

## **3 RESULTS**

The first part of this research was a retrospective study. The sampling frame utilised for the sample selection was the list of AMA women counselled between February to July 2003 and February to July 2004, from Department of Human Genetics, National Health Laboratory Services, Johannesburg. The information recorded included the age of the women, their HIV status and the choices these women made regarding prenatal testing for chromosome abnormalities in the fetus. The second part of this study was an investigation of the perception that the HIV positive women had as to the impact of HIV on themselves and their fetus. This information was gathered through the use of a questionnaire, which was completed by the HIV positive women in the 2004 sample.

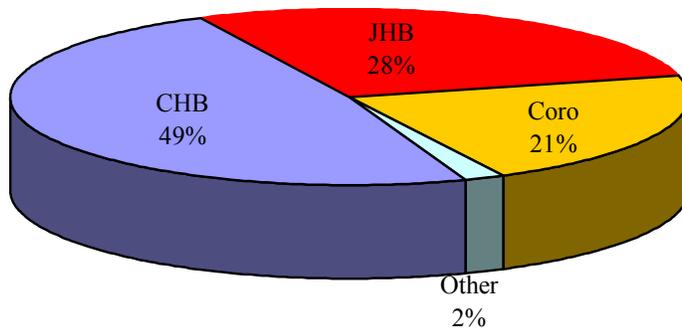
### **3.1 File Search**

#### **3.1.1 Patient Demographics**

The subjects in this study were women from the urban areas of Johannesburg and surrounds, who were from varying educational and socio-economic backgrounds. The majority of patients were of African origin, but there were also patients of mixed ancestry and Caucasians. The majority of patients, 98% (343/350), were seen at three academic hospitals in Gauteng where weekly Genetic Counselling Clinics are held at Coronation and Johannesburg Hospitals, and four times per week at the Fetal Medicine Centre, Chris Hani Baragwanath Hospital, Soweto.

### 3.1.2 Patient Numbers

The total number of patients counselled and recorded in this study was 350. In the February to July 2003 sample, 169 AMA women were counselled, an average of 28 per month, and in the period from February to July 2004, 181 AMA women were seen, an average of 30 per month.



**Figure 3-1 Proportion of patients seen at three main Genetic Counselling Clinics in the two six-month periods of 2003 and 2004 combined**

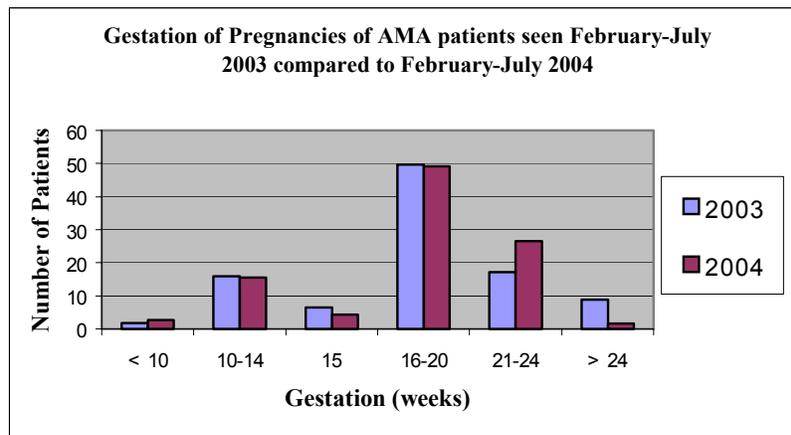
Figure 3-1 illustrates the combined number of the patients seen during the six months of 2003 and 2004: 169 (48%) of the women were seen at Chris Hani Baragwanath Hospital, Soweto, 99 (28%) at Johannesburg General Hospital and 75 (21%) at Coronation Hospital. The remaining seven (2%) patients were counselled at Kalafong Academic Hospital in Pretoria, and at the Donald Gordon Medical Centre, Parktown, Johannesburg.

### 3.1.3 Gestation of Pregnancy

**Table 3-1 Comparison of pregnancy gestation of AMA women seen at the Genetic Counselling Clinics**

<b>Gestation</b>	<b>2003 Patient Number</b>	<b>2004 Patient Number</b>
<10	3 (1.8%)	5 (3%)
10-14	27 (16%)	28 (16%)
15	11 (7%)	8 (5%)
16-20	84 (50%)	89 (49%)
21-24	29 (17%)	48 (27%)
>24	15 (9%)	3 (2%)
<b>TOTAL</b>	<b>169</b>	<b>181</b>

Pregnant AMA women counselled for the risks of chromosome abnormalities are offered invasive prenatal testing up to the end of the 23<sup>rd</sup> week of pregnancy. Amniocenteses are not routinely offered after this gestation, as the time of fetal viability is approaching, and obstetricians have been unwilling to perform TOP after 24 weeks gestation (Christianson, personal communication, 2005). There was no difference (Table 3-1 and Figure 3-2) in the number of women between 16 and 20 weeks gestation seen at the clinics ( $p=1.000$ ) in the two groups. The number of women who presented too late for prenatal testing, ie those who were more than 24 weeks pregnant, had decreased significantly by 2004 ( $p=0.0028$ ).



**Figure 3-2 Comparison of the gestation of pregnancies of women attending Genetic Counselling for AMA in two six-month periods**

### 3.1.4 Prenatal Testing

As Table 3-2 illustrates, the proportion of women who chose to have prenatal testing for chromosome abnormalities did not vary significantly between the two six-month groups: 58 (34%) had amniocentesis in 2003, and 52 (29%) in 2004 ( $p=0.300$ ).

**Table 3-2 Prenatal diagnosis for chromosome abnormalities, 2003 and 2004.**

<b>Year</b>	<b>Amniocentesis Number (%)</b>	<b>No Amniocentesis Number (%)</b>	<b>Total</b>
<b>2003</b>	58 (34%)	111 (66%)	169
<b>2004</b>	52 (29%)	129 (71%)	181
<b>Total</b>	110 (31%)	240 (69%)	350

Table 3-3 records the number of women seen at the different clinics, and the number and proportion who chose to undergo invasive prenatal testing for chromosome analysis. The seven (2%) patients not seen at the main centres of genetic counselling are grouped together under the title of “Other”.

In the two year-groups only one CVS, in 2004, was performed. When prenatal testing is therefore referred to as “amniocenteses” it includes this CVS.

**Table 3-3 Number of AMA women seen at the main centres for genetic counselling.**

<b>Hospital</b>	<b>Testing Number (%)</b>	<b>No Testing Number (%)</b>	<b>Total Number</b>
<b>Chris Hani Baragwanath</b>	61 (36%)	108 (64%)	169
<b>Johannesburg General</b>	28 (28%)	71 (72%)	99
<b>Coronation</b>	20 (27%)	55 (73%)	75
<b>Other</b>	1 (14%)	6 (86%)	7
<b>Total</b>	110 (31%)	240 (69%)	350

The uptake of invasive prenatal testing for chromosome abnormalities (Table 3-3) ranged between 20/75 (27%) at Coronation Hospital and 61/169 (36%) Chris Hani Baragwanath Hospital. No statistically significant difference was seen in the uptake of invasive prenatal testing between the different clinics ( $p=0.272$ ). The group of seven patients seen elsewhere was too small (2%) to analyse effectively.

### 3.1.5 HIV Status

There was a statistically significant increase in the number of patients whose HIV status was known in 2004 compared to the women seen in 2003 ( $p=0.010$ ). Of the 169 women of AMA counselled in the 2003 group, the HIV status was known for 98 (58%). Of the 181 women counselled in the 2004 group, the HIV status of 129 (71%) women was known (Table 3-4).

**Table 3-4 HIV status of AMA women attending Genetic Counselling Clinics in the six months of 2003 and 2004.**

AMA Women	2003	%Total	%Known HIV Status	2004	%Total	%Known HIV Status
HIV Negative	83	49%	85%	100	55%	78%
HIV Positive	15	9%	15%	29	16%	22%
Total Known Status	98	58%		129	71%	
Unknown Status	71	42%		52	29%	
<b>Total</b>	<b>169</b>			<b>181</b>		

From Table 3-4 it can also be seen that in the 2003 sample, 83 (49%) patients were HIV negative and 15 (9%) were HIV positive, with the remaining 71 (42%) of unknown status.

Therefore a total of 98/169 (58%) patients in the 2003 sample were of known HIV status; 85% of these were HIV negative and 15% were HIV positive. In the 2004 sample, 100 (55%) patients were HIV negative and 29 (16%) were HIV positive, with the remaining 52 (29%) of unknown status. Therefore a total of 129/181 (71%) patients in the 2004 sample were of known HIV status; 78% of these were HIV negative and 22% were HIV positive.

Although the HIV status of more women was known in the six months of 2004, there was no statistically significant increase in the percentage of women of known status who tested HIV positive in the 2003 group; 15 (15%) of 98 women in 2003, compared to 29 (22%) of 129 women in the 2004 group ( $p=0.235$ ).

### 3.1.5.1 HIV status and Prenatal Testing

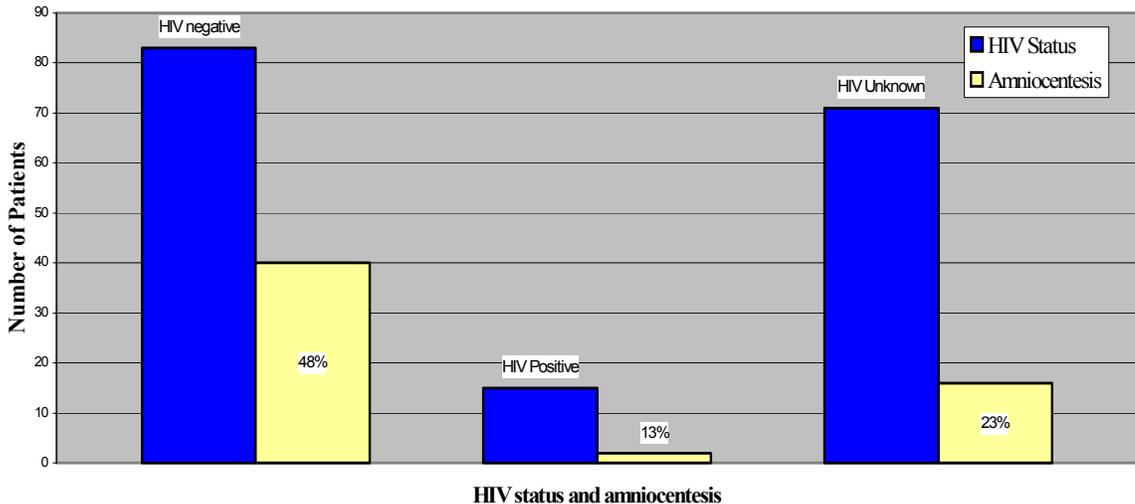
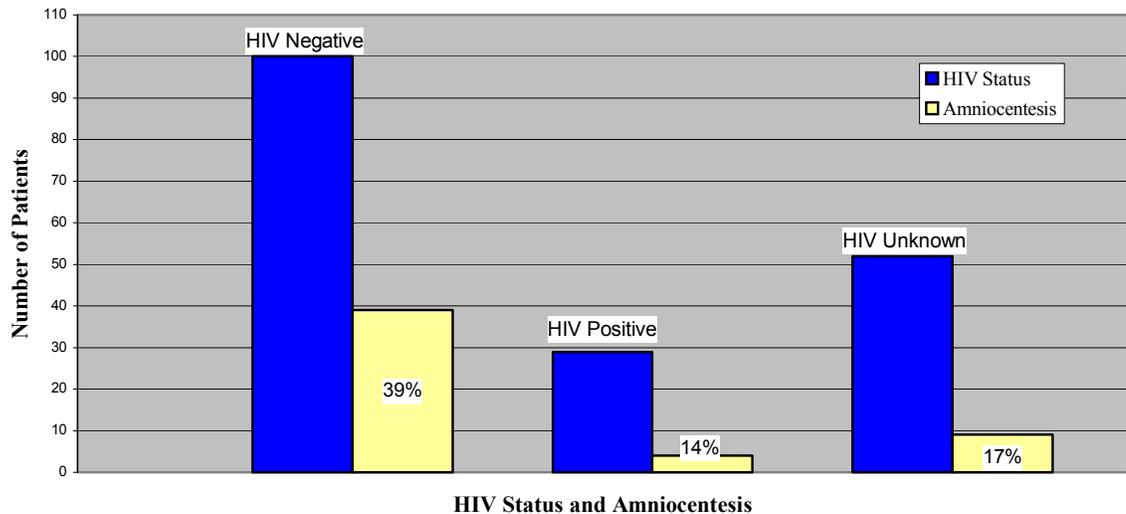


Figure 3-3 HIV Status and Amniocentesis Uptake: February to July 2003

Figure 3-3 illustrates that 40 (48%) of the 83 HIV negative women in the 2003 study group accepted amniocentesis for chromosome analysis of the fetus, relating to their advanced age. This was in contrast to those women who were HIV positive, where 2 (13%) of the 15 had prenatal testing. There was therefore a strongly statistically significant difference in the uptake of prenatal testing between the HIV negative and HIV positive women ( $p=0.006$ ). Amniocentesis uptake among the women whose HIV status was unknown was 23% (16/71) in the 2003 sample group.



**Figure 3-4 HIV Status and Amniocentesis Uptake: February to July 2004**

Figure 3-4 illustrates that 39 (39%) of the 100 HIV negative women in the 2004 study group accepted amniocentesis for chromosome analysis of the fetus, relating to their advanced age. This was in contrast to those who were HIV positive, where 4 (14%) of the 29 had prenatal testing. This is a statistically significant difference in uptake of prenatal testing ( $p=0.013$ ). The amniocentesis uptake among the women whose HIV status was unknown was 17% (9/52) in the 2004 sample group.

Combining the data from both six-month study groups, 79 (43%) of 183 HIV negative women had amniocentesis, with 6 (14%) of the 44 HIV positive women and 25 (20%) of the 123 women of unknown HIV status choosing to have prenatal testing (Table 3-5).

There was therefore an extremely significant difference in uptake of amniocentesis, with the HIV positive women appreciably less likely to have prenatal diagnosis for chromosome analysis than the HIV negative women ( $p < 0.001$ ).

**Table 3-5 Rates of amniocentesis uptake in HIV negative, HIV positive and HIV unknown women.**

<b>Prenatal Tests</b>	<b>HIV negative</b>	<b>HIV positive</b>	<b>HIV unknown</b>
<b>2003</b>	40 (48%)	2 (13%)	16 (23%)
<b>2004</b>	39 (39%)	4 (14%)	9 (17%)
<b>Total</b>	79 (43%)	6 (14%)	25 (20%)

From Table 3-5 it is clear that there was no difference in the uptake of invasive prenatal testing between HIV positive women of the 2003 and 2004 groups: two (13%) of 15 HIV positive women in 2003, and four (14%) of 29 HIV positive women in 2004 chose prenatal testing ( $p = 1.0000$ ). In 2003, 16 (23%) of 71 women of unknown HIV status had prenatal testing, compared to 2004 where nine (17%) of 52 women of unknown HIV status had prenatal testing for chromosome abnormalities; there was no significant decrease in the number of amniocenteses performed on women whose HIV status was unknown ( $p = 0.5064$ ). A total of 110 amniocenteses were performed in the two six month periods combined, and 25 (23%) of these were on women of unknown HIV status.

### **3.1.6 Maternal Age and Prenatal Testing**

In the six months of 2003, 47 (28%) patients were 40 years and older; 20 (43%) of these had amniocenteses. Of the 122 (72%) patients younger than 40 years, 38 (31%) had

amniocenteses. Data from the 2004 group, showed a similar pattern: 61 (34%) women were 40 years and older, with 23 (38%) of these choosing amniocentesis. Of the 120 (66%) women less than 40 years of age seen in 2004, 29 (24%) accepted invasive prenatal testing. Combining the data from the two six-month study groups shows that there was a significantly higher uptake of invasive prenatal testing in the older women compared to those younger than 40 years. Table 3-6 illustrates that 67 (28%) of the 243 younger women chose to have invasive testing, while 43 (40%) of the 107 older women underwent invasive prenatal testing ( $p = 0.024$ ).

**Table 3-6 Uptake of prenatal testing in older and younger AMA women.**

<b>Age Group</b>	<b>Amniocentesis Number (%)</b>	<b>No Amniocentesis Number (%)</b>	<b>Total</b>
<b>&lt;40 years</b>	67 (28%)	176 (72%)	243
<b>40+ years</b>	43 (40%)	64 (60%)	107
<b>Total</b>	110 (31%)	240 (69%)	350

Table 3-7 illustrates that there was no statistically significant difference in HIV positive rate in these two age groups, with 32 (13%) of 243 tested women younger than 40 years being HIV positive, compared to 12 (11%) of 107 tested women aged 40 years and older being HIV positive ( $p=0.612$ ).

**Table 3-7 Comparison of HIV status of older and younger women of AMA.**

<b>Age Group</b>	<b>HIV Positive (%)</b>	<b>HIV Negative or Unknown Status (%)</b>	<b>Total</b>
<b>&lt;40 years</b>	32 (13%)	211 (87%)	243
<b>40+ years</b>	12 (11%)	95 (89%)	107
<b>Total</b>	44 (12%)	306 (88%)	350

### 3.1.7 Impact of Counsellor

No significant difference could be established between uptake of the amniocentesis and the counsellor involved (Table 3-8): grouping counsellors according to their background, doctors versus non-doctors, it was shown that there was no significant increase in the number of patients agreeing to testing where they had been counselled by a doctor rather than a counsellor or nurse ( $p=0.269$ ). The sample was too small to compare uptake of prenatal testing between individual counsellors and doctors.

**Table 3-8 Uptake of prenatal testing between patients seen by either a genetic counsellor or a doctor from the Department of Human Genetics.**

<b>Counselled</b>	<b>Amniocentesis Number (%)</b>	<b>No Amniocentesis Number (%)</b>	<b>Total</b>
<b>Counsellor</b>	89 (30%)	206 (70%)	295
<b>Doctor</b>	21 (38%)	34 (62%)	55
<b>Total</b>	110 (31%)	240 (69%)	350

## 3.2 Questionnaire

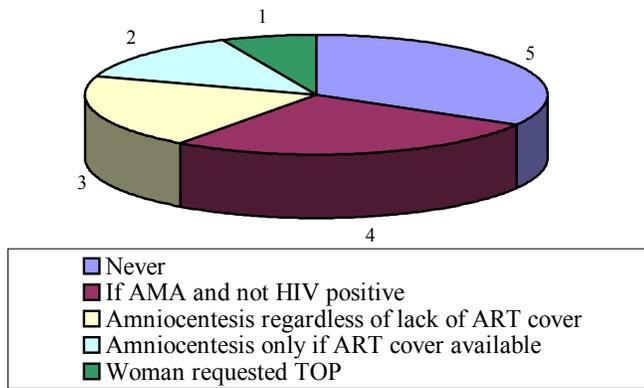
The second part of the study was a survey, utilising a questionnaire as the research instrument. The questionnaire was developed in consultation with a clinical geneticist. Women in the six-month 2004 sample who were HIV positive were invited to answer questions regarding their HIV status and the pregnancy. Of the 181 women, 29 (16%) were of known HIV positive status, and 15 (52%) of these voluntarily participated.

Twelve (80%) of the 15 women said their pregnancy was unplanned, and only three (20%) were aware of the risks associated with AMA.

Of the 15 women, three (20%) patients said that they had not been given any advice regarding the risks of mother to child transmission (MTCT). Twelve (80%) women were advised about avoidance of breastfeeding. Ten women (67%) remembered being told about the value of taking nevirapine at the onset of labour. Not all of these women were clear on how this affected the risk of infection in the baby: eight women (53%) knew that a risk of the baby being infected remained but that it was reduced. Four (27%) thought there was no risk of MTCT with the use of nevirapine perinatally, one woman (7%) thought her baby would also be infected because of her HIV positive status, one (7%) woman thought the risk of transmission would remain high, while one (7%) woman said she did not know what effect the nevirapine would have regarding MTCT.

Nine (60%) of the women said that they had told their partners about their HIV positive status, and five (33%) said their partners had also been tested.

Four (27%) of the women said that they would have agreed to prenatal testing if they had not been HIV positive, two (13%) would have agreed to testing if antiretroviral cover was readily provided and three (20%) said they would have amniocentesis regardless of HIV status or availability of antiretroviral prophylaxis. Five (33%) women said they would not have wanted testing even if they had been HIV negative. One (7%) woman requested a termination of pregnancy and was referred to the gynaecology outpatients department for further management (Figure 3-5).



**Figure 3-5 Circumstances under which the HIV Positive patients would consider amniocentesis.**

Women who are HIV positive and pregnant have the option of selective termination of pregnancy up to 20 weeks gestation because of the risk of mother to child transmission of HIV during pregnancy and birth (South Africa. Government Gazette, 1996: 4). Eight (53%) of the 15 women said they had been advised about the risk of the baby becoming infected with HIV, but only two (13%) women remembered being told about the option of termination of pregnancy because of this risk. Of the 15 women, five (33%) said they would consider the option of termination of pregnancy, six (40%) said they would not consider a termination based on HIV transmission risk, and four patients (27%) were already too far advanced in their pregnancies to be offered a termination.

There was a second HIV positive patient, who did not answer the questionnaire, but requested termination of pregnancy and was referred to the gynaecology outpatients department, Chris Hani Baragwanath Hospital.