



Reproductive choices made by South African mothers who have a child with Down syndrome

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To the Editor: During pregnancy parents prepare psychologically for the birth of a healthy child. With the birth of a child with a congenital disorder such as Down syndrome (DS), loss of the anticipated healthy child is immediately experienced. This loss creates a crisis for parents, the psychosocial effects of which are immense.¹ Among the issues they have to confront is whether or not to have more children.

DS is common in South Africa, being documented in 1.8 and 2.01 per 1 000 live births in urban and rural black populations respectively.² More than 50% of babies with DS are born to women of advanced maternal age (AMA) (> 35 years).² Children with DS have intellectual disability and dysmorphic features and may have cardiac abnormalities, recurrent infections and intestinal obstruction, among other problems. In South Africa up to 65% of children with DS die before 2 years of age.³

The prevalence of DS pregnancies varies with maternal age.³ The risk rises from under 1:1 000 live births in women under 25 years to approximately 1% at age 40 years and 7% at 48 years.³

Women at increased risk of giving birth to a child with DS should have the option of prenatal screening. This is undertaken by determination of AMA, biochemical screening and ultrasound scanning.³ Women at increased risk should, after genetic counselling, be offered prenatal diagnosis and if applicable termination of pregnancy (TOP).²

Few papers have dealt with women's choices after the birth of a child with DS with regard to reproductive behaviour, prenatal screening and diagnosis in subsequent pregnancies.⁴ The single study of black African mothers with a child with DS reported that their reproductive behaviour remained unchanged after the child's birth.⁵

Objective

This study aimed to determine the reproductive decisions made by South African women who had a child with DS.

A structured questionnaire was used to interview 50 South African women (36 black, 4 Asian and 10 white) with a child

with DS surviving to at least 1 year of age. The questionnaire assessed the mothers' knowledge of DS before diagnosis, what counselling was received and how this knowledge was utilised. Information was also obtained on the mothers' use of family planning, knowledge and use of prenatal screening and diagnosis, and what decisions would be made in future pregnancies.

Results

The mothers' ages at the birth of the child with DS ranged from 18 to 45 years, and 21 (42%) were of AMA. Seventeen (34%) of them knew about DS before their affected child was born; this applied to 9 (90%) of the white women but only 7 (19%) of the black women. In most cases knowledge of DS was very basic.

None of this cohort of women had had prenatal diagnosis in the pregnancy with their child with DS. After the birth of this child, 38 (76%) said they would have prenatal diagnosis in future pregnancies, 7 (14%) would not, and 5 (10%) were unsure.

When asked about TOP, 21 (42%) of the women interviewed said they would consider terminating a pregnancy if DS were detected, 26 (52%) would not, and 3 (6%) were unsure. Of white women, 4 (40%) would consider TOP, 4 (40%) would not and 2 (20%) were unsure. Of the black and Asian women, 19 (53%) and 3 (75%) respectively would not terminate an affected fetus (Fig. 1).

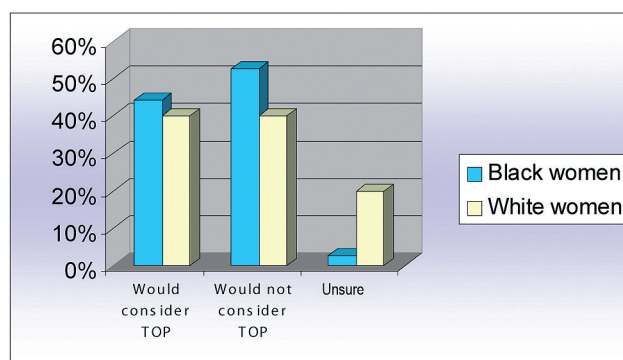


Fig. 1. Comparison of white and black mothers' choice with regard to TOP of a fetus with Down syndrome.

When the mothers were asked whether they were using any contraception after the birth of their child with DS, 12 (24%) had not used or were not using contraception. The majority of the mothers (38, 76%) had used and were still using contraception. After their child with Down syndrome was born, almost all (35, 97%) of the black women did not have

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further children while 5 (50%) of the white women had further children. Of the women who did have further children, all received some form of prenatal testing.

Only 38 (76%) of the mothers received early counselling from a nurse, doctor or genetic counsellor upon receiving the diagnosis of DS. The majority of the white women (9, 90%) received counselling, compared with 26 (72%) of the black women and 3 (75%) Asian women. Of the 7 mothers who had subsequent children after their child with DS was born, 6 had received counselling.

Discussion

The results of this study correlate with other studies, confirming that:

1. Black African women do not generally know about DS and are unaware of the risks to women of AMA of having a baby with DS.⁶

2. Many black African women of AMA are not being offered genetic counselling and prenatal diagnosis.⁶

The results indicate that the majority of women will opt to have prenatal diagnosis if they know they are at an increased risk of having a baby with DS. This highlights the need for increased awareness of prenatal screening and diagnostic services on the part of health practitioners, to ensure they refer women early and appropriately in pregnancy for genetic counselling and the option of prenatal diagnosis. The public should also be informed about DS and the risks of AMA, the availability of genetic counselling and prenatal screening and diagnosis.

Many of the women in this study received some counselling after the birth of their child with DS that seemed to impact on

their subsequent reproductive behaviour. The majority used contraception, and only few have had subsequent children. This contrasts with findings that the reproductive behaviour of Tanzanian women remained unchanged after the birth of a child with DS.⁵ These women had, however, not received counselling. Those of our subjects who did have children subsequent to the birth of their child with DS also all had some form of prenatal screening or diagnosis, a further indication that the counselling they received after the birth of the affected child impacted on their future reproductive behaviour.

Genetic counselling for DS aims to inform individuals and families of the nature and cause of DS, its prognosis and treatment and the probability of having children with DS in future pregnancies, with the options available for risk reduction and prevention.⁴ The results documented in this study indicate that the majority of South African mothers of children with DS living in Gauteng are receiving counselling that impacts on their future reproductive behaviour. This finding confirms the need for parents of infants and children with DS to be referred and given genetic counselling.

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