

Public's perception and attitude toward genetic testing in Jazan region

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ABSTRACT

Background: With the advancements in genetic testing, a differentiated evaluation for susceptibility to diseases is becoming applicable to many disorders. Understanding the circumstances and promoting the widespread use of these tests in the Saudi setting requires understanding public opinion and attitudes. This study aimed to determine the perception and attitudes of the public in the Jazan region to genetic testing. **Material and Methods:** A cross-sectional survey study of 507 participants was conducted in the Jazan region. The data were collected through an online questionnaire containing demographic information and statements assessing public perceptions and attitudes. **Results:** Our findings showed that perspectives toward genetic testing, especially premarital and prenatal testing, are generally positive and consistent with previous research. Approximately 79.1% of the participants had a positive attitude toward supporting a compulsory governmental decision of genetic screening before marriage, and 67.3% were willing to perform such testing in the future. More than half of the participants were willing to allow pregnancy termination if there was a higher probability of genetic disease in the baby. In contrast, only 29.6% agreed with the decision to divorce due to the higher probability of genetic disease in their children. The predictors for a positive attitude to genetic testing were nationality, marital status, and monthly income. **Conclusion:** The results of the present study indicate that there are acceptable perspectives and attitudes toward genetic testing, especially premarital and prenatal testing.

Keywords: Attitude, genetic testing, Jazan region, perception, public

Introduction

Genetic testing is an essential medical diagnostic method for identifying heritable alterations or differences in chromosome architecture or gene sequences manifested in modified protein expression. Such a test's result can identify the mutated gene or chromosome, which can assist in determining a person's

risk of acquiring genetic illnesses.^[1,2] A range of tests are conducted to identify genetic diseases at various stages of human development accurately. These include detection for carriers of inherited disorders; screening for those with a familial history of various cancer types; screening for metabolic, endocrine, and hematological disorders in newborns; and screening for congenital birth defects and chromosomal abnormalities at the prenatal stage.^[3-5]

The quality of life for parents and children is significantly impacted by most congenital abnormalities that are detected

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by prenatal screening, many of which result in miscarriage or infant mortality, even in non-fatal cases.^[6-8] Prenatal screening is particularly well-suited to this requirement because it can provide early and non-intrusive risk assessment, empowering families and healthcare professionals to become better informed, make timely and thoughtful decisions, seek further testing, and be emotionally and physically ready for the child's health needs or the likely outcomes of pregnancy.^[9] Numerous eminent experts in the fields of mother and child health have recommended the provision of prenatal screening services to all pregnant women, or a significantly larger subset of them, as soon as they start prenatal care.^[10,11]

In Saudi Arabia, most tertiary hospitals provide prenatal diagnostics by amniocentesis and chorionic villus sampling to diagnose single-gene disorders. Non-invasive prenatal screening is being done in a few centers, but it has yet to be widely available nationwide.^[12] Cytogenetic analysis is typically accessible through conventional karyotyping; however, molecular karyotyping is limited to a few facilities. Saudi Diagnostic Laboratory (SDL) at King Faisal Specialist Hospital and Research Center (KFSHRC) is the primary molecular diagnostic laboratory, testing for 66 single-gene diseases and 16 different inborn errors of metabolism.^[13]

There was more significant debate in Saudi Arabia over the premarital screening program than the neonatal screening program, which was generally approved. Following much discussion, a law requiring screening for certain prevalent types of hemoglobinopathies before granting a marriage contract since 2002.^[13] The concept of genetic counseling and genetic screening poses many challenges in the Islamic world, especially in the Kingdom of Saudi Arabia, as it must be implemented within the framework of religion and culture through the Islamic moral and cultural context of the people and society. Despite lacking resources, technology, and expertise, community genetic counseling is still available in an individual's language.^[14] Moreover, the Islamic Jurisprudence Council of the World Islamic League (Organization of Islamic Countries) offers a significant agreement in preventing and controlling genetic diseases in Islamic society. For instance, it allows for the option of abortion under certain specific circumstances, supporting the benefits of Molecular Genetics and Bioengineering to Muslims, and legitimizes the pre-marital medical screening of Genetic Blood Disorders.^[14]

A differentiated assessment for susceptibility to diseases is becoming applicable to numerous conditions with the current developments in genetic testing. Public perception and attitudes are essential pillars for comprehending the situation and advocating the application of these tests widely in the Saudi context. The Saudi population's favorable perception and attitude toward genetic testing, primarily influenced by educational background and family history of genetic disease, is bolstered by the public's strong willingness.^[15] This societal support is evident in the public's readiness for genetic testing in Saudi Arabia, particularly for conditions such as breast cancer and Alzheimer's

disease.^[16,17] Compared to the other contexts in the Arabic world, the willingness to undergo genetic testing is relatively increased with genetic diseases in relatives.^[18] Our study aimed to investigate the public's perception of genetic testing in the Jazan region. In addition, it tried to analyze the attitudes toward it and focused on how demographic variables influence people's perceptions and choices about genetic testing.

Material and Methods

Study design and participants

This descriptive study used a non-probability convenience sampling technique in the Jazan region, southwest of Saudi Arabia, north of Yemen, between January 2023 and March 2024. The study was conducted among the public, including males and females above 18 years living in the Jazan region, who agreed to participate and excluded those who did not fulfill the inclusion criteria, declined to participate, or did not complete the questionnaire. The sample size for this study was calculated as 384 participants by using the sample size formula for studies organized according to a cross-sectional study design. The study used the parameters of $P = 50\%$ to provide the maximum sample size, 90% confidence interval, and an error of not more than 5%. In addition, the study assumed a non-response rate of 25%, and then the sample size increased to 507 participants.

Data collection tool and the collection procedure

The data were collected through a questionnaire containing demographic information (age, gender, nationality, educational level, occupation, marital status, and monthly income). The perception/attitude statements were prepared using a collection of essential information on prenatal testing for genetic disorder screening utilizing validated tools used in previous studies.^[19,20] The questionnaire contained 10 statements assessing public perceptions with responses graded as "Yes," "No," and "Do not know." The questions assess the decision of marriage and divorce, the termination of pregnancy related to genetic results, and the willingness to participate in genetic studies. Furthermore, the attitude five statements were included in the questionnaire with the 5-graded Likert scale ranging from 1 to 5, with responses starting from 1 representing "Strongly disagree" to 5 representing "Strongly agree." Then, a pilot study with 20 participants, excluded later from the sample, was conducted to test whether the questionnaire's timing was appropriate and statements were understandable. Before data collection began, participants were asked to read and sign a permission form.

Data presentation and statistical analysis

Statistical Package for Social Sciences software version 23.0 (IBM SPSS Inc., Chicago, IL) was used for data analysis. All information gathered via the questionnaire was coded into variables. Cronbach's alpha test was calculated to assess the reliability of the questionnaire and any adjustments to the data collection instrument required, and it showed an internal consistency of 0.78. Frequencies were used to give a general

overview of the data. Descriptive and inferential statistics involving the Pearson Chi-square test and one-way analysis of variances (ANOVA) test were used to present the results. A *P* value of less than 0.05 was regarded as statistically significant.

Likert-scale questions were recorded based on the attitudes of 1–5 participants, which gave a score of –25 to 25 in the questions. All the responses were converted to percentages and then were categorized into negative (<33%), Fair (34%–67%), and positive (>67%).

Results

In total, 507 participants were included in this study. The participants' characteristics are shown in Table 1, with females representing 76.1%. The 18–25-year age group participants comprised the most (41.2%), and 49.3% were married. Of the participants, 98% were Saudi, 44.2% worked in the governmental sector, 75.7% had a university degree educational level, and 40.6% had a monthly income below 5000 Saudi Riyal.

Table 1: Demographic characteristics of the participants (n=507)

Characteristics	Frequency	Percentage
Age (years)		
18–25	209	41.2
26–35	72	14.2
36–45	132	26
>45	94	18.5
Gender		
Male	121	23.9
Female	386	76.1
Nationality		
Saudi	497	98
Non-Saudi	10	2
Educational Level		
Non-educated	1	0.2
Primary school	4	0.8
Intermediate school	9	1.8
Secondary school	88	17.4
University	384	75.7
Above University level	21	4.1
Occupation		
Working (governmental sector)	224	44.2
Working (private sector)	25	4.9
Retired	10	2
Student	184	36.3
Not working	64	12.6
Marital status		
Single	230	45.4
Married	250	49.3
Widow/Widower	9	1.8
Divorced	18	3.6
Income		
<5000 SR	206	40.6
5000–10000 SR	98	19.3
>10000 SR	203	40.0

n=Number, SR=Saudi Riyal

We asked the participants if they had previously performed any genetic testing to assess their practices regarding prenatal testing, including prenatal testing. We found that only 4.1% performed such tests, and 67.3% of them were willing to participate in future genetic testing.

Approximately 90% of the participants believed that genetic studies have a role in detecting genetic diseases and enabling early treatment [Table 2]; however, only 0.4% believed that the results of genetic tests need to be more accurate. The pregnancy termination decision, if there is a higher probability of genetic disease in the baby, was chosen by almost more than half of the participants.

The majority of study participants (85.6%) had a positive attitude about genetic testing, whereas a minority had fair or negative attitudes, as shown by the overall attitude score calculation. The assessment of who supported a compulsory governmental decision of genetic screening before marriage showed that 79.1% of the participants strongly agreed, 4.3% were neutral, and 0.2% strongly disagreed. Regarding advocating for easy access to genetic testing, 54.2% strongly agreed, 13.2% were neutral, and only 3% strongly disagreed. Regarding performing genetic mapping for every newborn and whole family member showing familial diseases, 59.8% and 61.9% selected strongly agree, respectively, while 0.6% and 0.4% strongly disagreed, respectively. On the contrary, approximately 13.2% of the participants strongly agreed never to try any genetic testing, as shown in Figure 1. The positive attitude was significant to nationality, marital status, and monthly income.

As shown in Table 3 the regression analysis revealed no influential association between the demographic variables and the participant perceptions. However, the attitude was significantly related to nationality and marital status (*P* = 0.000 and 0.04, respectively).

Figure 2 shows the common diseases that need to be detected early by genetic testing. Cancers, sickle cell anemia, and mental disorders were the frequently chosen diseases by the participants in this study.

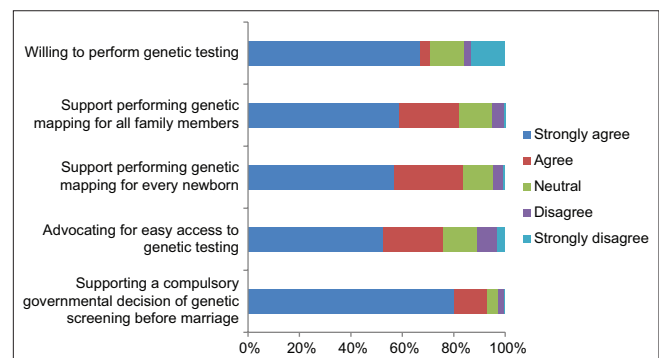


Figure 1: Participants' attitudes toward genetic testing

Table 2: Public perceptions regarding genetic testing (n=507)

Perception statements	n	%	P
I believe that genetic studies have a role in early detection of genetic diseases and enable early treatment	461	90.9	0.025
Decision to do genetic testing before marriage	453	89.3	0.119
Decision to cancel the marriage, If genetic testing indicated a higher probability of genetic disease	449	88.6	0.110
Decision to divorce due to higher probability of genetic disease in children	150	29.6	0.000
Pregnancy termination decision if there is a higher probability of genetic disease in the baby	269	53.1	0.098
Decision to have another child knowing that he has a higher probability of genetic disease	26	5.1	0.826
Genetic studies raise the race superiority issues	180	35.3	0.664
Genetic studies lead to cures for rich people only	126	24.9	0.562
I believe that all matters are in the hands of God, so no need for genetic testing	16	3.15	0.732
I believe that the results of genetic tests are inaccurate	2	0.40	0.732

n=The number of the participants who answered (Yes) in each statement

Table 3: The impact of demographic variables on public perception using the linear regression model

Variable	B	S.E.	Standardized Coefficients beta	P	t	95% CI for B	
						Lower	Upper
Age	0.035	0.145	0.016	0.241	0.810	-0.251	0.321
Nationality	0.620	0.859	0.033	0.721	0.471	-1.068	2.308
Gender	-0.213	0.284	-0.034	-0.749	0.454	-0.772	0.346
Educational Level	-0.142	0.214	-0.032	-0.665	0.507	-0.563	0.278
Occupation	-0.107	0.114	-0.065	-0.937	0.349	-0.331	0.117
Marital Status	0.262	0.211	0.069	1.241	0.215	-0.153	0.676
Income	0.011	0.179	0.004	0.061	0.952	-0.340	0.362

CI=Confidence interval; SE=Standard error. P<0.05 is considered statistically significant

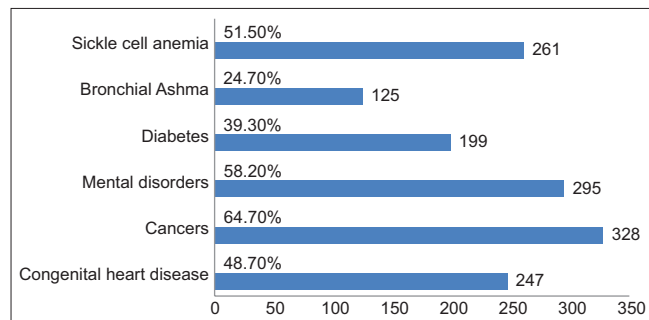


Figure 2: The common diseases that participants most need to detect early through genetic testing (n = 507)

Discussion

Researchers and stakeholders in Saudi Arabia launched medical genetic services through persistent efforts involving prenatal testing. In Saudi Arabia, clinical genetic services are offered by genetic counselors, clinical and metabolic specialists, diagnostic labs, and preventive and educational initiatives.^[12] Since then, genetic services have advanced with genetic counseling, testing, and diagnosis. The development of genetic testing in Saudi Arabia was further aided by the acceptance of clinical genetics as a specialization and by more significant financing for genetics services.^[13]

Numerous new, unusual diseases have been discovered in Saudi Arabia due to the elevated prevalence of consanguinity in this area, particularly in rural areas.^[13] To find the underlying gene alterations causing common diseases and inherited new disorders,

geneticists in these areas work in conjunction with research teams in the Kingdom of Saudi Arabia.^[13] Furthermore, several survey investigations were carried out to assess the degree of comprehension, viewpoint, or consciousness among the general population. The public's perception of genetic testing in Saudi Arabia is still relatively narrow.^[16,21] Thus, it is imperative to provide an update on the general public's perspective and opinions toward genetic testing. This survey study aimed to address a research gap by investigating the public's perception of genetic testing in the Jazan region of Saudi Arabia.

Our findings showed that perspectives toward genetic testing, especially premarital and prenatal testing, are generally positive and consistent with previous research.^[18,20,22] However, we found that only 4.1% had undertaken such testing and that 67.3% were willing to participate in genetic testing. A potential barrier to translating knowledge into clinical practice may be attributed to the state of general public awareness of genetics and access to testing services not funded by Saudi insurance, which may burden the individual economy. Furthermore, many other factors, such as beliefs and concerns about the privacy of genetic data, may influence willingness versus actual participation. The majority (89.3%) of participants agreed to do genetic testing before marriage, and a similar percentage (88.6%) decided to cancel marriage if genetic testing indicated a higher probability of genetic disease. On the contrary, the pregnancy termination decision if there is a higher probability of genetic disease in the baby was agreed by only half of the participants (53.1%). This result is equivalent to one Saudi study assessing the practices toward reproductive-decision making and concluded that there

were a higher percentage of public acceptances of prenatal testing; however, the decision to terminate a risky pregnancy was comparably low, especially in those without a family history of genetic disorders.^[23] Medical termination of pregnancy is still viewed as socially or culturally inappropriate in many Arab nations and is often frowned upon in Muslim communities. However, according to the findings of one study in Oman, prenatal diagnosis is a viable method of reproduction for Omani Muslim couples seeking to avoid genetic diseases that meet the requirements for termination under the Islamic Council of Fatwa.^[24]

Although the general attitudes were favorable toward genetic testing, there was uncertainty about genetic testing among approximately 13% of participants. Only a tiny percentage felt it might be inaccurate, while others relied on submission to God's will without interference. This trend demonstrates that even if it does not present new ethical and societal challenges, moving beyond current perceptions and attitudes may revitalize the debate about the social, religious, and ethical consequences of genetic testing, particularly the debate over borders in Arab-Islamic regions. Our findings align with other studies documenting relatively favorable attitudes toward genetic testing related to marital status and monthly income.^[25,26]

The worldwide endeavor to uncover the causative mutations of Mendelian disorders has significantly benefited from genetic studies conducted on the Saudi population, especially in autosomal recessive diseases, where consanguinity marriage is prevalent. Establishing a next-generation sequencing-based assay facility in Saudi Arabia in 2016 marked the beginning of a new era in providing genomic medicine and genetic diagnosis for various diseases.^[27] Our study demonstrated that the diseases that caused significant concerns for the participants were cancers, sickle cell anemia, and mental disorders, as the participants frequently chose them.

This study has some strengths as it focused on populations with sufficient demographic diversity and employed a self-administered online questionnaire to facilitate participants' quick and effortless expression of opinions to assess the degree of comprehension, viewpoint, and attitude among the general population regarding such a vital topic. On the contrary, this study's weakness was related to the measuring tool's reliance on participants' recall, which may have introduced recall variability.

Our findings identified acceptable perspectives and attitudes toward genetic testing, especially premarital and prenatal testing. In addition, many participants were willing to participate in genetic testing. Our data suggest a lack of statistically significant influence of demographic variables on the perspectives; however, the positive attitudes were influenced by marital status, monthly income, and nationality. More awareness and precise knowledge about genetic testing may improve the possibility of accepting genetic testing and planning positive strategies for the future. Moreover, further studies are needed to explore and compare other regions.

In conclusion, this study sheds light on the perception and attitude of the Jazan region toward genetic testing and the extent of its impact on the decision-making process of the Saudi people in social and religious contexts. To ensure that people make informed decisions, we strongly recommend that the general public be adequately informed about the benefits, risks, and limitations of genetic testing through increased efforts to educate the medical community and caregivers. Moreover, to bridge the information gap among the general population, we advise the government to organize awareness campaigns on the benefits of genetic testing.

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Conflicts of interest

There are no conflicts of interest.

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