exclusively breastfeed, though 46 (86.8%) had planned to breastfeed even prior to the counselling session.

## **5.5. DISCUSSION**

This is one of only a few studies in South Africa considering factors that might influence mothers in their infant feeding decisions and assesses their psychological circumstances in the context of the “real life” situation of the PMTCT Programme as it was being applied in four health facilities in a peri-urban setting in Pretoria. Our study was therefore not an intervention study and no effort was made to repeat the counselling process and sharing of information to reinforce this. Earlier studies in South Africa, which reviewed progress of the PMTCT sites, found considerable variation across PMTCT sites, with high uptake of replacement feeds in urban settings whereas in rural settings mothers opted

for breastfeeding.<sup>37</sup> Subsequent research from PMTCT sites in KwaZulu-Natal, Eastern Cape and Western Cape Provinces in 2005 documented that infant feeding counselling was the weakest programmatic component in all three sites with only 35% (12 out of 34) of mothers informed on the HIV transmission risks by mode.<sup>39</sup> Our study provides information on infant feeding choices prenatally and postnatally among HIV-infected women and links this data to indicators of psychosocial wellbeing as well as socio-economic factors. We also compare prenatal feeding intentions with postnatal feeding practice and explore the factors that influenced adherence or non-adherence to the original choice.

This study again demonstrates that decisions on infant feeding choices within the South African National PMTCT programme are individually made and very complex, thus continuing to pose challenges, as has been extensively documented elsewhere.<sup>41,167,168</sup> There are both internal (mother's own choice) and external influencers (family and health care workers) that impact on HIV-infected women's infant feeding decisions. We found in our study that 14.6% of mothers are not empowered to independently make decisions concerning their infant feeding choices. This clearly has profound implications for the process and content of counselling about infant feeding. Women recruited into our study were exposed to only two counselling sessions as part of VCT, in accordance to the standard PMTCT guidelines.<sup>36</sup> Our study did not attempt to verify the quality of the antenatal counselling provided. All the counsellors who had contact with mothers in the four clinics had undergone a five-day training course on VCT, which included one day of infant feeding counselling. In assessments from elsewhere it has been documented that this five-day training is inadequate<sup>173</sup> whilst other authors report that the ideal counselling training should be as long as 22 days.<sup>170</sup>

In the more urban and peri-urban settings in which this study was conducted, more women (76%) chose to formula-feed, regardless of the fact that only 30%

of these same women had direct access to piped water in their homes and that the median per capita income in the households was only R320.00. In addition, 75.8% of the women in this study were unemployed. Whilst the majority of HIV-infected mothers (80%) had access to electricity and 63% had a refrigerator, these two items alone would not guarantee that formula-feeds would be safely prepared, especially as direct access to clean water would have been problematic for 70% of the women. Indeed, other data from PMTCT sites in South Africa raise a growing concern over bacterial contamination of formula-feeds.<sup>34,35</sup>

The fact that a large majority of mothers in our study indicated the intention to formula-feed may be reflective of the strong influence of the counselling they had received in the PMTCT programme and points towards a need for more in-depth training and attitudinal support of the counsellors. Research from Tanzania demonstrates the influence and power of the counsellor in that 82% of urban and rural mothers felt confident to formula-feed if advised to do so by a health worker and if the formula milk was made available free of charge.<sup>171</sup> The statement cited by 70% of the study respondents that “formula feeding is best for a baby’s health” clearly shows the misunderstanding that might have arisen in the counselling process. In light of the research evidence that early exclusive breastfeeding is not more risky for vertical transmission and contributes to HIV-free survival<sup>28,30,61,172</sup> as compared to formula-feeding, it is important that HIV-infected mothers should receive adequate and thorough counselling on the risks of formula-feeding and not be unilaterally directed towards it without the full application of the AFASS criteria.

Others have found that health workers themselves are misinformed about the HIV transmission risk from breastfeeding and in some cases lack simple lactation management guidance, and this results in them imparting mixed messages and exerting misguided authority over the mothers.<sup>173,174,175</sup> It is of concern that in a review of four PMTCT country programmes, namely Kenya, Malawi, Botswana

and Uganda, it was found that 70% of all the health workers were unable to correctly estimate the HIV transmission risk through breastfeeding. In addition it was found that infant feeding options were mentioned in only 307 out of 640 (48%) of the observations of PMTCT counselling.<sup>169</sup>

We found a significant association between measures of active coping, disclosure to partner, marital status and intention to breastfeed. Women who intended to breastfeed had a lower active coping ability (adjusted odds ratio - AOR 0.88, 95% CI: 0.82-0.94) than those selecting to formula-feed and were thus less likely to reframe their current situation in a positive light. These women selecting to breastfeed were less likely to have disclosed their status to their partners or husbands (AOR 0.54, 95% CI: 0.30-0.99), were twice as likely to be married (AOR 2.06, 95% CI: 1.03-4.12) and were twice more likely to know that not all breastfed babies are infected with HIV (AOR 2.11, 95% CI: 1.14-3.90). These findings indicate that even among married women, non-disclosure of HIV status continues to be a hindrance to exclusive breastfeeding, despite the woman's own knowledge of the risks of HIV transmission through breastfeeding.

Of those mothers who were planning to breastfeed, 70% considered this method "best for baby's health." This finding is similar to that of others documenting that this decision lay in the entrenched knowledge that breast milk is best and this often outweighed the perceived risk of HIV transmission through breast milk.<sup>176</sup> Twelve percent of the mothers planning to breastfeed stated that this option was more affordable. This response may imply that the women were not aware at this time that formula milk was available "free of charge" from the health facility or that they had already factored in the cost of purchasing the equipment that is required for preparation of formula-feeds such as teats, bottles and cleaning materials. Alternatively, the mothers may have been considering the additional cost of travelling to health facilities to collect milk at regular intervals from the

health facilities. Similar complexities around the provision of free infant formula have been alluded to elsewhere.<sup>38,177</sup>

In our study we established that mothers who at the antenatal stage planned to formula-feed were more likely to have had greater exposure to HIV either through knowing a family member with HIV or having frequent contact with a person living with HIV. Furthermore, almost 50% of the mothers planning to formula-feed had disclosed their status to their partners. Other studies in South Africa have also emphasised that HIV disclosure remains a challenge that is of even greater significance in the context of infant feeding decisions.<sup>178</sup> In other countries it has been observed that 39% of mothers who hesitated to choose formula-feeding for their infants predominantly feared the partner's reaction and 31% feared the family circle's reaction.<sup>42</sup>

It is of interest to note that 8% of mothers planning to formula-feed prenatally stated that breastfeeding was "too complicated" and some explained this by specifically mentioning that adherence to exclusive breastfeeding with abrupt cessation would "be difficult" for them to practice. This finding is similar to documentation from other Southern African countries where the phenomenon of exclusive breastfeeding followed by abrupt cessation was not a cultural norm and not everyone had the skills to carry out this process whilst reducing the likelihood of breast health problems.<sup>179,180</sup>

Our study also provides information on infant feeding by HIV-infected mothers and how feeding choices change in practice after the baby is born as compared to prenatal feeding intent. This study found that significantly more mothers (75%) adhered to their prenatal infant feeding choice of formula-feeding whilst only 50% of mothers antenatally selecting to breastfeed adhered to this after the birth of their babies ( $p < 0.001$ ). This finding is in total contrast to the findings in KwaZulu-Natal where there was 78% adherence to breastfeeding and only 42%

adherence to replacement feeding.<sup>170</sup> Low adherence to replacement feeding was also observed in pilot PMTCT programmes in Botswana.<sup>22</sup>

It is highly likely given the more peri-urban setting of our 4 study sites that women may have perceived formula feeding to be “more feasible” and that they might have been better able to adhere to the AFASS criteria if they were practicing replacement feeding. Further it is possible that the quality of counselling that was offered to mothers in the 4 study sites, was such that there was a bias towards encouraging replacement feeding given that 80% of our study participants used electricity for cooking and more than 60% owned a refrigerator. Yet not all the conditions required for AFASS would have been met given that only 30% of our study participants had direct access to piped water for cooking.

The factors that were significantly associated with the change from formula-feeding intent to breastfeeding practice were younger age of the mother, limited disclosure to others, limited partner support and sharing of the home with anyone else other than a partner ( $p < 0.05$ ). These findings, similar to others documented elsewhere, indicate that infant feeding practices become even more complex without the necessary support that can only be obtained through disclosure of one’s HIV status.<sup>168,188,181,182</sup>

Though the standardised stigma scales that we applied in this research did not identify differing levels of stigmatisation among formula- and breastfeeders, the existence of stigma related to formula-feeding is shown by the number (69 out of 154) of women stating that they make up “excuses” to explain why they are not breastfeeding. Clearly the fact that women responded to this statement emphasises that choosing to formula-feed is not always the “easier” or more acceptable option even in a peri-urban setting where our research took place. The implication is that there is still persistence of formula-feeding-related stigma

in the community. This has also been documented in other PMTCT sites in South Africa.<sup>183</sup>

Whilst the overall uptake of breastfeeding among the HIV-negative women was as high as 94%, none of these mothers practiced exclusive breastfeeding, similar to findings highlighted in studies elsewhere in Africa.<sup>176,184,185</sup> Only a third of these mothers initiated breastfeeding within one hour of birth, 24.5% within two hours and there were 21% who initiated breastfeeding a day after birth. Such delays in breastfeeding initiation demonstrate that sub-optimal feeding practices prevail in the communities where this study was undertaken. Data from Ghana points to the merits of early initiation of breastfeeding and adherence to exclusive breastfeeding as an intervention to contribute to the reduction of neonatal mortality.<sup>186</sup>

It is important to note that in gathering data on postnatal feeding practices, this study tried to overcome recall bias by ensuring that at each of the three visits up to three months the same question was repeated to assess if the mother had ever breastfed. It is still possible, however, that even with this intervention, not all mothers would recall adequately their true adherence to exclusive breastfeeding, let alone fully understand the importance of this feeding practice. Further mothers may find it difficult to recall exactly when they ceased altogether to feed their infants breastmilk; a factor that may lead to exaggerated duration of exclusive breastfeeding, given our wide range of 42 days. Others have noted that recall bias persists when gathering data on infant feeding practices with mothers often forgetting the actual duration of exclusive breastfeeding.<sup>33</sup>

In addition, the HIV-negative mothers as well as the HIV-infected mothers introduced semi-solids and other liquid foods to the infant diet as early as one day after birth. When HIV-infected women ran out of free formula supplies they reported substituting this milk with foods or liquids of lower nutrient density from as early as six weeks after birth. This finding is similar to that from the Ivory

Coast where it was documented that, following cessation of exclusive breastfeeding, mothers introduced foods of insufficient dietary diversity to the diet of their children at six months and this inadequate complementary diet resulted in impaired growth and 37% stunting rates in the next 12 months.<sup>189</sup> In Zimbabwe, HIV-negative mothers also introduced fluids or food other than breast milk significantly sooner than recommended.<sup>32</sup> On the basis of the findings among the HIV-infected and non-infected mothers it would appear that sub-optimal infant feeding practices were common within the setting of our study.

Some of the early breastfeeders or mothers who only breastfed between day one and seven stated that they were forced to breastfeed in the hospital as they had not disclosed or there was no formula milk available (38%), whilst 6% said they were forced by family members to breastfeed and 18% breastfed as a means of comforting the newborn baby. It is of concern that mothers in our study and in other studies conducted elsewhere in South Africa<sup>183</sup> who delivered in hospitals faced an immediate dilemma at delivery as not breastfeeding would amount to disclosure of their HIV status, because hospital personnel were expecting them to breastfeed. As a result mothers reported that they were “forced” to breastfeed by hospital staff after delivery. Clearly the PMTCT programme has fallen short of identifying those women who are HIV-positive through the records, but most importantly there presently does not seem to be a facilitated process that enables women to be confident enough to disclose their status and preferred infant feeding choice.

Data from Africa has revealed discrepancies between the knowledge on infant feeding and HIV transmission and the actual beliefs of health care workers. A study in Malawi found that even though 18 health care workers understood the benefits of exclusive breastfeeding on child health, only 11 of them believed that children should be exclusively breastfed for six months. Further, in the focus group discussions it emerged that though the health care workers understood

the various modes of HIV transmission, they, together with a sample of mothers, over-estimated the transmission risk from breastfeeding. The health care workers also found the recommendation on early cessation of breastfeeding among HIV-infected women to be against the cultural norm in Malawi where breastfeeding continues for up to two years.<sup>188</sup> In South Africa there is additional documentation on the difficulties that are posed by early cessation of breastfeeding in the PMTCT context.<sup>189</sup> Others have developed culturally sensitive and appropriate counselling tools that incorporate the belief systems of the counsellors and the local context as a means of addressing counsellor bias.<sup>192</sup>

We found that by six weeks postnatally 21% of the formula-feeding mothers had run out of formula milk supply on occasions. On the basis of the reasons they cited for the shortage it would appear that the calculations for the number of tins that a woman should be entitled to may not be sufficient in relation to the actual nutritional needs of the children. The issue of formula supply also raises concern that, since so few of the mothers in our study mentioned that when they ran out they would buy formula, it may mean that mothers who selected this feeding option were not necessarily better-off financially. Affordability of infant formula is one of the criteria that are supposed to be assessed when counselling a HIV-infected mother who selects this feeding option. Another reason mothers cited for formula shortage was that the supply at the health facility ran out. The inconsistent formula supply at the clinics in our study led mothers to provide other lower nutrient and energy density replacement feeds such as water, glucose water or rooibos tea. In other cases the mothers mentioned that they would feed their infants semi-solid porridge as a substitute to infant formula.

Thus our findings are consistent with the predicted risks that the provision of free infant formula may lead to more women practicing mixed feeding<sup>30</sup> due to the inconsistent formula supply. Other studies in South Africa have documented that inconsistent formula supply from health facilities to HIV-infected mothers

remains a constraint, primarily attributable to “inflexible” health facility policies and a “lack of formula supplies at the clinics”.<sup>183</sup> Beyond the health system constraints in the supply of infant formula, in Nigeria it was felt that some of the barriers to formula-feeding included high cooking fuel costs, unreliable electricity supplies, poor access to safe water and poor storage facilities.<sup>47</sup> Other data from the PMTCT programme in Botswana indicated that adherence to either exclusive breastfeeding or exclusive formula-feeding was “sub-optimal” as mixed feeding is considered the cultural norm in these communities.<sup>22</sup> During the conduct of this research between June and August 2005 there were reported cases of formula milk shortage in South Africa, including at two of the clinics falling under the Serithi Project<sup>191</sup>. This situation made health workers raise questions on the lack of sustainability of the provision of free formula, the need to provide access to more than one branded formula in the PMTCT programme and the resurgence of the debate as to whether, instead of free formula, HIV-infected mothers choosing this method of infant feeding could not be given a choice of the type of formula they select for their infants rather than over-relying on only one infant formula whose availability is not always guaranteed.

## **5.6. SUMMARY**

Our study findings corroborate the UNAIDS statement of 2006 that “the complex relationship between breastfeeding and HIV transmission risk to the newborn underscores the importance of extensive, culturally appropriate counselling on breastfeeding to new mothers who are living with HIV”.<sup>2</sup>

This study re-affirms that counselling on feeding choices for HIV-exposed infants must be extremely sensitive to numerous internal and external factors impacting on that decision. We found that HIV-infected women who had better coping skills, more education (though not statistically significant), who were married and

who had disclosed to their partners tended to choose formula-feeding after undergoing the routine PMTCT counselling process. This study further emphasises the importance of support to HIV-infected women in their infant feeding decisions, to enable disclosure and improved coping. Community-wide efforts are needed to enable HIV-infected women to independently make their infant feeding choices, relative to their own household circumstances. Such support may be in the form of frequent counselling sessions, regular antenatal contact with the mother and including, where possible, home visits. Without this package of interventions mothers will continue to find it difficult to address the psychosocial issues pertaining to their status and to make truly independent and informed infant feeding decisions.

Our findings on postnatal infant feeding practices in comparison to antenatal choices have highlighted the challenges posed by the application of PMTCT guidelines in relation to the socio-cultural complexity of advice on infant feeding. The poor adherence to exclusivity of either infant feeding choice reflects either poor maternal knowledge on the importance of exclusive feeding or limited knowledge of counsellors. Without adequate counselling support to enable mothers to assess the optimal infant feeding option that is suitable for her own individual and household setting, HIV infected women will continue to struggle with selection of the appropriate method of feeding. Frequent training and mentorship of counsellors, including periodic updates needs to be made an essential component of the PMTCT package in South Africa. Indeed counselling support needs to be provided antenatally, and especially postnatally to enable mothers to adhere to exclusive infant feeding. Our study findings point to the fact that the support that HIV-infected women need in making their infant-feeding decisions will entail psychosocial, community-wide interventions and frequent counselling sessions to assist them in coping with and disclosing their status. Improving the quality of infant feeding counselling for all mothers and the

promotion of exclusive breastfeeding at family level are key to enhancing HIV-free survival.