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41 See reference 1:127–8.
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ECHO

Attitudes to carrier screening for deafness genes

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About one child in a thousand in Britain is born deaf. The cause is genetic in about 60% of cases (0.6 per 1000 births) and about 30% of genetic deafness (0.18 per thousand births) is syndromic and 70% (0.42 per 1000 births) non-syndromic (no other clinical features). About 80% of non-syndromic genetic deafness (about a third of all congenital deafness) is thought to be caused by recessive genes. About 33 recessive genes for non-syndromic deafness have been mapped and 17 identified. Mutations in the connexin26 gene are responsible for about 17% of severe and 30% of moderate non-syndromic congenital deafness in Britain. One mutation, the 35delG allele, is more common in Mediterranean countries than in northern Europe. Testing for connexin26 mutations is possible but unlikely to be used in the UK because it would detect only a minority of cases of non-syndromic deafness. Advances in genetic testing, however, will probably make screening for several recessive deafness mutations feasible and increase the detection rate.

There is insufficient knowledge about public attitudes to carrier screening for recessive non-syndromic deafness and antenatal detection. Deaf people who belong to deaf communities may be against screening and some may prefer to have a deaf child. People with close family members who are deaf are more likely to be in favour of screening, antenatal diagnosis, and possible termination of pregnancy. Researchers in Aberdeen have surveyed non-deaf pregnant women.

One hundred and four women completed a questionnaire after reading an information sheet about genetic deafness. Only four knew of a family member having been born deaf but 26 knew somebody who had been born deaf. None believed themselves to have a high risk of having a deaf child. Twenty five would definitely, and 48 probably, have carrier screening for a recessive deafness gene and if both partners were shown to be carriers 32 women (definitely) and 45 (probably) would want antenatal diagnosis. With a positive antenatal diagnosis, however, only one woman would definitely want termination (6 probably). The mean value placed on carrier screening (willingness to pay) was £42. This value was significantly related to perception of risk, intention to have other antenatal screening tests, low maternal age, and positive attitudes to screening in general.

Most women would value carrier screening and antenatal diagnosis for deafness but few would wish to abort an affected fetus.

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