

Determinants of parents' decisions before and after prenatal testing for Down's syndrome

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Objective

This study assessed the awareness of Down's syndrome (DS) among Indian parents, and their decisions when opting for prenatal testing in future pregnancies, the choices they would make regarding continuation of pregnancy in the case of a diagnosis of DS, and the factors primarily affecting these choices.

Methods

Participants were recruited in two groups: Parents of children with DS (n=36), and expecting parents that have not had children with DS (n=34). Both groups were given questionnaires or structured interviews on their understanding of DS and its implications, and the decisions they might expect to make in the case of future pregnancies. Responses were analysed both quantitatively and qualitatively by thematic analysis.

Results

Of parents of children with DS, 37. 5% had heard of prenatal testing when pregnant, and only 2. 7% were aware of any DS charities. Of the 70 participants, 52. 9% had heard of DS; 56. 3% reported that they would opt for serum screening, 52. 5% for amniocentesis and 4. 4% for cell-free fetal DNA. Concerns most commonly expressed with these tests were lack of definitive diagnosis (36. 7%), risk of miscarriage (44. 6%) and cost (49. 1%), respectively. In the case of a positive DS diagnosis, 83. 6% of those certain of their decision stated they would choose to discontinue the pregnancy. There was a significant effect of religion on this decision. Concerns most commonly expressed about having a child with DS were uncertainty whether it would eventually be able to live independently or earn a living (50%) and frequent hospitalisations (36. 1%).

Conclusion

The results suggest a need for greater focus on public awareness of DS and availability of charitable resources for parents, their primary concerns (repeated hospitalisations, uncertainty of the child's self-sufficiency) being largely financial. Understanding the factors that are of importance to parents in opting for prenatal testing and raising children with DS indicate areas of emphasis for genetic counseling.