



Social and Ethnic Differences in Attitudes and Consent to Prenatal Testing

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KEY FINDINGS

We asked over 400 white indigenous and UK Pakistani women their views about prenatal testing and pregnancy termination for a range of different conditions. We compared the attitudes of women from different ethnic and educational backgrounds, and we looked to see if there was any evidence that different women held similar views about which conditions justified testing and which did not. Women's reasons for the views they held were explored in interviews with 60 of the participants, and with 17 mothers of children with genetic disorders. We finished the study by considering the implications of our results for consent procedures.

- The great majority of women wanted testing, and would consider termination, for some conditions but not others
- Only 6% of UK Pakistani women and 4% of white indigenous women wanted no prenatal testing at all.
- 25% of UK Pakistani women and 6% of white indigenous women would not consider termination for any of the 30 conditions on the study list.
- For the great majority of conditions, fewer than a quarter of women would consider a termination of pregnancy.
- UK Pakistani women wanted testing for more conditions, but would consider termination for fewer conditions, than would white women.
- For some conditions, attitudes to termination were more favourable in Pakistani women.
- More educated white women held the least favourable attitudes to prenatal testing, but education did not influence attitudes to termination.
- Women from all groups were most in favour of testing, and of termination, for the same four conditions - anencephaly, trisomy 13 or 18 (which cause severe learning difficulties and death within months), quadriplegia, and Duchenne muscular dystrophy.
- The consistency in women's identification of "severe" conditions was strongly supported by the qualitative results, but there was a great diversity of views about the "less severe" conditions.

RESEARCH TEAM

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The study used a combination of quantitative and qualitative research methods to obtain the views of over 400 white indigenous and UK Pakistani women about prenatal testing and pregnancy termination for a range of different conditions. About half the sample were from each ethnic group, and half of each group were educated beyond GCSE level. Questionnaires and interview schedules were piloted, and administered in English, Urdu, or Mirpuri.

Participants had all recently had a baby. They were recruited antenatally (because it was easier to access them), but data were collected postnatally (because of the potentially sensitive nature of the subject matter); 77% of those recruited completed questionnaires. These contained 30 brief descriptions of different (unnamed) conditions, and women indicated for each whether they would want a prenatal test, and a termination should the baby be affected. To encourage concentration on the conditions, rather than on currently available testing procedures, participants were asked to assume the test would be done early in pregnancy, using routinely collected blood, and it would tell them definitely whether or not the baby had the condition.

Data from 420 women were analysed using standard statistical methods, supplemented by more advanced techniques to explore data structures. Qualitative data from 60 semi-structured interviews were analysed using a framework approach, supported by NVivo software.

The data on prenatal testing showed:

- Except for the minority of women who wanted testing for everything, or for nothing, most women did not have an attitude to prenatal testing that was independent of the condition being

referred to. Most women would have testing for some conditions but not others.

- Pakistani women wanted testing for more conditions than did white women.
- Less educated women wanted testing for more conditions than their more educated counterparts.
- The less educated Pakistani sample differentiated least between conditions, and the more educated white sample differentiated the most.
- The four subgroups converged at the “more serious” end of the spectrum.
- The great majority of women in all four subgroups wanted prenatal testing for: anencephaly, trisomy 13 or 18 (which cause severe learning difficulties and death within months), quadriplegia, Duchenne muscular dystrophy, and severe learning difficulties.

Results regarding termination were:

- Most women did not have an attitude to termination of pregnancy that was independent of the condition being referred to. Most women would consider a termination for at least one of the conditions on the list.
- Pakistani women would consider a termination for fewer conditions than would white women.
- Education did not influence attitudes to termination of pregnancy in either white or Pakistani women.
- For the great majority of conditions, fewer than a quarter of participants would want a termination of pregnancy.
- The four subgroups were very similar in their attitudes for most of the conditions studied. For some conditions, attitudes to termination were more favourable in Pakistanis, for other conditions, they were more favourable in white women. For the majority of conditions, attitudes did not differ between groups.

- For a few conditions, there were differences in attitudes between education subgroups within the white sample; on each occasion, less educated women had the more favourable attitudes to termination of pregnancy.
- Attitudes between subgroups diverged at the “more severe” end of the spectrum.
- Despite the divergence, women from all four subgroups were most in favour of termination for the same four conditions (anencephaly, trisomy 13 or 18, quadriplegia, and Duchenne muscular dystrophy). The groups diverged in respect of the condition which ranked fifth overall, severe learning difficulties: white women were much more likely to favour termination for this condition than were Pakistani women.

In addition, it was clear that many women wanted prenatal tests even if they would not consider a termination of pregnancy for the conditions in question. The difference between the two attitudes was particularly marked in Pakistani women.

The rank ordering of conditions was very similar across subgroups in respect of attitudes to testing, and to termination.

In analyses which examined how closely associated the 30 conditions were in respondents' answers, a small group of conditions -anencephaly, trisomy 13 or 18, quadriplegia, Duchenne muscular dystrophy, and to a lesser extent, severe learning difficulties again stood out. (The analyses were conducted by Prof Tony Coxon of Edinburgh University.) Even women who on the whole rejected testing tended to make exceptions for these conditions. Interest in termination was lower than for testing, but again, if a woman who was essentially against termination was prepared to make exceptions to that

rule, these were the conditions seen to justify an exception being made. Patterns were much less easy to discern for the other 25 conditions. Women's views of “less severe” were much more divergent than their views of “more severe”.

The qualitative interviews corroborated the quantitative finding of a cluster of “more severe” conditions. Women gave a variety of reasons why they thought termination was justified in such cases. Both Pakistani and white women cited effects on the child, the parents (especially the mother) and other children. Pakistani women were more likely to mention religion as a reason for not having a termination, but most thought that serious conditions justified making an exception to this rule. The possibility of family and community disapproval was not an important factor for women in either group.

Interviews conducted with women who had a child (or had lost a child) with a genetic disorder provided additional insights into what parenting a child with a disability or health problem might entail. Overall, this group had more favourable attitudes to termination than the main sample.

When focus groups were shown the items included in the “most severe” cluster of conditions, a clear consensus emerged that members would want tests for all the conditions on the list, and the reasons given were very similar to those given by women who had been interviewed. For the less severe conditions, the cluster approach to prenatal testing was not acceptable to focus group participants, except for people who “wanted to know everything”. Most participants wanted to make their own choices.

About the Project

Although there is an extensive literature on psychosocial aspects of testing for genetic disorders, work on prenatal testing has been dominated by a small number of conditions for which practicable prenatal tests have been available for some time. However, recent advances in DNA technology mean that prenatal tests are now available for a growing number of conditions. In the clinical setting, this means that achieving informed consent is becoming a major problem. In the media, regular stories about “designer babies” convey an impression of widespread acceptance by the public of pregnancy termination for the most minor of problems.

This project provides much needed evidence to inform these debates. It is the first piece of research to seek the opinions of a large and varied sample of women, all of whom had recently had a baby, and were aware of the issues raised by prenatal testing. It is the first study to look specifically at similarities and differences in the attitudes held by individual people, and the first to compare the attitudes of different educational and ethnic groups to testing for different disorders.

Advanced statistical analysis methods were used to identify patterns in the quantitative attitude data. To complement the statistical findings, the study team conducted interviews with a large and varied sample of women, including some who had had a child with a genetic disorder, to help understand the reasons women had for the views that they held.

The study's combination of numerical data and in-depth understanding of individual perspectives has enabled the researchers to dispel many myths. Of the “designer baby”, there was absolutely no sign. Pregnancy termination was acceptable to the great majority of women taking part in the project, but only for a small number of very disabling conditions. Compellingly, the same conditions were identified, in the quantitative and in the qualitative data, by women from different ethnic and educational backgrounds.

When focus groups were shown the items included in the most severe cluster of conditions, a clear consensus emerged that members would want tests for all the conditions on the list, and the reasons given were very similar to those given by women who had been interviewed. For the less severe conditions, the cluster approach to prenatal testing was not acceptable to focus group participants; most participants wanted to make their own choices.

As a source of high quality information on a subject of great public and professional interest, the results of this study are unrivalled in the UK or elsewhere.

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