

# Attitudes towards Genetic Diagnosis in Pakistan: A Survey of Medical and Legal Communities and Parents of Thalassemic Children

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## Key Words

Genetic screening · Abortion · Consanguinity ·  $\beta$ -Thalassemia

## Abstract

**Objectives:** It was the aim of this study to assess the attitudes of doctors, medical students, lawyers, parliament members and parents of thalassemic children towards genetic diagnosis in Pakistan. **Study Design:** A cross-sectional descriptive survey was conducted among representative samples. **Results:** Five hundred and seventy doctors, 49 lawyers, 178 medical students, 89 parents of thalassemic children and 16 members of parliament (MPs) were included in the survey. The groups showed considerable difference in their attitudes towards different aspects of the issue. A large proportion (88.5%) agreed to the idea of genetic diagnostic screening, especially the parents of thalassemic patients. Premarital carrier screening was favored by 77% of the respondents. Prenatal screening was most favored by the parents of thalassemic children (94.4%). Likewise, a majority of parents of thalassemic children were in favor of abortion in

case of an affected fetus. Genetic self-screening was also favored most by the parents of thalassemic patients (78.2%). Only 24% of the doctors favored making genetic screening mandatory, whereas 63% of the parents agreed to the idea.

**Conclusion:** Attitudes regarding genetic diagnosis are markedly different among various societal groups in Pakistan. The parents of the affected children strongly favor genetic screening as does the medical community, though not as strongly as the parents. The legislative groups, particularly the MPs, are reserved in their support. Genetic diagnosis can help decrease the disease burden in the future. However, it raises a number of ethical issues, which need to be addressed. It is important to educate the population about potential benefits as well as ethical dilemmas involved so that the general public is able to make the right decisions for themselves and their families. Copyright © 2007 S. Karger AG, Basel

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## Introduction

The advancements in molecular genetics and the completion of the human genome project have raised the possibility of genetic diagnosis [1]. Markers for both monogenic as well as complex genetic disorders are being discovered with each passing day. These developments offer tremendous opportunities for better diagnosis and management of diseases on the one hand [2], but raise a large number of moral, ethical and legal issues, on the other. It is imperative that a debate be started in every country to predict and address these issues and that laws are promulgated to protect the rights of citizens.

Pakistan is a country of 150 million, the sixth most populous nation in the world. A majority (97%) of the population is Muslim [3]. There are five major ethnic/lingual groups, namely Punjabis, Sindhis, Pashtoons, Baluchis and Muhajirs, which usually do not intermarry. There is a strong cultural preference to marry within the family [4]. As a result, there is a heavy burden of genetic disease in the population. The carrier rate of  $\beta$ -thalassaemia trait approaches 5–8% [5]. Abortion is legally prohibited in the country except for when the mother's life is in danger. However, it remains widely practiced as a method of contraception in unsafe conditions [6]. The literacy rate is low and there is a lack of medical knowledge in popular culture. At the moment, Pakistan does not have a population carrier-screening program for thalassaemia. However, a service for prenatal diagnosis of  $\beta$ -thalassaemia was introduced in Pakistan a decade ago. Two renowned Islamic scholars, consulted before the service was introduced, ruled that a pregnancy could be terminated if the fetus is affected by a serious genetic disorder, and if termination is before 120 days (17 weeks) of gestation [7].

Genetic screening is sufficiently different from other sorts of testing to require additional debate and scrutiny [8]. Firstly, genetic information is familial. Thus, the results of one individual may reveal information about a kin. This raises the question as to what extent patient privacy should be maintained [9]. Secondly, the risks of genetic diagnosis may not be obvious as they are psychological, social and economic [10]. It is the prerogative of the patients that they be informed in this respect. Discrimination may become a problem [11]. The government has a role to play in protecting its citizens from discrimination [12]; similarly, it should also safeguard the rights of the unborn child. However, the same calculus of protection from discrimination cannot be applied when a patient's genetic results affect the safety of other individ-

uals. Thirdly, results of genetic tests will only be probabilistic, as the final outcome depends both on the genes as well as the environment [1, 13]. It is unknown what impact probability testing would have on reducing disease prevalence. People do not always make the most rational choices even when they have absolute information. Furthermore, prenatal genetic diagnosis and selective abortion in case of an affected fetus raises a number of ethical issues [14]. It is important to separate genetic testing from eugenics. 'Decreasing the quantity of population, improving its quality, and furtherance of eugenics principles' [15] should not be the goal of genetic diagnosis.

The forementioned discussion underscores different ethical and moral questions raised by genetic diagnosis. The technology is no longer on the horizon, it is already with us. Laws, rules and regulations are essential to resolve conflicts. The attitudes and opinions of various groups within society that have a stake in this technology need to be taken into account, and conclusions drawn from them will help future policy making on the issue [16, 17]. It is towards this goal that we endeavored to assess the opinions of doctors, medical students, lawyers, members of national parliament (MPs) and parents of children with thalassaemia towards genetic diagnosis.

## Methods

### *Study Design*

We conducted a cross-sectional survey of different societal groups of the Pakistani population.

### *Study Population*

The study population consisted of doctors, medical students, lawyers, parents of thalassaemic children, and MPs. From a total of 28,650 licensed medical practitioners in Karachi [18], 570 were randomly contacted from different large and small hospitals around the city. There are about 6,500 medical students currently enrolled in several public and private sector medical colleges in Karachi, recognized by the Pakistan Medical and Dental Council [18], and 178 were randomly surveyed. Registered lawyers based in Karachi were randomly selected [19]. A total of 49 lawyers were interviewed. The parents/guardians of thalassaemic children were contacted in a major blood transfusion facility in the city. Eighty-nine such parents were interviewed. The population of patients with  $\beta$ -thalassaemia major in Karachi is estimated to be 5,250 [20]. National MPs were also randomly selected and interviews were conducted in Karachi, Islamabad and Peshawar. The MPs included in the sample represented all major political parties of the country, including religion-oriented parties.

### *Sampling Method*

A stratified sampling method was used for the study. Convenience sampling was done to select the individuals within each stratum. This was done to account for the difficulty in obtaining

**Table 1.** Description of study subjects

|                   | n   | Age distribution |       |       |       |       |              | Males/<br>females | Married<br>% |
|-------------------|-----|------------------|-------|-------|-------|-------|--------------|-------------------|--------------|
|                   |     | up to 25         | 26–35 | 36–45 | 46–55 | 56–65 | 66 and above |                   |              |
| Doctors           | 570 | 231              | 230   | 72    | 32    | 5     | –            | 302/268           | 41.8         |
| Lawyers           | 49  | 4                | 21    | 9     | 10    | 3     | 2            | 43/6              | 65.3         |
| Medical students  | 178 | 175              | 3     | –     | –     | –     | –            | 77/101            | 4.5          |
| Parents/guardians | 89  | 18               | 36    | 28    | 5     | 2     | –            | 45/44             | 88.8         |
| MPs               | 16  | –                | 2     | 7     | 7     | –     | –            | 11/5              | 93.8         |

lists of all the members of each group, and the difficulty in contacting the respondents.

#### Sample Size

The sample of each group was calculated using WHO Sample Size Calculation 2.1. A confidence interval of 95% was used and an absolute precision of 0.03. Total sample size was calculated and each group had a representative share. The overall response rate was 77.3%. Among individual groups, the response rate was the lowest in lawyers, where only 26.9% of the estimated sample size could be completed. The most frequent reason cited for refusal of participation was lack of time.

#### Ethical Approval

Ethical approval was obtained from the Ethics Review Committee of Aga Khan University, Karachi. The selected participants had the choice to refuse to take part in the study. The study questionnaire did not obtain any information that could identify the participants.

#### Data Collection and Interviews

No prior information about genetics was assumed in the respondents. The respondents were put in scenarios to assess how they would respond to a particular question raised by genetic diagnosis.

#### Questionnaire

We made a standardized questionnaire that provided a brief explanation and description of genetic screening and contained case scenarios followed by a set of open- and close-ended questions. The questionnaire was coded for data entry. No limits were placed on answers to open-ended questions. English and Urdu versions of the questionnaire were developed. These questionnaires were tested on medical and nursing students before use in the study.

#### Interviews

Each of the participants was given the choice to respond in English or in Urdu. Doctors, medical students and lawyers were administered the questionnaire, which they had to complete themselves. One of the investigators was always there to answer any questions. In case of the parents of thalassemic children and the MPs, face-to-face interviews were conducted and the information recorded by the investigator in the same questionnaire.

#### Data Analysis

The questionnaire was coded for entry in SPSS version 11.0 for windows. All data were entered and checked by the same as well as an additional investigator. Data analysis included simple frequency determination.

## Results

We recruited a total of 902 subjects in the subject categories described earlier. The sample consists of 53% males and 47% females; 41% were currently married. Half the population was over 25 years of age, while the other half was between 15 and 25 years (mean age  $29 \pm 8.78$  years). This relatively younger population was due to a majority of young doctors and medical students in the sample. The study sample has been characterized in table 1.

Attitude assessing the acceptability of genetic screening showed an overwhelming affirmative response, with a majority (88.7%) being in favor of genetic diagnosis. The parents/guardians of thalassemic patients showed an overwhelming positive response of 95.5%, while MPs were highly skeptical with only a third in favor of genetic diagnosis (table 2).

Of all respondents who agreed to genetic screening, prevention of transmission of genetic diseases was cited as the most common justification for genetic screening (75.3%). Other reasons cited in support were identification of common diseases in the population (45.5%) and the right to know about themselves (63%).

Of the 11% of the study population who did not accept genetic screening, 38.3% believed there were other preventable diseases, which should be sorted out first. Other reasons were fear of discrimination (26%), increase in abortion rates (34%), and individual stress (30%). Interestingly, religion influenced the opinion of only a small proportion (6%) of the respondents.

**Table 2.** Acceptability of genetic screening in different groups

| Study groups      | Response   |            | Total number of respondents |
|-------------------|------------|------------|-----------------------------|
|                   | yes        | no         |                             |
| Doctors           | 513 (90)   | 57 (10)    | 570                         |
| Lawyers           | 39 (79.5)  | 10 (20.4)  | 49                          |
| Medical students  | 158 (89)   | 20 (11)    | 178                         |
| Parents/guardians | 85 (95.5)  | 4 (4.5)    | 89                          |
| MPs               | 5 (31.3)   | 11 (68.8)  | 16                          |
| Overall           | 800 (88.7) | 102 (11.3) | 902                         |

Figures in parentheses are percentages.

Of our respondents, 77% were of the opinion that there should be genetic screening of couples before marriage to assess the risk of genetically transmitted diseases in their future offspring (table 3). However, 20% of these people believed results of such a test should not affect the couple's decision to marry; 86.4% believed that there is an increased risk of transmission of genetic diseases due to cousin marriages, and 82.5% were of the opinion that consanguineous marriages should be discouraged. Knowledge that consanguineous marriages lead to increased risk of genetic disease was significantly lower in parents of thalassemic children; there were only 41.6% who thought it raised risk (table 4).

Attitudes towards prenatal screening amongst parents of thalassemic patients differed markedly as compared with the other groups (table 5). Some 94.4% of them are in favor of prenatal screening, compared with 77.4, 51 and 70.8% of doctors, lawyers and medical students, respectively, in case of a scenario of a child expected to have a life of disability due to a genetic disease. Only 1 MP (6%) was in support of any sort of prenatal screening.

Support for abortion is less prominent than support for screening. In this case also, the choice for abortion has the highest support in parents of thalassemic children, followed by doctors. MPs had the lowest support for abortion, much less than any other group in the study (table 6).

There were mixed responses towards getting genetically screened: about 50% of doctors, medical students and lawyers, whereas the proportion was much higher in parents/guardians of thalassemic patients in whom a majority (78.2%) would like to be genetically screened. At the other end of the scale were the MPs, none of whom wanted to be genetically tested. The most common rea-

**Table 3.** Acceptability of premarital carrier screening in different groups

| Study groups      | Increased risk |            | Total number of respondents |
|-------------------|----------------|------------|-----------------------------|
|                   | yes            | no         |                             |
| Doctors           | 438 (76.8)     | 132 (23.2) | 570                         |
| Lawyers           | 32 (65.3)      | 17 (34.7)  | 49                          |
| Medical students  | 134 (75.3)     | 44 (24.7)  | 178                         |
| Parents/guardians | 84 (94.4)      | 5 (5.6)    | 89                          |
| MPs               | 6 (37.5)       | 10 (62.5)  | 16                          |
| Overall           | 694 (77)       | 208 (23)   | 902                         |

Figures in parentheses are percentages.

**Table 4.** Knowledge about the increased risk of genetic disease associated with consanguineous marriage

|                   | Increased risk |            | Total number of respondents |
|-------------------|----------------|------------|-----------------------------|
|                   | yes            | no         |                             |
| Doctors           | 527 (92.5)     | 43 (7.5)   | 570                         |
| Lawyers           | 37 (75.5)      | 12 (24.5)  | 49                          |
| Medical students  | 170 (95.5)     | 8 (4.5)    | 178                         |
| Parents/guardians | 37 (41.6)      | 52 (58.4)  | 89                          |
| MPs               | 8 (50)         | 8 (50)     | 16                          |
| Overall           | 779 (86.4)     | 123 (13.6) | 902                         |

Figures in parentheses are percentages.

sons for refusing the concept of self-genetic testing were no utility of the test (78%), anxious of the results (75%), and fear of discrimination (37%); religious reasons for refusal were rare. In response to whether genetic testing should be made mandatory or voluntary, 24% of doctors and even 63% of parents/guardians of children with thalassemia said it should be mandatory.

## Discussion

Our study is the first of its kind in Pakistan. A higher proportion of the study sample has demonstrated positive response towards genetic diagnosis. However, it is not clear whether the respondents in the sample do understand the potential risks and benefits of genetic diagnosis. In medical ethics, it is the prerogative of persons to choose for themselves [21]. However, patients' autonomy de-

**Table 5.** Attitudes towards prenatal genetic screening

| Scenario              | Doctors    | Lawyers   | Medical students | Parents/guardians | MPs     |
|-----------------------|------------|-----------|------------------|-------------------|---------|
| Short life expectancy | 327 (57.4) | 19 (38.8) | 92 (51.7)        | 80 (89.9)         | 0       |
| Life of disability    | 441 (77.4) | 25 (51)   | 126 (70.8)       | 84 (94.4)         | 1 (6.3) |
| Expensive treatment   | 354 (62.1) | 21 (42.8) | 91 (51.1)        | 77 (86.5)         | 0       |

The data indicate the number of people who favored prenatal genetic screening in a given scenario. Figures in parentheses are percentages.

**Table 6.** Attitudes towards abortion

| Scenario              | Doctors    | Lawyers   | Medical students | Parents/guardians | MPs     |
|-----------------------|------------|-----------|------------------|-------------------|---------|
| Short life expectancy | 177 (31)   | 15 (30.6) | 46 (25.8)        | 64 (71.9)         | 1 (6.3) |
| Life of disability    | 366 (64.2) | 17 (34.7) | 92 (51.7)        | 67 (75.2)         | 1 (6.3) |
| Expensive treatment   | 199 (34.9) | 12 (24.5) | 38 (21.3)        | 61 (68.5)         | 1 (6.3) |

The data indicate the number of people who favored abortion in a given scenario. Figures in parentheses are percentages.

depends upon the information provided by the physician and is subject to the patient's understanding. There is evidence that when information about the potential negative aspects of genetic screening is provided, the interest decreases [22].

Previous studies that looked at the acceptability of population carrier screening for inherited disorders have also found both a great deal of interest and acceptability for the test. Honnor et al. [23] found that the population carrier screening for cystic fibrosis offered in a community setting in Western Australia was acceptable to almost half of the respondents. Decruyenaere et al. [24] reported that the majority of respondents in their study had no objections to population-wide carrier screening.

As can be envisioned, the affected segment of the population holds more affirmative views towards genetic screening. In our study, parents of children with thalassemia major had a very high support for premarital and prenatal screening. Conway et al. [25] reported 90% of the parents of affected children to be in favor of prenatal diagnosis. Only 10% of the parents felt that screening should be limited to affected families. This is in congruence with our findings.

The medical community also holds positive attitudes towards genetic diagnosis. Both general practitioners and

medical students were in support of genetic screening. Other studies about the attitudes of the medical community towards genetic diagnosis have found similar results. Watson et al. [26] found that 75% of the health care professionals in their study believed that introduction of carrier screening at community level is worthwhile. Around 90% of the doctors in our study favored population carrier screening.

Attitudes about whether genetic screening should be made mandatory or remain voluntary differed greatly between the various groups. Parents/guardians of thalassemic children strongly supported the mandatory idea. When asked why, parents/guardians of thalassemic children gave the following response: 'The government should take control of it and make it mandatory since children are the asset of a nation'. Another comment was: 'Nobody should have to undergo this terrible ordeal that we are going through'.

In all except the medical community, there was a lack of awareness of the fact that consanguineous marriage increases the risk of genetic disease. This was especially ironic in parents of thalassemic children, 58.4% of whom thought this concept was wrong.

It can be noted from the results that families with a child suffering from a severe genetic illness, namely



thalassemia, were strongly in favor of abortions in case of a positive prenatal result. In response to why they wanted to abort a child with disability or a lifespan of less than 20 years, a normal response was: 'Both the parents and the child suffer such a great deal if this disease is present. Hence, it is better to relieve pain in the beginning. I have been bringing my child for monthly transfusions for 12 years now, since she was only 6 months old'.

This finding is in agreement with other studies on similar subjects. Pandey et al. [27] reported that the majority of families affected with hemophilia felt that they would opt for termination of pregnancy if the fetus were affected. In a study conducted in Nigeria, Durosinmi et al. [28] found that more than half of the parents of children affected with sickle cell anemia were in favor of abortion in case of a positive prenatal result.

It would be quite relevant here to compare our results with the attitudes towards prenatal screening and selective abortion for thalassemia among Pakistanis in the UK, a country where screening is widely introduced. Modell et al. [29] reported the uptake of prenatal diagnosis by British Pakistanis as 73% in the first trimester, with 11 out of 12 affected pregnancies being terminated, and 39% in the second trimester with 4 of 7 affected pregnancies being terminated. This is consistent with our findings where on average 64% of the parents of affected children were in favor of abortion in the case of an affected fetus. In the above-mentioned study, the uptake of prenatal diagnosis and the proportion of selective abortions decreased in the second trimester of pregnancy. In our study as well, a number of respondents expressed the common view that Islam permits abortion only within the first 120 days of pregnancy and they stressed that prenatal testing, and if needed, abortion, should be within this time period.

The attitudes of people representing ethical committees or other law-proposing bodies may be contrary to the views of families affected by genetic disease. In a study of 77 members from 28 different ethical review committees, Reynolds [30] found that only 26% of the respondents agreed to screening for a disease that reduces life expectancy by 50 years. This is similar to our findings that lawmakers (MPs) and lawyers were the groups with the lowest support for genetic diagnosis, premarital and prenatal screening, and MPs were staunchly and unanimously against abortion. However, given the small sample size of this group (particularly the MPs), it cannot be firmly stated that their views represent those of the whole legislative community in Pakistan.

Overall, we can safely say that the opinions on issues pertaining to genetic diagnosis are sharply divided within Pakistani society. There is a particular pattern to this division. Those whose lives are more deeply influenced by genetic diseases hold positive attitudes towards genetic testing. On the other hand, the lawmakers and law professionals are on the opposite side having their reservations about the issue.

We are not in a position to give judgment which of the two views is more reasonable. But when the time comes for relevant law making in Pakistan – judicial or parliamentary – and the implementation of the incumbent law, this sharp difference of views between those most affected by the laws and those who make the laws could be detrimental. We hope that when legislators pen relevant laws they are actively aware of this sharp conflict of opinion. In true democratic spirit, it is the people's voice that matters most. However, it is quite likely that legislators follow their own judgment. Media and civil rights pressure groups must raise awareness of genetic disease, the upcoming prospects of genetic diagnosis, and the ethical questions raised by this technology. The views of those most affected by genetic disease must be voiced when the time for action comes.

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