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Attitudes to Prenatal Testing and Termination of Pregnancy in Saudi Arabia

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Key Words
Prenatal testing · Genetic disorders · Pregnancy, termination

Abstract
Objective: To assess the attitudes of Saudi parents towards prenatal diagnosis and termination of pregnancy for a range of different genetic disorders. ***Methods:*** Two hundred Saudi parents (100 fathers and 100 mothers) completed a structured questionnaire which sought their views about each of 30 different conditions. ***Results:*** The great majority of people would consider a termination of pregnancy for at least one of the conditions studied. Mothers and fathers held similar attitudes towards prenatal diagnosis, but mothers' attitudes towards termination of pregnancy were more favourable. Parents' collective attitudes towards prenatal diagnosis and towards termination of pregnancy were correlated. ***Conclusions:*** Saudi parents are favourably inclined towards prenatal diagnosis, and consider termination of pregnancy to be acceptable for some conditions. New technologies provide parents with more reproductive choices but also present them with more dilemmas.

Work was conducted at the King Faisal Hospital and Research Centre, Riyadh.

Introduction

The development of diagnostic technology for detection of fetal abnormality began in the 1960s and 1970s, with the use of amniocentesis to assess rhesus disease in the fetus [1]. Although the tests that have been offered to date are available because of technology as well as the burden or prevalence of the condition, advances in molecular biology will soon make it possible to offer parents prenatal testing for a large number of different genetic disorders. Genetic diseases are a significant health care and psychosocial burden for the patients, their families, the health care system and the community as a whole [2]. Internationally, two very different positions can be distinguished regarding the role of prenatal testing: (1) reducing the incidence of disease in a population [3] and (2) offering reproductive choice [4].

Previous studies in Saudi Arabia have focused on parents' attitudes towards prenatal diagnosis and termination of pregnancy in the case of haemoglobinopathies [5]. Although there has been growing interest in the attitudes of Western populations towards prenatal testing, little is known about Arab populations [6]. In addition, attitudes toward prenatal diagnosis for a range of different genetic conditions have not been investigated in Saudi Arabia. This is surprising, as a major factor in the decision to terminate a pregnancy for abnormality is known to be the perceived 'severity' of the condition diagnosed, as report-

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ed by different studies [7–10]. However, many studies have found that people perceive the severity of genetic disorders differently [11–17]. Therefore, the present study seeks to benefit from recent developments in the field of prenatal diagnosis, and to assess the views of Saudi parents toward prenatal diagnosis and termination of pregnancy for a range of different genetic conditions.

Methods

The study questionnaire contained 72 items in total, and consisted of two sections. Section 1 (12 items) collected demographic information about the respondents. Section 2 contained 30 scenarios covering a range of different conditions, developed for use in a UK study [17]. For each scenario, there were two questions, covering attitudes to prenatal testing and to termination of the pregnancy. Parents were given three options for each scenario (no, yes, not sure).

The scenarios in section 2 briefly described the condition as it affects a child; the names of specific disorders were not mentioned: e.g., instead of Turner's syndrome, 'child would be a very short female who might have some medical problems, a normal lifespan and would not be able to have children'; instead of anencephaly, 'child would be born without a brain and die before or soon after birth'; instead of thalassaemia, 'child would have a blood condition, require blood transfusions and medical treatment throughout life and have a shortened lifespan'.

The scenarios all reflected real conditions, and included mental, physical and sensory disabilities. Prenatal tests for some of the conditions are already available, and could feasibly be developed in some form for most of the others in the foreseeable future. In Saudi Arabia, however, prenatal testing is not offered routinely for any of the conditions, so for these parents, all tests were being offered on a hypothetical basis, and this was made clear, as were the risks of prenatal diagnosis procedures.

The questionnaire was designed to be interviewer administered, because Saudi people are not familiar with self-completion questionnaires. The study recruited parents from visitors to outpatient clinics at the King Faisal Specialist Hospital and Research Centre (KFSHRC) in Riyadh, Saudi Arabia. All were Saudi and accompanying a relative to the hospital. They came from different regions in Saudi Arabia, because KFSHRC has facilities which are not available in other hospitals.

Because of the custom of consanguineous marriage, genetic conditions are relatively common in Saudi Arabia, and the idea of a genetic disorder is a familiar one to Saudi parents. To reduce the influence on parents' attitudes of direct experience with particular conditions, potential participants in the study were asked if they had a child affected by a genetic disorder, and those who answered yes were not considered eligible to participate.

When parents agreed to participate in the study, the researcher interviewed fathers in one room, and a trained nurse interviewed mothers in another room. However, because of the way clinics and waiting rooms were organized, it was not possible to ensure that both members of a couple were interviewed. Recruitment continued until 100 fathers and 100 mothers had been interviewed. The interview took from 20 to 25 min for each individual.

The questionnaire data was entered into the Statistical Package for the Social Sciences (SPSS) programme. Data was initially summarized in the form of frequencies and percentages, based on the three categories of response in the questionnaires. A total score reflecting each participant's attitudes to testing was then calculated by scoring the no, not sure, and yes responses as 0, 1 and 2, respectively, then adding the scores across the 30 conditions to give a measure with a minimum value of 0 (would not want testing for any of the 30 conditions) and a maximum of 60 (would want testing for all of the 30 conditions). A total score reflecting attitudes to termination for fetal abnormality was similarly calculated for each participant.

The study was conducted from July 2002 to February 2003.

Results

The majority of parents were happy to express their views, and 94.8% (200/211) of those approached agreed to participate. Four parents declined because of the sensitive nature of the subject matter, and the other 7 gave practical reasons for non-participation, such as not wanting to miss transport home.

The mean age of the fathers was 35.2 (SD = 6.5), range 21–50 years. The mean age of the mothers was 30.9 (SD = 5.9), range 21–45 years.

The views of all respondents were first summarized for each condition separately in terms of the percentage giving each reply. Figures 1 and 2 show the percentage of 'yes' responses for prenatal testing and termination of pregnancy, respectively. For consistency of presentation, in both figures the conditions have been ranked (and numbered from lowest to highest) according to the percentage of 'yes' responses in the combined sample to the questions about termination of pregnancy.

Acceptance of prenatal testing was highest for severe learning difficulty, thalassaemia, quadriplegia, Duchenne muscular dystrophy and lowest for cleft lip and palate, coronary disease at 50 years of age, Alzheimer's disease, and the child not being of the sex desired by the parents. For termination of pregnancy, acceptance was highest for children born without brain (anencephaly), for trisomy 13 or 18, severe learning difficulty, and quadriplegia, and lowest for children not of the sex desired by parents.

Statistically, it is important to know whether parents have significantly different views of prenatal testing and termination of pregnancy for different genetic conditions. The non-parametric Cochran Q test for the difference between correlated proportions was used because, in this study, the same participants had expressed their views about the 30 conditions to be compared. Differ-

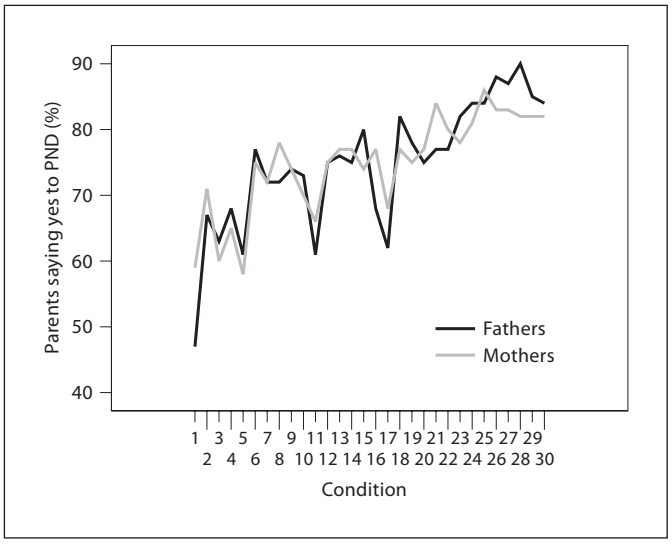

Fig. 1. Parents' attitudes to prenatal diagnosis (PND) as regards different conditions. 1 = Not preferred gender; 2 = cleft lip and palate; 3 = coronary disease at age 50 years; 4 = mild learning difficulties/mental handicap; 5 = Alzheimer's disease; 6 = deafness; 7 = grossly overweight; 8 = moderate learning difficulties/mental handicap; 9 = blindness; 10 = autism; 11 = dwarfism; 12 = cancer; 13 = Huntington's disease; 14 = fragile X; 15 = cystic fibrosis; 16 = Turner's syndrome; 17 = high risk of alcoholism; 18 = absent limb; 19 = epilepsy; 20 = Klinefelter's syndrome; 21 = phenylketonuria; 22 = schizophrenia; 23 = diabetes; 24 = proteus syndrome; 25 = Duchenne muscular dystrophy; 26 = thalassaemia; 27 = quadriplegia; 28 =severe learning difficulties/mental handicap; 29 = trisomy 13 or 18; 30 = anencephaly.

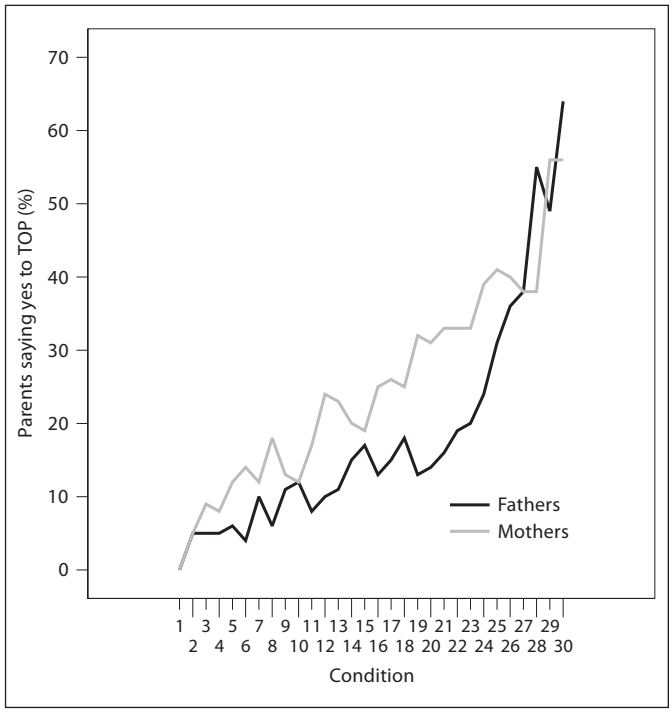

Fig. 2. Parents' attitudes to termination of pregnancy (TOP) as regards different conditions (listed in the legend to fig. 1).

ences between conditions were highly significant in the case of prenatal testing ($Q = 396.2$, $p < 0.001$) and termination of pregnancy ($Q = 977.4$, $p < 0.001$). These findings indicate that Saudi parents held very different attitudes to the different conditions in this study.

In order to find out if there was a relationship between parents' collective attitudes toward prenatal diagnosis and their collective attitudes towards termination of pregnancy, Spearman's test was used to find the correlation between the two sets of attitudes, based on the numbers saying 'yes' for each condition. It should be noted that some kind of positive relationship was anticipated, since at an individual level, people who said 'no' to prenatal diagnosis did not say 'yes' to termination of pregnancy. However, of those who wanted prenatal diagnosis (usually the majority), only a proportion wanted termination of pregnancy, so the relationship between the two attitudes at a collective level remains of interest. It was found that the collective responses correlated significantly and positively with each other (Spearman's rho = +0.334, $p < 0.001$).

Individual Parents' Attitudes to Prenatal Testing and to Termination of Pregnancy for the 30 Conditions

When total scores were calculated for attitudes to prenatal testing, 33% of mothers were found to have scores in the 56–60 range, indicating that they wanted testing for all, or nearly all, the conditions on the list. The corresponding figure for the fathers was 18%. At the other end of the spectrum, only 3% of the mothers and 3% of the fathers wanted no prenatal testing at all.

Using a similar procedure, it was found that 12% of the mothers would not consider termination for any of the conditions on the list. The corresponding figure for the fathers was 8%.

Comparing total scores, it was found that mothers and fathers had similar, and very favourable, attitudes toward prenatal diagnosis (maximum score is 60; medians are 53 and 56, respectively). Exploratory analyses revealed no significant differences for any of the 30 conditions. However, mothers had significantly more favourable attitudes than fathers towards termination of pregnancy (maxi-

mum score is 60, medians are 18.5 and 12, respectively; Mann-Whitney U = 3,924, Z = –2.63, p = 0.008).

Differences between specific conditions were not predicted in advance, but were investigated as a guide to future research. These exploratory analyses showed that mothers were more favourable towards termination of pregnancy than fathers in 10 conditions: proteus syndrome (39 vs. 24%; p = 0.033), schizophrenia (33 vs. 19%; p = 0.036), phenylketonuria (33 vs. 16%; p = 0.008), Klinefelter's syndrome (31 vs. 14%; p = 0.006), epilepsy (32 vs. 13%; p = 0.002), Turner's syndrome (25 vs. 13%; p = 0.046), Huntington's disease (23 vs. 11%; p = 0.037), cancer (24 vs. 10%; p = 0.014), moderate learning difficulty (18 vs. 6%; p = 0.015), and deafness (14 vs. 4%; p = 0.024). Fathers were significantly more favourable than mothers towards termination of pregnancy in severe learning difficulty (55 vs. 38%; p = 0.023). These differences (especially the one going against the overall trend) might have arisen by chance and future research would be needed to confirm the findings reported.

Discussion

This study was successful in assessing Saudi parents' attitudes towards prenatal diagnosis and termination of pregnancy in a range of 30 different conditions, and a wide range of views was discovered. There was an unexpectedly high level of acceptance of prenatal diagnosis and termination of pregnancy for a range of different conditions in this Muslim sample, but there were also big differences between conditions.

According to the findings in the present study, the characteristics of each condition have a large impact on Saudi parents' attitudes to prenatal diagnosis and termination of pregnancy, which is similar to the findings of studies conducted in Western populations [15]. Studies which have looked at attitudes to prenatal diagnosis and termination of pregnancy without specifying the kind of condition that causes impairment or disability to the child [18–20] must therefore be interpreted with caution. In particular, it must not be assumed that parents who reject termination for some conditions will reject it for all conditions. In the present study, 88% of mothers and 92% of fathers would consider termination for at least one of the 30 conditions investigated.

When conditions in the present study were ranked according to the parents' attitudes towards termination of the pregnancy, it was found that in the cases of mild disorder or in the cases of severe clinical conditions, rank orders were similar to those reported from other populations [12, 15, 17]. For instance, data from participants in the present study and in the above three studies showed that the situation in which they would be least inclined to favour termination of the pregnancy was sex preference (0.4, 2, 1.9%, respectively), and one of their highest-ranked choices was severe learning difficulty (58, 55, 35.7%, respectively). For prenatal diagnosis [15, 17] a similar trend was found in rank order for sex preference (18 and 34.4%, respectively) and one of the highest conditions in the ranking order was severe learning difficulty (68 and 78%, respectively).

In the present study, besides severe learning difficulties, termination was found to be most acceptable for anencephaly, trisomy 13 or 18, quadriplegia, and thalassaemia. These conditions are in some respects very different, suggesting that parents are considering the wider impact on the child and family of having a particular condition, rather than making distinctions based on a single 'organizing principle' such as mental or physical disability.

Overall, attitudes towards termination of pregnancy were more favourable in the mothers than in the fathers in the present study. The reasons can only be speculative, but it may be that mothers had a greater appreciation than fathers of the day-to-day realities of bringing up a child with certain kinds of disabling conditions. Attitudes towards prenatal diagnosis were highly favourable, and very similar in men and women. The methods used to recruit and identify participants in the present study did not permit the views of husbands to be compared directly with the views of their wives. However, it follows from the overall figures that differences in views may arise between the two members of a couple, particularly for some conditions, which has implications for present and future counselling services.

For most of the conditions studied, the majority view of parents was that they wanted prenatal diagnosis to find out whether their baby had a particular condition, but they were not willing to consider termination of pregnancy for that condition. For a small number of conditions, however, a substantial proportion of parents said they were willing to consider a termination, indicating that Muslim parents' reasons for wanting prenatal diagnosis are complex and differentiated. Parents faced with a real decision may not of course behave as they thought they would, and many factors other than perceived severity, including gestation, family composition, experience with the condition, and parents' level of education [18–23] are known to influence the decision to terminate an affected pregnancy, when that option is available.

In the past, Islamic authorities in Saudi Arabia have allowed termination of pregnancy only if the woman's life was at risk. After the awareness of genetic conditions increased, and prenatal diagnosis became possible, the Islamic authorities had to give a fatwa (an Islamic edict) based on the severity of the condition, the criterion being whether or not it is treatable, in the physicians' view, in order to safeguard family life by preventing the birth of children with such conditions. Therefore, Islamic authorities agreed that two physicians should decide whether the condition is severe or not. They will decide what they think and tell the Islamic authority. Alkuraya and Kilani [5] showed the importance of the fatwa to Muslim parents and how their attitudes to termination of pregnancy changed after they were told the correct fatwa. However, physicians sometimes have different opinions about the severity of a condition [16] and parents' views are not necessarily taken into account. Physicians need to have a clearer view about parents' perspectives, so these can be conveyed to the religious authorities. By these means, parents' views may influence whether or not a condition is classed as severe by the religious authorities, and hence, whether or not termination is permitted.

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