ORIGINAL ARTICLE

Attitudes to prenatal diagnosis and termination of pregnancy for 30 conditions among women in Saudi Arabia and the UK

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ABSTRACT

Objective The aim of this research was to compare attitudes between women from different cultural and/or religious backgrounds toward prenatal diagnosis (PND) and termination of pregnancy (TOP) for 30 different conditions.

Methods A questionnaire examining parents' attitudes toward PND and TOP for 30 different conditions was completed by 100 Saudi, 222 UK-White, and 198 UK-Pakistani women. Comparison of overall attitudes with PND and TOP between groups was carried out, and a total score reflecting attitudes was obtained.

Results In general, there were positive attitudes toward PND among the three groups surveyed. The attitudes of Saudi and UK-Pakistani women toward PND were more favorable than UK-White women. Overall, acceptance of TOP was lower than for PND. For the majority of conditions, acceptance of TOP was highest in Saudi women and lowest in UK-Pakistani women.

Conclusion Attitudes toward TOP were significantly different between the three groups and may be influenced by cultural and/or religious factors. Availability of social services, genetic counseling, and rehabilitation centers may also influence attitude toward PND and TOP. © 2012 John Wiley & Sons, Ltd.

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INTRODUCTION

Previous studies have explored the public's opinion of genetic testing and how the characteristics of genetic disorders might influence people's attitudes toward prenatal genetic screening and termination of pregnancy (TOP).[1,2] Studies in Europe and in other western populations have suggested that, on average, around one-third to one-half of the population would hypothetically consider the termination of an affected fetus. However, these figures vary widely and seem to correlate with the perceived severity of the abnormality.[1,3,4] In a non-western population, a study of attitudes in Pakistan[5] has reported parents making the same kinds of distinctions between conditions. Although comparatively little is known about the attitudes of Arab populations,[6–10] it can be anticipated that the reaction to prenatal testing will vary from one country to another, depending on the population's religious beliefs, health care system, traditions, and cultural background. The population in Saudi Arabia investigated in the present study is distinctive in these respects: although Saudis share many common cultural aspects with Arabs and Muslims worldwide, their culture is unique in many ways.

For example, the way that Saudi families live alongside other families, sharing common interests and lifestyles may increase the likelihood of stigma, because nothing can be hidden from other families. Saudi parents are very careful, if anything happens to their children, such as genetic abnormalities, not to tell anyone, to save the family's face.[11] Therefore, a disabled child would create major changes in the family's social life, such as isolating the family from others and keeping the family constantly busy, and unable to think about their social life.[12] Those who suffer from the stigma of disease are socially isolated[13]; hence, stigmatization may be less visible or more widespread, depending on where the parents of disabled children live. Additionally, female carriers of certain genetic condition might be labeled as not fit for marriage.[14] Until recently, studies of attitudes to prenatal testing and TOP conducted in Saudi Arabia focused on parents' attitudes toward prenatal diagnosis and TOP for hemoglobinopathies[15]

and assumed that religious belief was the main factor that influenced parent's attitudes.[11,15,16] Attitudes toward the prenatal diagnosis of different genetic conditions were neglected, even though such conditions are common in Saudi Arabia and studies elsewhere have found that people perceive the severity of genetic disorders differently. A recent study in Saudi Arabia[17] showed that attitudes of people from Saudi to prenatal testing and TOP also varied markedly depending on the condition being tested for. Al-Sulaiman and Hewison[17] used the same survey instrument as in the previous work where the attitudes of White and Pakistani women were compared with the UK. Thus, there is an opportunity to undertake a comparative analysis. Because the focus of the studies was attitudes to different conditions, not to current testing technologies, participants in both studies were asked to consider a hypothetical situation in which testing did not carry a miscarriage risk. The aim of this study is to present a comparison of the views of Saudi women and women from other cultural and/or religious backgrounds toward prenatal diagnosis (PND) and TOP for a range of different conditions.

PARTICIPANTS AND METHODS

Details of the samples and data collection methods used in the UK and in Saudi Arabian studies have been reported previously.[3,17] A questionnaire seeking attitudes toward prenatal testing and TOP for 30 different conditions were self-completed or interviewer assisted as required. These conditions were the following: (1) not preferred gender; (2) cleft lip and palate; (3) mild learning difficulties/mental handicap (LD/MH); (4) coronary at 50 years old; (5) Alzheimer's disease; (6) grossly overweight; (7) autism; (8) blindness; (9) deafness; (10) dwarfism; (11) moderate LD/MH; (12) cystic fibrosis; (13) fragile X syndrome; (14) Huntingdon's disease; (15) cancer; (16) Turner's syndrome; (17) absent limb; (18) high risk of alcoholism; (19) Klinefelter's syndrome; (20) epilepsy; (21) phenylketonuria; (22) schizophrenia; (23) diabetes; (24) quadriplegia; (25) severe LD/MH; (26) proteus syndrome; (27) thalassemia; (28) Duchene muscular dystrophy; (29) trisomy 13 or 18, and (30) anencephaly.

The questionnaire was translated to Urdu and Arabic languages. The questionnaire contained scenario descriptions of 30 unnamed conditions and asked two questions for each condition: whether participants would consider a prenatal test and whether participants would consider a termination for an affected pregnancy. The response options for each of the two questions were 'no', 'not sure', or 'yes'. The questionnaire was completed by White and Pakistani women in the UK and by Saudi women in Saudi Arabia. All participants had recently had a healthy baby.

The total number of completed questionnaires was 100 from Saudi, 222 UK-White, and 198 UK-Pakistani women. For the comparison of overall attitudes between groups, it was necessary to summarize attitudes across conditions in order to avoid multiple comparisons. Each woman could say 'no', 'not sure', or 'yes' to prenatal testing for each of the 30 conditions. To obtain an overall measure of attitudes to testing, these alternatives were scored as 0, 1, and 2, respectively, and the scores added across conditions, giving 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 was then calculated for each participant following a similar procedure. During the interview with the parents, the various disease manifestations and consequences on the fetus or the child for each of the 30 conditions were fully described and all the parent's questions were adequately answered. All the interviews were conducted in a private setting and lasted for at least 60–90 min. The interviewer gave a reasonable time for reflection and some of the interviews lasted more than 2 h. The parents were not selected on the basis of age, education, social, or geographical background.

RESULTS

Descriptive summary for each condition

Figures 1 and 2 show the percentages of Saudi, UK-White, and UK-Pakistani women answering 'yes' to the questions about prenatal testing and TOP, respectively. For clarity, the same rank ordering of conditions is used for the two graphs, namely, the percentage of women in the combined UK sample saying 'yes' to prenatal testing. For brevity, the names of conditions rather than the scenario descriptions are used in presenting the results.

Figure 1 shows a high degree of similarity in the attitudes to PND of Saudi and UK-Pakistani women across conditions. For the majority of conditions, UK-White women held noticeably less favorable attitude toward PND, although attitudes converged at the 'more serious' end of the spectrum, where at least three quarters of women in all three groups wanted PND for anencephaly, Trisomy 13 or 18, quadriplegia, Duchene muscular dystrophy, and severe learning difficulties.

Figure 2 shows a somewhat different pattern. For most of the conditions, Saudi women had more favorable attitudes to TOP than either White or UK-Pakistani women. This was true for all conditions, except severe LD/MH, trisomy 13, quadriplegia, and born without brain. Women from all three groups tended to be most in favor of termination for the same conditions: anencephaly, trisomy 13 or 18, quadriplegia, Duchene muscular dystrophy and severe learning difficulties.

Group comparison of attitudes toward prenatal diagnosis

The median value of the total PND attitude measure was 42 for the White UK women, 56 for the UK-Pakistanis, and 56 for the Saudi women. The full range of scores (0–60) was observed in all three groups. Because of the markedly non-normal distribution of scores, the three groups were compared using the non-parametric Kruskal–Wallis test. This confirmed what was apparent from Figure 1: White women in the UK had significantly less favorable attitudes toward prenatal testing than the other two groups (chi-square = 46.8, d.f. = 2, $p < 0.001$).

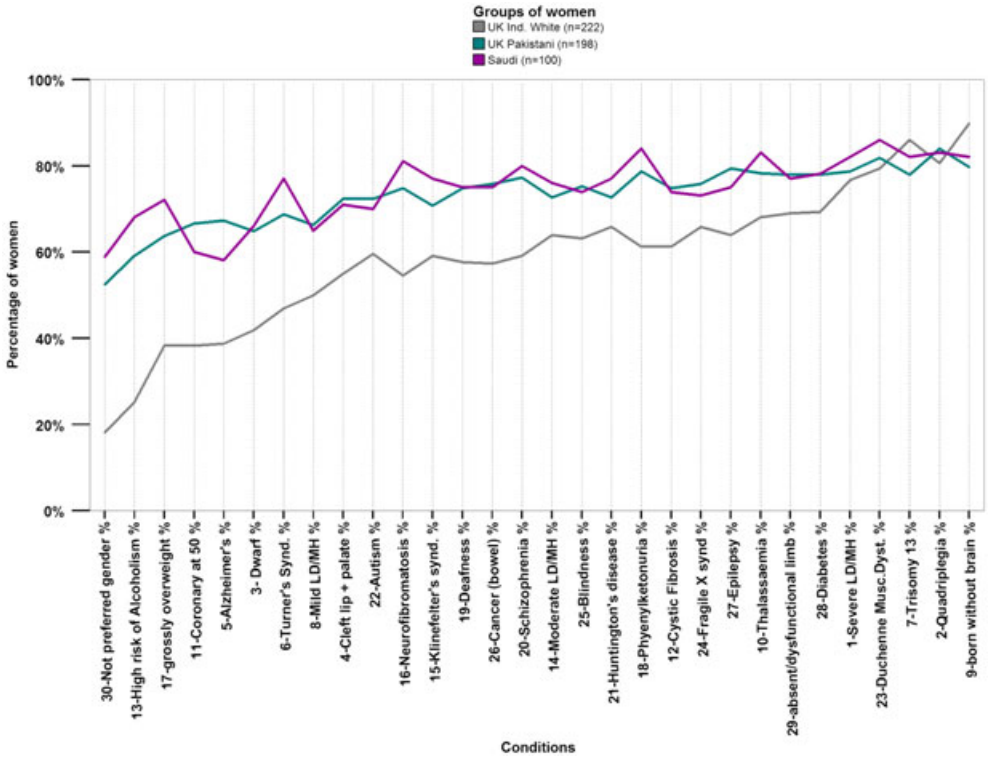

Figure 1 Attitudes toward prenatal diagnosis for 30 conditions

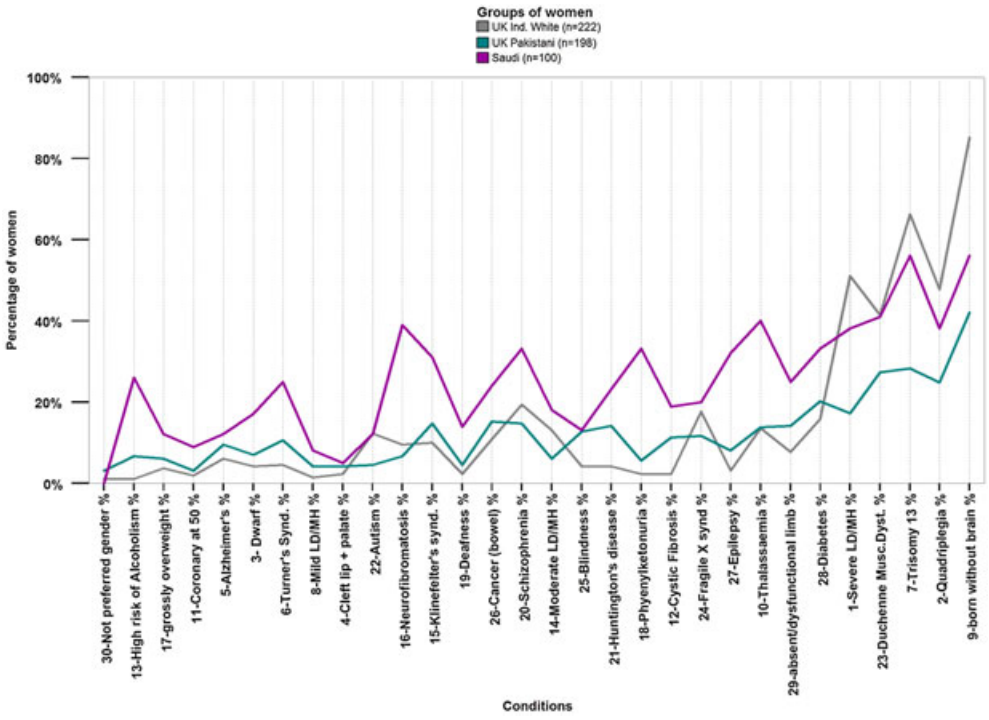

Figure 2 Attitudes toward termination of pregnancy for 30 conditions

Group comparison of attitudes toward termination of pregnancy

The median value of the total TOP attitude measure was 16.5 for the White UK women (range 0–47), ten for the UK-Pakistanis (range 0–55), and 18.5 for the Saudi women (range 0–58). When the three groups were compared using the Kruskal–Wallis test, this showed that attitudes toward termination were significantly different between the groups (chi-square = 20.3, d.f. = 2, $p < 0.001$), with UK-Pakistanis having the least favorable attitudes.

DISCUSSION

Although there is much data concerning western populations and their attitudes toward prenatal testing, these attitudes have scarcely been explored in Arab populations[9] and previous studies in Western countries may not be applicable to Arab societies. This knowledge is very much needed, because genetic disorders are relatively common in the Arab world. The present study was aimed at examining Saudi Muslim women's attitudes toward PND and TOP and comparing them with those of women from different cultures and religious beliefs.

The present study indicated that in all three groups, the majority of women had a positive attitude toward prenatal testing for most of the conditions presented. Saudi women were significantly more favorable to prenatal diagnosis than UK-White women. However, attitudes to prenatal diagnosis were very similar in Saudi and UK-Pakistani women possibly because of the same religious background. The attitudes toward PND of Saudi and UK-Pakistani women were more favorable than those of UK-White women in respect to all but two conditions: trisomy 13 or 18 and anencephaly that cause death at or soon after birth. A possible explanation for this is that Muslim women may not want to go through the religious dilemma associated with TOP for conditions where fetuses will die early or soon after birth.

Attitudes to TOP were much less favorable than attitudes to PND in all three groups; Saudi women held the most favorable attitudes and UK-Pakistani women the least favorable. Contrary to this overall trend, the highest proportion of 'yes' responses for a condition where the child would be born without a brain was among UK-White women (85%). Saudi women were much less approving, (56%) and UK-Pakistani women were the least favorable (43%) toward TOP in such a condition. Attitudes toward TOP for trisomy 13 or 18 showed a similar pattern: the percentage of 'yes' responses were 67%, 56%, and 30% among UK-White, Saudi, and UK-Pakistani women, respectively. This pattern may indicate the influence of religious factors. Muslim parents may think that the conditions where the child will die early represent a mercy bestowed by God upon the parents and the affected child: the burden will be less and there need be no guilt feelings regarding the child's death. Additional factor that may contribute to this is the access to health care resources especially for Saudi women who live in remote areas where good health services may not be available.

Despite the fact that the Saudi women and UK-Pakistani women were Muslims, the two groups had significantly different attitudes toward TOP, which indicates that religious beliefs are only one of the factors that influence attitudes in these circumstances. The reasons for the relatively favorable attitudes in the Saudi group are unclear, but availability and ease of access to health resources may be implicated. Health and other services for a disabled child, and support groups for parents, are certainly more available in the UK than in Saudi Arabia. In Saudi Arabia, social and genetic counseling services are almost unheard-of at villages or even towns outside Riyadh city (the capital). Therefore, the level of support for families with disabled children will be limited and this will certainly influence a more favorable attitude toward TOP. This is not a new concept as previous studies also indicate that lack of health services and rehabilitation centers in the villages increased parents' suffering and made it difficult to cope with their affected child and this will certainly influences parents' attitudes toward TOP.[18,19] Cultural factors may also have an effect on Saudi women attitude toward TOP. Saudi parents usually worry about their daughter's future when she has any kind of impairment or disability, because in traditional marriage arrangements, a mother will enquire after and prefer for her son a wife who is free from impairment or disability, even though the prophet Mohamed (peace be upon him) encouraged Muslim men to look for piety in a bride above other qualities. In Saudi Arabia, cultural importance is also placed on sexual identity and fertility,[20] both of which Saudi parents often associate with physical or behavioral attributes.[21]

The present paper reports responses to hypothetical questions. Evidence from other sources that does, however, lend support to the conclusion that many Muslim Arab parents will accept TOP for a range of fetal anomalies. A study in Tunisia found high levels of acceptance of pregnancy termination for a number of different conditions.[6] Notably, the parents in this study also resembled Saudi parents in that some of their decisions reflected concerns about infertility and about the physical and behavioral manifestations of the condition. Jaber *et al.*[7] asked Israeli Arab mothers who had recently had a child with a congenital anomaly if they would accept a termination of a future affected pregnancy: over half said they would, although timing (before 120 days) was a critical consideration for many. In Lebanon, a study of medical records found no difference in the uptake of invasive prenatal testing following the triple test between Muslim, Christian, and Druze women.[8] Further afield, Arif *et al.*[5] sought to understand the apparent contradiction between the cultural and religious norms in Pakistan and the relatively high rate of pregnancy termination. Using a questionnaire similar to those used in the present study, these authors found high rates of acceptance of prenatal testing, and attitudes to termination that varied across the five conditions studied, from 33% acceptance in the case of Turner's syndrome to 56% for trisomy 13 or 18.

Our study have one limitation which is that hypothetical scenarios of various conditions may not reflect the choices people make in the real world, once acting as 'parent' of an affected child or unborn fetus with a medical condition

In conclusion, Saudi women resemble White and UK-Pakistani women in holding more favorable attitudes to prenatal testing than to TOP. Less expected is the study finding that of the three groups studied, the most favorable attitudes to termination were held by the Saudi women, a pattern that was seen in all but two conditions. Very little is known about the ways in which individual parents in different cultures make the difficult decision about continuing or ending a pregnancy affected by a particular condition and the extent to which religion, culture, and society influence such decisions. Availability of social services, genetic counseling, and rehabilitation centers may also influence attitude toward PND and TOP.

WHAT'S ALREADY KNOWN ABOUT THIS TOPIC?

- In Muslim populations, attitudes toward prenatal diagnosis and termination of pregnancy are influenced by religious beliefs and perceptions of the severity of the tested for condition.

WHAT DOES THIS STUDY ADD?

- Saudi women were more accepting of termination of pregnancy than UK-Pakistani women. Therefore, religious affiliation is not a strong indicator of attitudes. Further research is needed on the social and cultural factors that influence reproductive decision in different Muslim populations

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