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Kronik Hastalıklardan Etkilenenlerin Genetik Testlere İlişkin Bilgileri ve Tutumları

Knowledge and Attitudes Towards Genetic Testing in Those Affected with Chronic Diseases

Selim Altan[1], Sırrı Çam[2]

[1]Manisa Celal Bayar Üniversitesi Tıp Fakültesi, Tıbbi Etik Anabilim Dalı, Manisa, Türkiye
[2]Manisa Celal Bayar Üniversitesi Tıp Fakültesi, Tıbbi Genetik Anabilim Dalı, Manisa, Türkiye

e-mail: selimaltan@hotmail.com, sirricam@gmail.com
ORCID: 0000-0001-8817-3210
ORCID: 0000-0002-0972-8896
*Sorumlu Yazar / Corresponding Author: Sorumlu Yazar: Selim Altan[1]

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Öz

Giriş ve Amaç: Genetik, modern tıbba giderek daha fazla nüfuz etmektedir. Gelişmekte olan Müslüman ülkelerde bilgi ve tutum arasında bir ilişki olup olmadığı araştırılmalıdır. Bu çalışma, kronik hastalığı olan bireylerin genetik bilgi düzeyleri ile genetik testlere karşı tutumları arasındaki ilişkiyi araştırmayı amaçlamaktadır.
Gereç ve Yöntemler: Kesitsel tipteki bu çalışma, kırsal ve kentsel alanlarda yaşayan bir ve / veya daha fazla kronik hastalığı olan bireyler arasında yürütülmüştür. Katılımcılardan anket formlarını doldurmaları istendi.
Bulgular: Çalışmaya 346 kişi katıldı ve ortalama yaşları 55.99 idi. Katılımcıların Genetik Bilgi düzeyi çok düşüktü ve çoğunluğu (yaklaşık %80) hemen hemen tüm ilgili sorulara yanlış cevaplar verdi. Kırsal alanlarda yaşayanlara göre kentsel alanlardaki katılımcıların tutum ve genetik bilgilerinin ortalama puanları daha yüksek bulunmuştur. Ayrıca genetik testler ve genetik konusunda daha olumlu tutumları olduğu tespit edilmiştir.
Sonuç: Kronik hastalığı olan bireylerin hastalıklarında uzman olduğu düşünülse de genetikte durumun bu olmadığı anlaşılmaktadır. Bu sonuç genetik gelişmelere kapalı olmaktan ziyade bilgi eksikliğinden kaynaklanıyor gibi görünmektedir. Buna ek olarak, çalışma Müslüman bir toplumdaki kaderci yaklaşımın genetik test yaklaşımında belirleyici olmadığını; bu nedenle, genetik sağlık hizmetlerini planlarken bu konulara dikkat etmek önemlidir.
Anahtar Kelimeler: Genetik testler, Kronik hastalıklar, Tutum.

Abstract

Objective: Genetics is increasingly penetrating modern medicine. It should be investigated whether there is a relationship between knowledge and attitude in developing Muslim countries. This study aims to investigate the relationship between the genetic information levels of individuals with a chronic disease and their attitudes towards genetic testing.
Materials and Methods: This cross- sectional study was carried out between individuals with one and / or more chronic diseases living in rural and urban areas were included in the study. Participants were asked to complete the questionnaire forms.
Results: 346 people participated in the study, and their mean age was 55.99 years. The level of Genetic Knowledge of the participants was very low, and the majority (about 80%) gave the wrong answers to almost all of the related questions. The mean scores of attitudes and genetic information of the participants in urban areas compared to those living in rural areas were found to be higher. In addition, it was found that they had more positive attitudes towards genetics tests and genetics.
Conclusion: Although it is thought that individuals with chronic diseases are experts in their diseases, it is understood that this is not the case in genetics. This result seems to be due to lack of knowledge rather than being closed to genetic

developments. In addition, the study revealed that the fatalistic approach in a Muslim society was not decisive in the approach to genetic testing; therefore, it is important to pay attention to these issues when planning genetic health services.
Keywords: Attitude, Chronic diseases, Genetic tests

1. Giriş

The social and economic negative consequences of chronic diseases, non-communicable diseases or lifestyle-related diseases are felt by all societies and economies [1]. 63% of all deaths in the world are caused by noncommunicable diseases. Approximately 80% of deaths from these diseases are observed in low- and middle-income countries. Cardiovascular diseases, cancer, chronic respiratory diseases and diabetes are four major diseases that cause 82% of deaths from noncommunicable diseases [2].

Genetic Tests, which are used in clinics with decreasing costs, are a type of screening tool applied to symptomatic, asymptomatic and healthy individuals. Genetic tests are based on the definition of changes in chromosomes, genes or proteins as a method. Today, thousands of genetic tests are used for various complex chronic diseases including cancer, diabetes, cardiovascular disease and Alzheimer's disease, and more are in the process of development [3-6].

With the impact of many factors in developed and developing countries, interest in these tests is increasing. These factors include the possibility of early diagnosis and thus the reduction of morbidity and mortality. In addition, negative (bad) test results can lead to a more regular life by changing the patient's lifestyle. This means less pain and anguish [7,8]. Nevertheless, test results do not mean that a chronic disease will occur in the individual.

Test results are also a major concern in terms of causing genetic discrimination. The possibility of incorrect test results leading to unnecessary medical interventions is seen as a serious obstacle to genetic testing. Despite these drawbacks, the public's opinions on genetic testing tend to develop in a positive way over time [9-11].

Neoplasms (15.3%), circulatory diseases (34.3%) respiratory disease (11.4%), congenital malformations, deformations and chromosomal abnormalities (1%) and metabolic (2.9%) diseases are diseases of genetic origin observed at high frequency in Turkey [12,13]. In a study of 589 individuals who had genetic problems in 2000 by Tekşen, it was found that individuals with relatively low levels of education had limited knowledge about advanced biotechnological procedures used in the early diagnosis of hereditary diseases [14]. In another study conducted in 2002, the majority of the 125 women (86.4%) who had prenatal diagnosis (high-risk pregnancy) stated that they had no prior knowledge of prenatal diagnostic tests but were pleased to present such a test [15]. Briefly awareness about genetic information and genetic testing is still an important problem in Turkey. This issue has not yet been explored sufficiently and has not been actively discussed even among experts [16]. The aim of this study was to investigate the attitudes of individuals living in urban and rural areas with multiple factorial diseases towards genetic testing; also to examine that there is a relationship between the levels of genetic information, health literacy and other variables of patients with their level of attitudes to genetic tests.

2. Materyal ve Metot

This cross - sectional study was carried out between 23.12.2017-20.08.2018. Participants were included in two groups (rural / urban). The first group consists of individuals living in rural areas of Manisa Yund Mountain; The second group consists of individuals who live in Manisa city center and apply to Medical Genetics outpatient clinic of MCBU Faculty of Medicine for any reason. Since the research regions did not have equal population, stratified sampling method was used. Three villages were randomly selected from the rural area of Mount Yund. The total population aged 20 years and older living in these villages was 1479. 196 individuals were included in this study. Epiinfo 7.0 program was used to calculate sample size. 150 people who were living in the city center and who applied to the Genetics outpatient clinic for any reason were included in the study. A total of 346 people agreed to participate in the study.

Participants have one or more of cardiovascular diseases, asthma / COPD, musculoskeletal diseases, cancer, endocrine system diseases, neurological diseases, gastrointestinal disease and other chronic diseases. There are no mental or physical obstacles in terms of understanding the purpose of research, answering survey questions, etc. Participants were divided into groups according to their disease. To provide meaningful comparison between the groups, participants were evaluated in terms of age [young-middle-aged (20-54), and middle-aged (55 and above)]; and according to the level of education divided into four groups (literacy-secondary education-university and graduate). The individuals invited to the research were informed about the subject and purpose of the study and their consent was obtained.

Participants were asked to complete; 1) Questionnaire about socio-demographic characteristics, 2) the validity and reliability of the Turkish version of the HLS-EU-Q16 scale by Emiral et al. 3) Genetic Knowledge Level questions 4) Knowledge and Attitude questions related to genetic tests (developed by the research team by literature review)

Data analysis

Data were evaluated using descriptive statistics (number, percentage distribution, mean, standard deviation), t test in independent groups and one-way analysis of variance (ANOVA). Statistical analyzes were performed using

SPSS 23.0.

3. Bulgular

The mean age of the 346 participants was 55.99 ± 16.46. 60.4% of the participants were women, 43.9% were primary school graduates, 14.5% were university graduates and 54.0% were income (Table 1).

Table 1. Distribution of research group according to sociodemographic characteristics

Age (ort±ss)	**55.99±16.46**	
Gender	N	(%)
Male	137	39.6
Female	209	60.4
Education level		
Ignorant	55	15,9
Primary school	152	43,9
High school	83	24,0
Graduate	50	14,5
Postgraduate	6	1,7
Economic level		
Income is more than expense	54	15,6
Income and expense equals	187	54,0
Income is less than my expense.	105	30,3

The level of Genetic Knowledge of the participants was very low, and the majority (about 80%) gave the wrong answers to almost all of the related questions. The answer to the question "Each disease has a gene" was 4.0% correct. In the question of the fact that “healthy parents can have children with hereditary diseases”, the participants gave an almost equal percentage of correct and incorrect answers (Table 2). According to the frequency of chronic diseases, 26.0% endocrine system and 22.0% were found to be cardiovascular diseases and 48.6% of all of them thought that the disease was hereditary (Table 3).

Participants were asked about religious sensibilities and worship 41.9% of the "I apply almost every day" were the answer (Table 4). More than half of the respondents (51.7%) stated that they did not know whether the problem of safety and confidentiality of genetic test results was solved. Participants stated that they believe genetic research is an important part of the progress and development of medicine (78.9%) (Table 5).

Table 2. Distribution of the participants according to their genetic information levels

	Right %	Wrong %
A human can see a gene with the naked eye.	28.3	71.7
Every disease has a gene	4.0	96.0
Gene is part of DNA	37.6	62.4
Different body parts contain different genes	10.1	89.9
Genes are larger than chromosomes.	10.1	89.9
Our inherited features may vary with human intervention	32.7	67.3
It is estimated that a person has 21,000 genes	19.9	80.1
Healthy parents can have children with hereditary disease.	44.8	44.8
Even if a person is a carrier of a disease gene, that can lead a healthy life.	41.3	58.7
All serious diseases are hereditary.	12.4	87.6
The child of a disease gene carrier is always the carrier of the same disease gene.	12.4	87.6

The mean scores of attitudes and genetic information of the participants in urban areas compared to those living in rural areas were found to be higher. In addition, it was found that they had more positive attitudes towards genetics tests and genetics ($p < 0.05$). According to the distribution of health literacy subscale subscale scores according to the region where the participants lived, the mean health care subscale score was higher in patients who applied to the outpatient clinic than in rural areas ($p < 0.05$). (Table 6). The mean scores of women for genetic tests were higher than males ($p < 0.05$).

There was no significant difference in the level of genetic information according to gender. The mean scores of the university graduates' attitudes and knowledge level about genetic tests were higher than the others ($p < 0.05$) (Table 7). When the distribution of the attitude, knowledge score and health literacy sub-field scores according to age were examined, the mean attitude scores and knowledge level scores of the people between the ages of 20-54 were found to be higher than those of the students ($p < 0.05$). In terms of religious sensitivity and adherence to worship, it was found that the responses did not make a statistically significant difference in the attitudes, knowledge level and health literacy lower scores of the genetic tests ($p > 0.05$).

Table 3. The presence of chronic disease among the participants and distribution by family history

Diseases	**N**	**(%)**
Cardiovascular diseases	76	22.0
Endocrine diseases	90	26.1
Gastrointestinal diseases	42	12.3
Musculoskeletal diseases	31	8.8
Neurological diseases	48	13.9
Others	59	16.9
Duration of disease		
0-5 years	163	47,1
6-10 years	145	41,9
10 years +	38	11,0
Whether the disease is hereditary or not		
Strictly hereditary	168	48,6
Partially hereditary	72	20,8
Not hereditary	106	30,6
Family history		
Cancer	37	10.7
Cardiovascular diseases	139	40.7
Endocrine diseases	120	34.7
Gastrointestinal diseases	83	24.0
Musculoskletal diseases	90	26.0
Neurological diseases	75	21.7
Others	48	13.9

Table 4. Distribution of participants according to religious sensitivity

Religious sensitivity	**N**	**(%)**
Has no effect in my life	1	0,3
Occasionally come to my mind and I apply	35	10,1
In my mind, I apply as soon as possible	118	34,1
I think and apply it almost every day	145	41,9
Every moment is on my mind and I apply	47	13,6

Table 6. Attitudes and distribution towards genetic tests, genetic information and health literacy according to total scores, as individuals living in rural or urban areas

	Settlement	Average	SD	p
Attitude Towards Genetic Testing	U	72,48	8,13	<0.001
	R	66,40	9,39	
Genetic Knowledge Level	U	3,71	2,85	<0.001
	R	1,99	1,92	
Health care	U	19,96	4,01	<0.001
	R	15,21	4,60	
Disease prevention	U	14,00	3,63	0,346
	R	10,97	3,01	
Health promotion	U	11,69	2,97	0,284
	R	9,75	2,90	
Total health literacy	U	45,65	8,26	0,788
	R	35,93	8,94	

U: Urban R: Rural, SD: standard deviation

4. Discussion

The aim of this study was to investigate the attitudes of individuals with chronic diseases to genetic tests. According to research findings, participants know little about genetics and genetic testing. However, their attitudes towards genetic testing are generally positive.

When the answers of the participants to the Attitude Questions are evaluated in general, some of them draw attention. For example, participants stated that they did not have satisfactory knowledge of genetic testing results and confidentiality issues (51.7%), also have serious suspicions about compulsory testing for their children. According to the participants, the idea of conducting a genetic test is frightening (28.6%), but it shows that in spite of everything, they want to know if they will have a disease. While most individuals believe that genetic information may facilitate decision-making on future plans, it may be thought that this information may lead to anxiety, depression, stigmatization, and even discrimination for a significant number of individuals [17,18].

It was found that people living in urban areas had more positive attitudes towards genetic testing and genetic knowledge than people living in rural areas. When the attitudes of the participants to the genetic information and tests according to their age were examined, it was found that the mean scores and genetic knowledge level of the individuals between the ages of 20-54 were higher. The mean scores of the attitudes towards genetic tests for patients with the disease for more than 10 years were found to be high [19].

When the data were analyzed according to the gender of the participants; it was found that the mean score of women in terms of genetic tests was higher than that of men. In one of the few studies conducting for the approach to genetic testing in Turkey women's interest in genetic testing was found to be significantly higher [15]. However, in a study conducted in Australia, it was

Table 5. Attitudes of the participants to the genetic tests

	Absolutely I agree %	I agree %	I do not know %	I don't agree %	Absolutely I don't agree %
The future of someone who has the possibility of genetic testing and who decides to do so may change.	20.5	36.4	33.5	8.7	0.9
I'd like to have a genetic test that lets me know if a cure for a completely unknown disease will appear in me.	21.4	37.9	19.7	17.9	3.1
It is not necessary for the family members to know the genetic test results of the individual.	8.1	43.1	17.9	25.7	5.2
The blood of the patient for diagnostic purposes should be used for genetic research regardless of the person's permission.	9.0	30.3	17.9	29.2	13.6
Genetic testing should be performed even if it shows that we are at risk for a particular disease.	13.9	37.6	23.1	21.4	4.0
The idea of doing a genetic test is frightening.	9.0	28.6	28.6	25.1	8.7
Genetic tests help in predicting / preventing some chronic diseases.	20.2	46.0	26.3	6.6	0.9
Genetic tests to determine the likelihood of chronic diseases should be made even if these diseases do not have preventive / therapeutic remedies.	14.7	40.8	19.1	21.4	4.0
Genetic testing of chronic diseases should only be performed if the cost / efficiency ratios are appropriate.	13.3	35.3	31.5	15.6	4.3
Parents should inform their children about the genetic test results of a disease without treatment.	17.6	54.0	14.5	12.4	1.5
I'd like to know if my chronic illness is hereditary.	24.9	40.5	13.0	17.9	3.7
People should have a genetic test for hereditary disease.	15.9	44.8	16.8	19.7	2.8
Genetic testing should only be performed for treatable or preventable diseases.	14.2	43.1	19.7	19.5	3.5
Genetic tests should be carried out in terms of the diseases that the newborn will encounter in adulthood.	16.2	41.3	27.5	13.0	2.0
The patient's siblings should also inform about the results of the genetic test performed for a disease without definitive treatment.	11.6	53.5	19.1	14.2	1.6
Genetic testing for a disease without definitive treatment is an unnecessary expense.	13.9	35.8	8.8	23.1	8.4
The problem of the safety and confidentiality of genetic test results has not yet been fully solved	8.7	28.3	51.7	9.5	1.8
Genetic research is promising in terms of finding a cure for diseases.	20.5	50.0	24.0	4.6	0.9
Genetic tests should be performed in childhood in terms of early diagnosis of diseases.	17.9	36.4	30.9	12.1	2.7
Genetic research is an important part of the progress and development of medicine.	26.0	52.9	15.7	4.0	1.4

observed that mothers were more abstinent in genetic tests to be done to their children [20]. However, many studies show that women have a more positive attitude towards approach to genetic testing than men [21]. Women, especially in developing societies, are more active than men about the health of their family members. With these aspects, they can be seen as a “orchestra conductor” in the context of health within the family. This feature is more dominant in families living in rural areas. For example, women are still more effective than men in case of "folk remedy" the preparation of the so-called folk prescriptions and other medical applications made from vegetable, animal and minerals [22].

When the research data are analyzed according to the education level of the participants, the levels and attitudes of the genetic information vary according to the education levels. For example, the average scores of individuals at higher education level for their attitudes towards genetic testing were found to be significantly higher than others. It was found that the low level of education was low (1.94). When we look at the results of research in some developed countries: for example, the level of education in Italy does not have a significant relationship with attitude; In the Netherlands, individuals with low levels of education show more interest in genetic testing than those with higher education [23,24]. On the other hand, it was determined that university graduates in Canada had a more positive approach to genetic tests than those with high school and lower education level [25].

Because the general education and intellectual level of the society is high in developed countries, individuals have detailed knowledge about the positive / negative aspects of genetic testing; therefore, it is important that they stay close to the genetic tests. In developing countries, Turkey, etc. due to the low level of general education and intellectual health, disease, treatment, and especially the community about genetic testing it is not sufficient and reliable information. Therefore, it can be said that the positive attitude towards genetic testing (high / low education level) is not based on accurate-reliable knowledge, but based on estimation.

When the data were examined in terms of the participants' religious beliefs, no significant difference was found. However, Turkey has adopted the religion of Islam in the majority of the population is thus expected to be effective on the results of a fatalistic approach. In other words, it can be expected that the group who considers himself / herself religious to be negative / insensitive to genetic tests with a fatalistic understanding in the context of a possible future disease. However, the research results do not correspond to this expectation. The relationship of the participants with religion was not a factor in their attitudes towards tests. A similar result is confirmed by a study conducted in Pakistan [26]. However, another study has shown that relatively few Christian religious women are more interested in genetic testing [27].

Rersearches of testing and identification of genes associated with various diseases in individuals have developed so rapidly that many unanticipated ethical problems arise due to test results [28,29]. Due to the misinterpretation of the research results, it can be considered as an important ethical problem because of the unnecessary treatment of the individual, organic, psychological, economic and social damage. On the other hand, the development of genetic tests and the entry into force of mandatory tests can be expressed as another ethical problem that insurance companies may narrow the scope of health insurance and reduce their benefits or increase premiums, as they will violate the privacy rights of the individual and lead to discrimination [30,31].

5.Conclusion

The results of the research show that the participants are weak in terms of genetic information but generally have a positive approach towards genetic tests. However, the public use of genetic testing in Turkey is still limited. As suggested by our study, there is a significant interest among those participating in the study at the rate of asking whether they would be susceptible to the disease. Therefore, with the decrease in the costs of the tests and the approval of the official social security institution, the use of the test is expected to increase. In this respect, the validity, priority, suitability of the Genetic Tests, trust in technology, quality control should be supported. Besides the importance and benefits of genetic testing due to economic constraints and cultural factors in developing countries such as Turkey, frequent complex chronic / for the inconvenience of the control and prevention priorities, control of smoking, reducing stress, prevention of mutagens exposure, healthy diet, proven effective, such as physical activity people the implementation of health measures should also be given importance.

Limitations

Researchers provided help to the individuals who could not fill the surveys alone, especially among those living in rural areas. This is one of the limitations of this study. The explanations made by the researcher may be incomplete or misunderstood by the participant.

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