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# LETTERS TO THE EDITOR

## Sociocultural problems in genetic counselling

We have recently encountered two cases which highlight the importance of sociocultural factors in genetic counselling.

*Case 1.* A Muslim couple was referred to the genetic clinic for counselling regarding the risk of recurrence of thalassaemia. The couple had previously had an abortion, a stillbirth, and two children who had died of thalassaemia major. It was a first cousin, consanguineous marriage. On investigation, both partners were found to be carriers for β thalassaemia. The husband was a graduate and a photographer by profession. During their first visit, he was accompanied by his wife and mother in law, but subsequently only the husband attended, indicating his wife's inability to attend the counselling session because of 'family commitments'. Two weeks later, his wife and mother in law came to the clinic and were anxious to know whether the wife alone was responsible for the occurrence of the disease. The husband had been harassing them, demanding permission for a second marriage or divorce.

*Case 2.* A similar situation of possible harassment of the wife was anticipated in a Hindu family with a child suffering from Duchenne muscular dystrophy. In this family, both parents were uneducated and of rural background. The parents were accompanied by the paternal grandfather of the child who was educated, with a postgraduate qualification. He requested us not to disclose the carrier state of the wife to the husband, as he anticipated harassment or request for a second marriage by the husband.

Genetic counselling must take into account complex psychological and emotional factors which may affect the consultation. The parents require assistance in dealing with emotions raised by the knowledge that they are both carriers for the same autosomal recessive condition if they are to make an informed decision with regard to management of the pregnancy. This information often leads to feelings of guilt, defectiveness, and loss of self-esteem.

The two cases reported here indicate how a situation can be exploited and misinterpreted in a male dominated society, especially when the wife is uneducated and from a rural background. The problem could be particularly serious in X linked recessive and autosomal dominant disorders where the wife is the carrier of the trait. High values are attached to the marital life of an Indian woman; separation, divorce, second marriage, and the status of the family and individual person in society are regarded differently in the Indian subcontinent compared to western countries. Extra caution is necessary in counselling parents from this background. In such a situation, both the parents and an older member of the family should be included in the counselling session to allow proper interpretation of the information provided to the couple. Written notes and subsequent follow up by a social worker should reinforce the counselling.

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