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Original Research Article

Attitude and awareness of the public toward genetic testing in Al-Madinah Al-Munawwara, Saudi Arabia

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ABSTRACT

Background: Genetic testing is a growing field that can provide valuable information about an individual's health, ancestry, and potential risks for various health conditions. While some people are aware of its potential benefits, others have concerns about the privacy of their genetic data, limitations of the testing, ethical issues, and disparities in access to testing and interpretation services. While genetic testing has the potential to provide valuable information, there are valid concerns about privacy, accuracy, and ethical issues. The public's attitudes toward genetic testing is shaped by various factors, including accessibility, cost, accuracy, and reliability of the testing and ethical and privacy concerns. A survey-based methodology was used to investigate the attitudes and awareness of the public toward genetic testing and identify the factors that influence these attitudes and awareness. Our study aimed to study the attitude and awareness of Saudi medical and non-medical students toward gene testing across different Universities in Al Madinah, Saudi Arabia.
Methods: A cross-sectional study was conducted on 274 participants. The data were analyzed descriptively using statistical package for the social sciences (SPSS).
Results: Across the 274 participants, the majority have agreed on the importance of gene studying especially in facilitating the marriage process and assuring healthier generations, while there was also a concern about the security and confidentiality of gene mapping and banking, screening for cancer, and cardiac disorder were on top of interest among the participants to use gene screening in.
Conclusions: In conclusion, genetic testing is essential for diagnosing genetic diseases, but predictive genetic tests have limited benefits due to gene-environment interactions. Advances in genome technologies have produced large amounts of sensitive genetic data. Genetic education is necessary to promote informed decision-making, reduce genetic essentialism, and improve genomics literacy. Most study participants acknowledged the significance of genetic disorder screening before marriage to improve their health and their offspring's health.

Keywords: Gene mapping, Screening, Off-spring, Diagnosing, Cancer, Genetic banking

INTRODUCTION

Genetic testing is a rapidly growing field that can provide valuable information about a person's health, ancestry, and potential risks for various health conditions. As such, public opinion on genetic testing is of great interest. While some people may be aware of its potential benefits, others may have concerns about the privacy of their genetic data, limitations of the testing, ethical issues, and disparities in access to testing and interpretation services.[1] Genetic testing analyses an individual's DNA, RNA, or chromosomes to identify genetic variations that may cause or increase the risk of developing certain diseases. The use of genetic testing has increased significantly over the past few decades, with many individuals opting for genetic testing for disease diagnosis, treatment, and prevention. Advances in genetic testing technologies have made it easier and more accessible for individuals to access genetic testing, and this has led to an increased interest in the use of genetic testing for various purposes, such as personalized healthcare.[2]

It is undeniable that genetic testing has the potential to provide valuable information about one's health and ancestry. For example, ancestry and health risk testing are popular applications of genetic testing. These tests can help individuals learn more about their family history, ethnic roots, and potential predispositions to various diseases. Additionally, genetic testing can be used to detect genetic disorders early, identify carrier status for certain conditions, and tailor medical treatment based on genetic information.[3]

However, there are valid concerns about genetic testing that may influence people's attitudes towards it. One such concern is privacy. Some people worry about how test results could be used for nefarious purposes or increased surveillance. Others worry about insurance or employment discrimination based on genetic information. These concerns are not unfounded, and it is important to address them.[4]

Another concern is the accuracy and reliability of genetic testing. Some individuals may be skeptical about the utility of genetic testing, questioning the implications of such information or the reliability of the results. This skepticism could stem from a lack of understanding, mistrust in science or technology, or concerns about potential misuse. While genetic testing has come a long way in recent years, it is important to acknowledge that not all genetic tests are equally effective, and results can sometimes be inconclusive or difficult to interpret.[5]

The accessibility and cost of genetic testing may also impact attitudes. As genetic testing becomes more affordable and accessible, it may be perceived as a more practical and useful tool. However, disparities in access to testing and interpretation services can contribute to concerns about equity. In addition, ethical issues related to genetic testing, such as informed consent, disclosure of results, and the potential for discrimination, can shape attitudes toward genetic testing.[6]

Several studies have explored the public's attitudes and awareness towards genetic testing. Some studies have found that the public generally has a positive attitude towards genetic testing, with a high level of interest in using genetic testing for disease prevention and personalized healthcare. For instance, a study has investigated the awareness and attitude of the Korean public toward genomic medicine and study. The study found that the majority of the participants were aware of genomic medicine and had a positive attitude toward it.[7] Furthermore, the study found that the participants had a high level of interest in learning about their genomic information and using it for disease prevention and personalized healthcare.[7]

In contrast, some studies have found that the public is concerned about the potential negative consequences of genetic testing. In a study conducted to explore the evidence of genetic discrimination and life insurance. The study found that genetic discrimination was a major concern among the participants and could affect their willingness to undergo genetic testing.[8] Similarly, another study conducted has explored the public's attitudes toward whole genome sequencing. The study found that the participants were concerned about the privacy and confidentiality of their genetic information and the potential misuse of this information by insurance companies or employers.[9]

Overall, the public's attitudes toward genetic testing is shaped by a variety of factors. While some view genetic testing as a valuable tool for learning more about one's health and ancestry, others may have valid concerns about privacy, accuracy, and ethical issues. As genetic testing continues to grow and evolve, it is important to engage in thoughtful discussions and make informed decisions about its role in our lives.[10]

In this study, we aimed to investigate the attitudes and awareness of the public towards genetic testing and identify the factors that influence these attitudes and awareness through a survey-based methodology to collect data from a representative sample of the population.

METHODS

Study design

This is a cross-sectional non-interventional quantitative survey among medical and non-medical students across different Universities (Al-Rayyan Colleges, Taibah University, Al Ghad International College) in Al-Madinah Al-Munawwara, we set the time duration for data collection between May 2022 and August 2022. We enrolled 274 students in the survey, Questionnaires were cascaded to all participated samples via Google Forms, and inputs were captured. The data was analyzed using statistical methods to identify any significant associations between demographic factors, such as age, gender, education level, income, and attitudes toward genetic testing.

Study population

The inclusion criteria were that participants shall be medical college students at the universities in Al-Madinah who agreed to participate in the project by signing the ethical form, while exclusion criteria were any other medical college students at the universities outside Al-Madinah in addition to those who were unwilling to participate in the project. Of the 342 responses, 274 met the above criteria and were used in the study.

Those with exclusion criteria were excluded from our study.

Data source

We applied a random sampling technique; the minimum effective sample was 274 participants; The sample size was calculated using We used RaoSoft® to calculate the sample size.[23] The minimum effective sample was 270, CI=95%, and margin of error=5.00%.

Written consent was obtained from every medical student willing to participate in data collection. All participants filled in a self-administered questionnaire.

Statistical analysis

The sample size was calculated using RaoSoft® software, in data analysis, we used IBM SPSS 25, and we applied t-test, ANOVA, and Chi-square test in setting the associations and correlations between the different variables. Data outcomes shall be significant based on a p value less than or equal to (0.05).

RESULTS

Baseline characteristics (sociodemographic data)

In our study, 274 consented participants have been enrolled and asked to participate in our cross-sectional study as per Table 1.

The majority of the participants were aged between 18-25, while they were almost divided between male and female, most of the participants were university students versus secondary school students (62.8% versus 37.2%) as well with regards to medical and non-medical participants, and lastly majority were single (72.3%).

Gene testing questionnaires in relation to marriage

Across the 274 participants, 8 questionnaires were asked to all participants related to gene testing and the future of current marriage with their couples as per Table 2, the majority of participants (79.9%) have agreed that to cancel the marriage of results of gene testing before marriage reveal birth disorder, 88.7% have also agreed that they will not have other baby birth if gene testing showed disorders for the upcoming off-spring. On the other hand, two-thirds of participants have said to keep the marriage regardless of the high probability of infection rate. Most participants have either agreed to make gene testing before marriage (89.9%) or support governmental regulations for mandated gene testing before marriage (72.6%).

Gene testing questionnaires in relation to gene mapping

Gene mapping questionnaires were asked to all our participants, majority of the participants (95.3%) have shared being not participated before in genetic studies, on the other side, (76.3%) of participants agreed or strongly agreed to support authorities in making gene mapping for every newborn in KSA, whereas (80.6%) have also agreed to do family disease mapping as per Table 3.

Table 1: Baseline characteristics.

Baseline characteristics (n=274)	Percentage
Age (%)	
18-25	56.2
25-35	28.1
More than 35	15.7
Sex (%)	
Male	54.7
Female	45.3
Educational level (%)	
Secondary	37.2
Collegiate`	62.8
Employment status (%)	
Medical student	36.9
Non-medical student	53.3
Genetic lab technician	9.9
Marital status (%)	
Single	72.3
Married	27.0
Divorced	0.7

Gene testing questionnaires in relation to gene banking

Across our participated sample, the inputs about the concept of gene banking questionnaires were gathered and analyzed, there were contradicting data between participants in terms of global accessing of genetic survey data across the world, so half of the participants don’t mind having world accessibility of this data while other half refuse, while, this percentage has increased (70.4%) of participants accepted the concept of genetic information banking with restricted actions, however, the majority of participants (54.7%) refused the concept of using gene banking to prove racial superiority over others, and lastly, (81%) of the sample have shown their readiness to participate in future genetic studies as per Table 4.

Disease screening preference

Several diseases scopes were offered to participants to rate them from the perspective of top diseases gene screening would be important in diagnosing and screening it, out of the 274 participants, (72.3%) of participants selected cancer gene screening would be essential, followed by cardiac diseases (53.6%), psychological disorder (44.9%), Sickle cell anemia (39.8%) and diabetes (39.1%) as per Table 5.

Table 2: Participant's responses on gene testing questionnaires related to marriage (n=274).

Participant's responses on gene testing questionnaires related to marriage (n=274)	N
If you know that your marriage or the marriage of your son/daughter to another party will inevitably lead to the birth of children with genetic or hereditary diseases (such as sickle cell anemia, or breast cancer), is it possible to cancel this marriage?	
Yes	79.9
No	20.1
If you knew after doing a genetic scan for you and your wife that the birth rate of another child with a genetic or hereditary disease is 100%, would you like to have other children from the same husband?	
Yes	11.3
No	88.7
Will the high infection rate (100%) lead to your separation from your husband?	
Yes	36.5
No	63.5
If the result of the genetic or hereditary examination of you and your husband/wife proves that the child with whom you will have a genetic or hereditary disease that leads to the birth of a child with a permanent disability or the death of the child shortly after birth, knowing that the pregnancy is still in the first weeks, do you support Do an abortion of the fetus?	
Yes	60.9
No	39.1
Do you support selling products in pharmacies to perform genetic tests that determine genetic traits?	
Strongly agree	48.9
Agree	22.6
I don't know	20.8
Dis-agree	5.5
Strongly dis-agree	2.2
Do you support a government decision that requires genetic testing (determination of hereditary traits) before marriage to detect the possibility of having children with genetic (hereditary) diseases?	
Strongly agree	72.6
Agree	18.6
I don't know	6.9
Dis-agree	1.5
Strongly dis-agree	0.4
If you are about to get married, will you do a genetic scan (determination of hereditary traits) for you and your spouse before marriage?	
Yes	89.8
No	10.2
If you knew after doing a genetic scan for you and your wife that the birth rate of another child with a genetic or hereditary disease is 100%, would you like to have other children from the same husband?	
Yes	85.0
No	2.2
I don't know	12.8

Table 3: Participant's responses on gene testing questionnaires related to gene mapping (n=274).

Participant's responses on gene testing questionnaires related to gene mapping (n=274)	N
Have you ever participated in a genetic study?	
Yes	4.7
No	95.3
Do you support the analysis of the complete genetic map (map of genetic traits) for every newborn in the Kingdom of Saudi Arabia?	
Strongly agree	47.1
Agree	29.2
I don't know	20.4
Dis-agree	2.6

Continued.

Participant's responses on gene testing questionnaires related to gene mapping (n=274)	N
Strongly dis-agree	0.7
Do you support making a family disease map (like a family tree), showing all diseases prevalent in the family, such as diabetes or high blood pressure and other diseases?	
Strongly agree	51.8
Agree	28.8
I don't know	14.6
Dis-agree	3.6
Strongly dis-agree	1.1

Table 4: Participant's responses on gene testing questionnaires related to gene banking (n=274).

Participant's responses on gene testing questionnaires related to gene banking (n=274)	N
Do you support conducting a genetic survey (hereditary characteristics) of the population of the Kingdom and publishing the survey information on a website that everyone in the world can access?	
Yes	50.4
No	49.6
If you know that the government will strictly monitor the genetic information bank and will not allow anyone to view its information except for scientific research after deleting personal information from it, then no one will be able to identify the identity of the people participating in scientific research, do you support the establishment of a genetic information bank?	
Yes	70.4
No	29.6
Do you support the views of some critics of the establishment of the genetic information bank that the availability of genetic information will lead to the following: It may be exploited by some peoples to prove their racial superiority	
Yes	45.3
No	54.7
Are you ready to participate in a genetic study?	
Yes	81.0
No	19.0

Table 5: Participant's outcomes towards top diseases for screening (n=274).

Participant's outcomes towards top diseases for screening (n=274)	N
Sickle cell anemia	39.8
Cancer	72.3
Asthma	20.4
Cardiac diseases	53.6
Psychological diseases	44.9
Diabetes	39.1
I don't want to do any tests	9.1

DISCUSSION

Genetic testing is an integral aspect of human health-related efforts, particularly in the context of genetic illness diagnosis. Traditionally, genetic tests for monogenic illnesses are administered in a clinical environment with an emphasis on examining the patient in the context of his or her family.[11] In recent years, genome technologies have dramatically decreased in price and risen in speed, resulting in their global development and the production of unprecedented quantities of sensitive genetic data.[12]

The growing rate of identification of illness-related genes and the availability of tests for them have promoted the notion that healthy individuals would be able to avoid future sicknesses through genetic testing.[13] However, due to the genetics of several illnesses, testing can only predict the clinical outcome with limited precision. Nonetheless, some predictive genetic tests, such as prenatal screening for phenylketonuria and sickle cell anemia, and testing of older children at risk for familial medullary thyroid cancer and multiple endocrine neoplasia type 2a, can have considerable advantages.[14] Genetic illnesses may have devastating financial, psychological, and physical impacts on individuals. They require more clinic visits and longer hospital stays, significantly impacting the healthcare system and economy.[14,15]

Multiple studies have emphasized genetic literacy's significance in public attitudes about involvement in genomics research.[16,17] Recent research on Qatari residents indicated that the desire to join genome projects is related to genetic knowledge, experience with genetic testing, and a family history of genetic illnesses.[18] Another study argues that improving genomics literacy, particularly through genetics education, could reduce the prevalence of genetic essentialism and promote a more nuanced understanding of the complex interactions between genes and the environment. It has also emphasized the importance of collaboration between scientists, educators, and the public to increase genomics literacy and promote informed decision-making in areas such as genetic testing and personalized medicine.[19]

Our study findings revealed that most participants recognize the importance of screening for any genetic disorder while seeking marriage for better health for themselves and their offspring. Also, most of the participants (88.7%) would not have another child assuming the high risk of developing the inherited disease the child, which is in line with a study in Riyadh aimed to assess the attitude of participants towards gene screening.[20]

In terms of going towards abortion of infants once confirmed being disabled, there was a kind of contradiction in the outcomes with a comparable value, with 60% following the abortion of the disabled infant while 40% would not. This outcome was inconsistent with other studies, like the one which has shown that 62.8% of participants shall go for an abortion decision once they have a confirmed diagnosis for their infant.[20] On the other hand, the strong bonding between both husbands can keep the marriage regardless of the association with genetic disorders. This outcome was consistent among almost two-thirds of the participants, while that was in line with the outcomes of the majority of the participants (90%) who shall go for pre-marriage gene screening for any inherited disorders in the offspring. This outcome was the same as other studies with outcomes of 85.6% of the participants shall go for pre-marriage gene testing.[20]

The attitude of participants towards national-level gene mapping for new offspring and gene screening for determining hereditary traits was also investigated. Our findings revealed that the majority either follow governmental gene screening (89.8%) or strongly agree and agree on enrolling all new infants into gene mapping for early detection of diseases and help in preventing the emergence of chronic diseases (76.3%). On the other hand, while most participants were interested in doing gene screening (81%), almost all the participated sample (95.3%) have never undergone gene screening. This outcome was in line with other outcomes which emphasized on (63.3%) had never undergone genetic testing before, and (71.5%) expressed willingness to undergo genetic testing.[21]

There was a kind of agreement among the participants in terms of the most important diseases for gene screening, either for the overall sample (274), or the strongly agree/agree participants for disease screening (209), cancer was at the top with almost three out of four of participants (72.3%), followed by cardiac diseases among more than half of the participants and psychological disorder (44.9%), this outcomes was matching to the international a survey of DTC genomic testing consumers (n=1,648) participating in the PGen study, a similar proportion of consumers are “very interested” in ancestry information (74%) and disease risk information (72%). Specifically, participants reported being “very interested” in learning about their risk for heart disease (67.8%), breast cancer (66.9%; women only), Alzheimer’s disease (66.3%), prostate cancer (59.9%; men only), skin cancer (59.4%), diabetes (55.3%), and colon cancer (52.7%).[22]

There were some limitations in our study, the small scale of the study sample and geographical distribution, and that it only focused on medical students and not involving public or non-medical participants, however, it also carries a promising direction for bigger national scale studies across Saudi aiming to increase awareness of the importance of gene testing for better and healthier community.

CONCLUSION

In conclusion, genetic testing plays a crucial role in human health-related efforts, particularly in the diagnosis of genetic illnesses. Advances in genome technologies have led to the production of unprecedented quantities of sensitive genetic data and the identification of more illness-related genes. However, the benefits of predictive genetic tests are limited, and the complexity of the gene-environment interaction necessitates a more nuanced understanding of the results. Improving genomics literacy, particularly through genetics education, could reduce the prevalence of genetic essentialism and promote informed decision-making in areas such as genetic testing and personalized medicine. Our study findings revealed that most participants recognized the importance of screening for any genetic disorder before marriage seeking better health for themselves and their offsprings.

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