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# The influence of HIV status on woman of advanced maternal age presenting for generic counselling

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# 2 METHODS

There were two parts to this study investigating the influence of HIV on women of AMA attending Genetic Counselling Clinics in Johannesburg. The first, and main component, was documenting and comparing data over two six-month periods, February to July 2003 and February to July 2004. The number of women of AMA, their age and HIV status, as well as their decisions surrounding prenatal testing for chromosome abnormalities in the fetus was documented. The second part of the study took place over the six months from February to July 2004 and, in addition to the above, investigated the HIV positive AMA women's perceptions regarding the impact of HIV on themselves and their fetuses. This was done using a questionnaire for the HIV positive AMA women in the 2004 sample.

## 2.1 File Analysis

### 2.1.1 Population

Pregnant women, 35 years and older, are routinely referred to the Genetic Counselling Clinics at three academic hospitals in Johannesburg – Johannesburg General, Coronation and Chris Hani Baragwanath Hospitals - by the Antenatal Clinics of these hospitals or from other secondary hospitals in Gauteng. AMA women who have not had ultrasound examination to determine the gestational age of the pregnancy are sent for sonar examination prior to counselling. If they are found to be less than 24 weeks gestation they are counselled about their risk for having a baby with a chromosome abnormality due to their advanced maternal age, and they are offered the option of prenatal testing. CVS is

available to women who are less than 14 weeks pregnant, while amniocentesis is performed until the 23rd week of pregnancy. AMA women requesting prenatal testing for chromosome abnormalities undergo the procedure on the same day when possible, or are booked for the procedure within the following week.

### 2.1.2 Setting

Weekly Genetic Counselling Clinics are held at Johannesburg General Hospital and Coronation Hospital, and AMA women attending these are offered amniocentesis for chromosome analysis of the fetus. At Chris Hani Baragwanath Hospital, Genetic Counselling Clinics are held up to four mornings a week. AMA women are counselled at the Fetal Medicine Centre, where they have access to both CVS and amniocentesis on the same day as counselling.

### 2.1.3 Sample

Two file searches of women of AMA attending the Genetic Counselling Clinics over two six-month periods were carried out. The first documented the period February to July 2003 and the second February to July 2004. The majority of AMA women - 343 (98%) of a total 350 - were seen at the three academic hospitals in Johannesburg. The other seven AMA women (2%) were from either the Kalafong Academic Hospital, Pretoria, seen during the six months of 2003, or the private clinic held at the Donald Gordon Medical Centre, Johannesburg.

The majority of AMA women seen at the antenatal Genetic Counselling Clinics were state patients and the cost of counselling, sonar and testing, as well as the cost involved in preparing a karyotype or PCR aneuploidy screen was carried by the hospital concerned.

### 2.1.4 Data Collection

In the six months of 2003, from February to July, a retrospective analysis of AMA files, containing the women's facesheets and any genetic test results, from the Department of Human Genetics, NHLS, Braamfontein, Johannesburg, was carried out. Facesheets contain patient information such as name, date of birth, occupation and address, as well as detailed obstetric and family histories, and notes documented during the counselling session. Files of women who were referred for AMA were accessed from the department's manual patient diagnosis cards.

Counselling of AMA women was carried out by individuals from varying backgrounds and qualifications. These included medical geneticists, clinical geneticists in training, a genetic nurse, genetic counsellors, genetic counsellor interns and trainee genetic counsellors. Most counselling was conducted in English and some in Afrikaans when both counsellor and counsellee were conversant in the language. If not, counselling was done through a translator fluent in English and the home language of the counsellee.

Information detailing patient age, pregnancy gestation, HIV status, clinic attended and counsellor seen, and decisions surrounding amniocentesis and termination of pregnancy was collected. This information was documented in an Excel spreadsheet.

In the six months of 2004, from February to July, similar information was gathered for AMA women, although the files were accessed shortly after the women had been seen in the clinics. However, prior to this period, the counsellors and doctors involved in AMA counselling were made aware of the importance of documenting HIV status in the AMA women's facesheets during the genetic counselling session.

## 2.2 Questionnaire

HIV positive AMA women attending the clinics in the six months of 2004 were invited to participate in a survey done using a questionnaire (Appendix A and B) which investigated their attitudes and knowledge regarding HIV in pregnancy, and their thoughts on the options of amniocentesis and termination of pregnancy based on the MTCT risk of HIV. Participating in the HIV positive survey added an extra ten minutes to the genetic counselling session. The questionnaire was completed at the end of the counselling session, after women had given their written consent and been assured of complete anonymity (Appendix C). Interviews were conducted by the doctors and genetic counsellors of the Division of Human Genetics, NHLS, and on completion were given to the researcher.

### 2.2.1 Patient Information

Data pertaining to the woman's age, parity, marital status and occupation as well as her gestation were documented. The date of the sonar examination, and the clinic attended were also documented. Thereafter a questionnaire was completed.

### 2.2.2 Check List

The questionnaire consisted of a combination of four open-ended and ten closed questions. The central questions focused on the AMA women's understanding of the risk of HIV mother to child transmission and its consequence; options around termination of pregnancy for this risk, as well as the women's attitude toward amniocentesis – with or without the transmission risk. Reasons for refusing amniocentesis in the HIV positive group were documented.

#### *2.2.2.1 Questions 1 and 2*

The first two questions asked if the pregnancy had been planned, and if the woman was aware of the increased risk of chromosome abnormalities with increasing maternal age.

#### *2.2.2.2 Questions 3 to 7*

The next five questions asked about HIV testing: when had testing been done, if the result was known and if the woman had informed her partner about the test. If the woman indicated that she had informed her partner about her positive result, she was asked if her partner had also been tested or intended to go for testing for HIV.

#### *2.2.2.3 Questions 8 to 10*

Women were asked what advice they remembered receiving regarding the impact of HIV on the future health and care of the baby. Options included the following: risk of baby becoming HIV positive, option of TOP up to 20 weeks gestation, the use of peripartum ART, and avoidance of breastfeeding to reduce the risk of MTCT. The women may not have been given any advice, or been given other advice which they were encouraged to share with the genetic counsellor. The counsellor was also required to ask what the woman thought the risk of MTCT was, with and without perinatal nevirapine prophylaxis, and to ascertain if the woman understood that HIV is a fatal disease.

#### *2.2.2.4 Question 11*

The women who were less than 20 weeks pregnant were asked if they would consider a TOP based on the risk of MTCT.

#### *2.2.2.5 Question 12 to 14*

Women were asked under what circumstances they would consider an amniocentesis. Question 12 was designed to distinguish between those women who would never have an amniocentesis, those who would have considered an amniocentesis if they were not HIV positive, and those who wanted amniocentesis but only with prophylactic ART cover. Question 13 asked if there were other factors which influenced the woman's decision regarding amniocentesis, and question 14 documented if the woman had prenatal testing for chromosome analysis.

## 2.3 Statistical Analysis

Statistical analysis was conducted by a statistician using the Stata Release 8 program to analyse the data from the two six month periods. The Fisher exact test was used, and all statistical tests were two tailed, with p values of $< 0.05$ considered significant. Data from the questionnaire was qualitatively analysed, as there were too few respondents for quantitative data analysis.

## 2.4 Ethical Considerations

HIV positive AMA women were given an information sheet (Appendix C) detailing the reasons for the study, and asked to sign the consent form if they agreed to participate in the study. They were guaranteed of complete anonymity and were assured that their care would not be compromised should they choose not to take part. The questionnaire and front sheet (Appendix A) were coded and the researcher detached the front sheet, containing the woman's name, and these were kept separate from the questionnaires to ensure confidentiality.

Ethical approval for this research project was granted by the Committee for Research on Human Subjects of the University of the Witwatersrand, Johannesburg (Appendix D).