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ORIGINAL ARTICLE

Knowledge and attitude of physicians, cancer patients, and the public concerning cancer-related genetic tests in Saudi Arabia

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ABSTRACT

Background: To evaluate knowledge and attitude toward cancer genetic tests (CGT) and cancer genetic counseling for improving underdeveloped CGT services and to achieve a better understanding of how cancer genetic services are being perceived in the Saudi society.

Methodology: An electronic survey was conducted targeting three different types of subjects; physicians, cancer patients, and public participants. Characteristics of the study population were summarized as frequencies, means, and standard deviations. The association between two categorical variables was evaluated by the Chi-square test and cross-tabulation. Multiple logistic regression analyses, using a backward stepwise elimination procedure, were performed to examine the potential impact of the variables. All the explanatory variables were calculated using the Statistical Package for Social Sciences (16.0) software program. Continuous variables were grouped into ordinal categories to facilitate inclusion in the multiple logistic regression analysis. Analysis of variance was used to measure knowledge scores with different independent variables.

Results: The public cohort showed a higher knowledge score than the patient cohort. A willingness to undergo CGT correlated with high knowledge in the public cohort [r (n = 1,083) = 0.12, p < 0.001), but with positive family history in the patient cohort [r (n= 100) = 0.29, p < 0.01]. Attitudes toward CGT were not correlated with a fear of stigma or privacy in the public cohort. The majority of physicians reported an increase in the number of patients seeking CGT and agreed that testing should not be performed without counseling as they would refer to appropriate patients accordingly. Physicians self-reported significant levels of uncertainty regarding CGT, such as qualifications, attitudes toward CGT, and confounding factors.

Conclusion: There is an overall positive attitude toward CGT in Saudi society. Public health actions are needed to enhance cancer genetic services for high-risk families.

Keywords: Cancer genetic tests, genetic counseling, Saudi Arabia, cancer genetic test knowledge, attitude.

Introduction

Cancer incidence in Saudi Arabia has remained relatively steady with approximately 2,500 new cases diagnosed annually in Riyadh city, Saudi Arabia (1). Public awareness of cancer and cancer-related care is reported to be limited in Saudi Arabia (2–6). A previous study (4) on attitude and behaviors of Saudis concerning breast cancer prevention showed that 96% of participants acknowledged the importance of early detection. However, only 23% reported that they underwent self-breast examination due to several factors, such as cultural traditions about modesty, being examined by a male physician, shortage of clinics specializing in women's health, a lack of female physicians at all levels of care, and belief among young women that breast exams are for the elderly (2).

Accounting for 5%–10% of all cancer cases, hereditary cancer risk counseling has grown rapidly in recent years to become a major area of specialization within genetic counseling (7). However, cancer risk counseling remains immature in Saudi Arabia, regardless of the

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development of different oncology centers throughout the country. Cancer genetic counseling services still is in a primitive state in Saudi Arabia; however, some health institutes have expressed interest in implementing this service as part of the health services provided to their patients (8). Acceptance of cancer genetic counseling services depends upon the awareness, attitude, and social influences (i.e., ethics, religion, economics, culture, law, education, etc.) of both physicians and the public (9). To date, no studies have been conducted to assess cancer genetic test knowledge, attitude, or behaviors among the general public, cancer survivors, or physicians in the Saudi Arabia population. The goal of this study was as follows: 1) to obtain a better understanding of how cancer genetic services are perceived in the general public, among cancer survivors and physicians in Saudi population; 2) to measure physician knowledge and attitude toward genetic counseling services, considering the influential role of healthcare providers in motivating patients to receive genetic counseling and risk assessment; and 3) to explore the acceptance of genetic counseling services in the Saudi society, as it relates to awareness, attitude, and social influences (i.e., ethics, religion, economics, culture, law, education, etc.) of both physicians and the public.

Subjects and Methods

A cross-sectional study was conducted using an electronic survey. The survey was designed to target three different populations, including physicians, cancer patients, and the public (physicians who had been diagnosed with cancer were instructed to respond as cancer patients). Participants were recruited using email list servers from the following organizations: Saudi Oncology Society, Saudi Cancer Society, Saudi Arabian Cultural Mission in the United State, and hospital intra-email systems has been used to reach physicians at National Guard Health Affairs, King Fahad Medical City and Security Forces Hospital, Riyadh, Saudi Arabia. Participation in the online anonymous survey was voluntary. This study was approved by the institutional review board of the participating institutes. Three surveys were designed based on a comprehensive review of the literature. The survey included data on the following: 1) demographics and personal information; 2) knowledge of cancer; 3) knowledge of cancer screening; and 4) attitude toward genetic counseling and early detection/screening programs. The inclusion criteria for the study were: 1) Saudi nationality and 2) 18-year old or older. The study excluded non-Saudi respondents and subjects younger than 18 years of age. The questionnaire validity and reliability was checked by item drafting process and face-validity checking with a multidisciplinary expert panel, and member-checking with potential respondents, which enabled the team to refine content. The survey was piloted with five eligible respondents of the target population before being released online. Characteristics of the study population were summarized as frequencies, means, and standard deviations (SD). The association between two categorical variables (i.e., demographic parameters, respondent's knowledge, and/or religion analysis) was evaluated by the Chi-square test and cross-tabulation. Multiple logistic regression analyses, using a backward stepwise elimination procedure, were performed to examine the potential impact of the variables. All the explanatory variables were calculated using the Statistical Package for Social Sciences (16.0) software program. The measurement of participants' knowledge was scored based on giving one point to correct answers and zero points to incorrect or uncertain (don't know) responses. A correct response was evaluated based on the current literature available on the topic. The knowledge score was computed by totaling the number of correct answers. The expected maximum total score was 15 points. Then the score was recorded as a dichotomous variable—low and high—with an arbitrary cut off point of 50% correct answers or more to evaluate knowledge levels. Continuous variables were grouped into ordinal categories to facilitate inclusion in the multiple logistic regression analysis. Analysis of variance was used to measure knowledge scores with different independent variables. All procedures followed were under the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000 (5). Informed consent was obtained from all patients before being included in this study.

Results

Physicians survey and reported qualifications

A total of 516 physicians from different specialties were invited to participate in the study; 105 (20%) returned a completed questionnaire (Supplementary-Table 1). When physicians were asked if they felt qualified to recommend genetic testing themselves, 34% felt that they were well qualified, 38% were somewhat qualified, 19% were not well qualified, 5% reported they were unqualified, and 4% were unsure. Physicians who considered themselves more qualified to recommend genetic counseling to their patients ordered genetic testing for inherited cancer susceptibility more often [Chi-square (2) = 20.97, $p < 0.001$]. Approximately 97% of physicians who thought they were not qualified or were unsure of recommending genetic tests had never ordered genetic testing for inherited cancer susceptibility.

Attitude toward the clinical utility of cancer genetic tests

Three questions were related to clinical utility concerned with issues of risk analysis, cost-effectiveness, and accuracy of cancer genetic tests. Nearly, 40% of physicians were unclear about the risk of cancer in patients that had a positive genetic test, whereas 55% of physicians disagreed with this statement and 5% of physicians were unsure of the meaning of a positive genetic test. More than one-third of physicians believed that cancer genetic testing in patients with a family history of cancer was not cost-effective (11.4% strongly agreed and 25% somewhat agreed), whereas 36% of physicians strongly disagreed

and 8% were unsure. Approximately 39% of physicians indicated that genetic tests for cancer susceptibility have too many false positives, false negatives, or ambiguous results, and 27% of physicians were unsure of how they felt about genetic tests for cancer susceptibility.

Attitude about cancer genetic counseling and genetic testing

The survey contained two questions that covered the issues of cancer genetic counseling and the availability of cancer genetic testing services. More than 64% of physicians strongly agreed that patients should not undergo cancer genetic testing unless they obtained counseling related to the risks, benefits, and consequences of the cancer genetic test. A total of 25% of physicians somewhat agreed that patients should not undergo cancer genetic testing unless they obtained counseling related to the risks, benefits, and consequences of the cancer genetic test and 4% were unsure. On exploring factors that influence recommending genetic testing for hereditary cancer syndromes, 80% of physicians reported that the patient's attitude and his/her family's attitude is somewhat important in recommending the cancer genetic tests. However, approximately 17% of physicians thought that the attitude toward cancer genetic testing was unimportant and 2% were unsure if it was important. Also, physicians were asked if they did not support cancer genetic testing because of concerns regarding the psychological impact of testing on patients, 42% of physicians agreed, 50.5% disagreed, and 8% were unsure.

Public and patient surveys, relatives with cancer and exposure to testing

A total of 1,187 participants completed the survey; 1,085 members were from the general public and 102 were cancer survivors (Supplementary-Table 2). Nearly, 59% of the public cohort reported having a relative with cancer, and the majority (80%) were first-degree relatives. However, public experience with cancer genetic testing was limited to only 17% and 13% of the public cohort were aware that their friends or family members had received cancer genetic testing. The same percentage (59%) of respondents from the cancer patient cohort reported having a relative with cancer. Cancer patient experience with cancer genetic testing was limited to 12%, whereas 17% of cancer patients were aware that their friends or family members had received cancer genetic testing (Figure 1).

Public and patient knowledge index and correlations with the knowledge index

A knowledge index was created by assigning one point for every question answered correctly and summing the scores. The mean total knowledge score for the public was 7.16 out of 15 (SD = 2.58) and the median was 7.00. However, the mean total knowledge score for patients was 4.98 out of 15 and the median was 5 out of 15 (SD = 2.95) (Supplementary-Table 3). In the public cohort, four demographic variables were significantly correlated with the knowledge index, including income [r (1083) = 0.58, $p < 0.001$], gender (female) [r (1083) = 0.26, $p < 0.001$], education [r (1083) = 0.23, $p < 0.001$], and age [r (1083) = 0.15, $p < 0.001$]. In the patient cohort, three demographic variables were significantly correlated with knowledge scores, including education [r (86) = 0.36, $p < 0.001$], gender (female) [r (100) = 0.33, $p < 0.001$], and income [r (99) = 0.22, $p < 0.05$]. A high knowledge score was not correlated with age, region, city, marital status, children, or religion.

Public and patient predictive genetic testing for cancer

Several confounding factors were assessed in the present study regarding cancer genetic testing. The majority of the patient (72.5%, SD = 0.737) and public (58%, SD = 0.73) participants were interested in predictive cancer

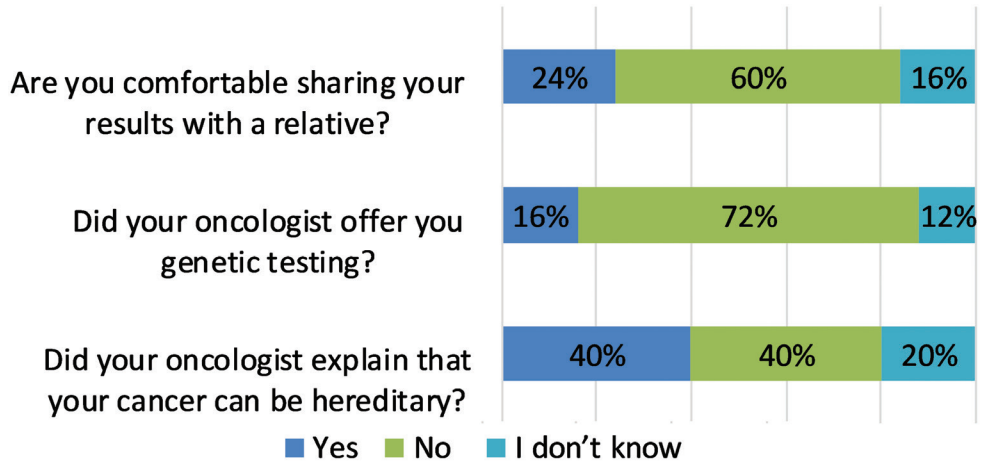

Figure 1. *Patient experience with cancer-related aspects.*

genetic testing. The main reason behind an interest in genetic testing for hereditary cancer syndromes for both patient and public cohorts was that it may help with cancer treatment (Figure 2). Both groups that declined to test, expressed further interest in testing if there was a family history indicating a need for testing. However, in the absence of cancer treatment, half of the public respondents and almost a quarter of patients lost interest in cancer genetic testing. A total of 17% of patients and 26% of public respondents stated that they would refuse genetic testing due to perceived stigma (Figure 3). A substantial majority of public and patient participants (75% and 84%, respectively) agreed that physicians were entitled to share cancer genetic test results with family members, even if it violated the test participant's privacy. However, 75% of respondents perceived that secrecy could be a barrier to cancer genetic testing. In the public population, knowledge of cancer genetic testing was significantly related to the willingness to undergo genetic testing to determine the risk of developing cancer before the age of 65 (r (1083) = 0.12, $p < 0.001$). Also, participants were interested in cancer genetic testing if genetic tests accurately predicted cancer risk (r (1083) = 0.11, $p < 0.001$). The patient's knowledge was significantly related to wanting to test for a higher cancer risk if there was a family history of cancer (r (100) = 0.29, $p < 0.01$).

Public and patient attitude concerning genetic counseling

Overall, the public (62%) and patient (71%) respondents were interested in cancer genetic counseling services compared with 19% of public participants and 13% of patients who were not interested in this service. Interestingly, 25% of public respondents who declined cancer genetic counseling services considered visiting a psychologist if their cancer genetic test result showed a high predisposition for developing cancer. However, 44% of patients did not express significant interest in visiting a psychologist if their cancer genetic test result showed a high predisposition for developing cancer.

Discussion

To date, the present study is the largest observational cancer genetic test study in Saudi Arabia. In the present study, both patient and public participants expressed interest in genetic testing for hereditary cancer syndromes, as similar to previous studies (10). In the public and patient cohorts, high income, gender (female), high education, and age were variables that correlated with the knowledge index. In the present study, higher knowledge scores correlated with a greater willingness to undergo cancer genetic testing in the public cohort. However, in the patient cohort, willingness to undergo cancer genetic testing correlated with a positive family history of cancer. Genetic counseling is defined as "the process of helping people understand and adapt to the medical, psychological, and familial implications of genetic contributions to disease" (11). There was a significant amount of uncertainty surrounding many aspects of cancer genetic testing among the physician respondents, including clinical utility, cost-effectiveness, discrimination, and patient confidentiality. Consequently, these results may affect cancer risk communication, the decision-making process, and/or medical management for cancer patients (12). The decision to outright decline cancer genetic counseling services or the preference for a psychologist may indicate a low understanding of the role of a genetic counselor among the public cohort. Additional education is required for physician and public populations, as genetic counseling improves the understanding of cancer genetics and genetic testing without adverse effects on cancer-specific worry, general

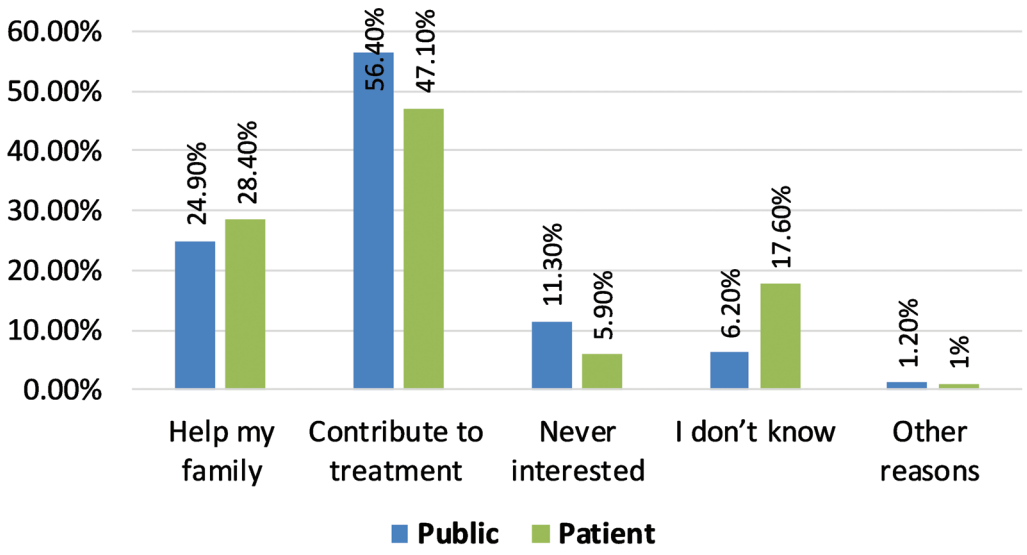

Figure 2. *Reasons behind the interest in genetic testing for hereditary cancer syndromes.*

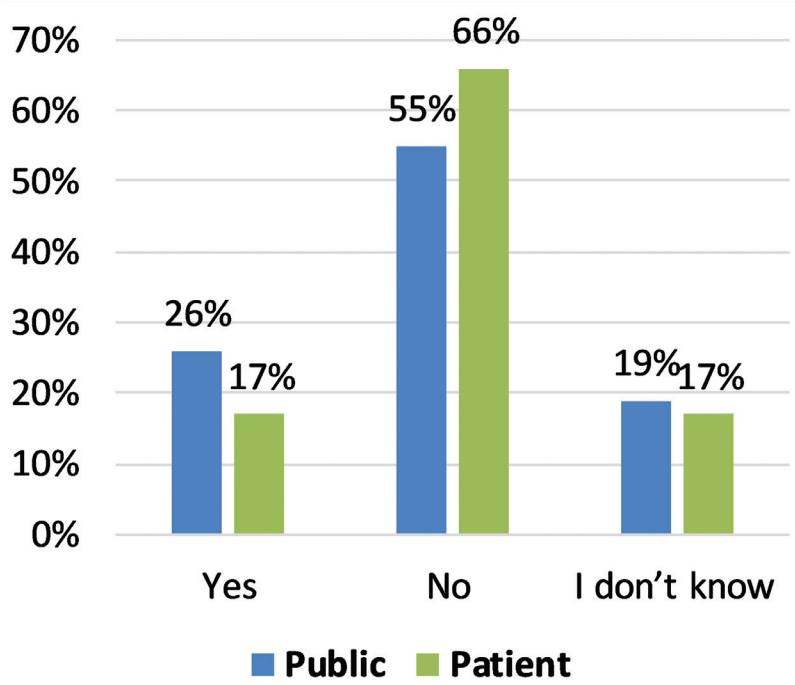

Figure 3. *Participants view on refusal genetic testing due to perceived stigma.*

anxiety, distress, and/or depression (13). The present study found that more than 84% of patient respondents and 58% of public respondents thought that doctors were entitled to share genetic test results with relatives if the results directly influenced their lives. Also, the next generation of physicians in Saudi Arabia embraces the idea of disclosure (14), hopefully helping to alleviate some of the stigmas previously discussed.

The present findings suggest a higher interest in genetic services between both patient and public cohorts. Also, physicians are interested in utilizing cancer genetic testing for their appropriate patients. To improve cancer genetic services in Saudi Arabia, it is important to investigate and address the social and cultural barriers that may exist. In the current study, physician expectations of increasing the number of cancer genetic tests performed were supported by patient interest in this service. Also, the uncertainty reported by physicians related to cancer genetic test results calls for more awareness and education. Therefore, the present study determined that there was limited knowledge of cancer genetic testing among patients; however, it did not correlate with a positive attitude towards cancer genetic testing, which may be explained by the desire of the Saudi population to utilize technology to reduce cancer risk. These data could be used to improve clinical cancer genetic testing, to educate patients about their diagnosis and its effect on extended family. Assessing knowledge and attitude towards cancer genetic screening among the Saudi population will help to understand the barriers that slow down the process of improving genetic services despite the views of an immediate need for these services. Moreover, physicians should be taught to be more comfortable while communicating hereditary cancer risk to patients and their families.

Conclusion

In conclusion, the present study reports that there is a broad interest and positive attitude towards genetic services to assess hereditary cancer syndromes in Saudi Arabia. Greater education of cancer genetic screening is needed across all Saudi populations. Further research should target overcoming the barriers to access (perceived or real) genetic services and exploration into factors that influence understanding in the Saudi society, as the vast majority of the current data is from patients of Western origin.

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List of Abbreviations

CGT	Cancer genetic tests
SD	Standard deviations

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None.

Declaration of conflicting interests
The authors declare that there are no conflicts of interest.

Ethical approval
This study has been approved by three ethical committees; King Abdulaziz Medical City—Riyadh, Saudi Arabia number SP13/008, and Julia Dykman Andrus Institutional Review

Board on 13 Sep 2013, and King Fahad Medical City—Riyadh, Saudi Arabia.

Consent for publication

Informed consent was obtained from the participants.

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Supplementary

Table 1. *Physician demographic.*

	Frequency	%
Nationality		
Saudi	63	60
Non-Saudi	42	40
Affiliation with academic institution		
Yes	68	64.8
No	37	35.2
Practice management		
Governmental	96	91.4
Commercial owned	5	4.8
Self-employed	4	3.8
Total physician in this practice		
1	3	2.9
2–5	21	20.0
6–10	22	21.0
11–15	15	14.3
16–30	16	15.2
<30	28	26.7
Number of patients per week		
<10	40	38.1
10–20	34	32.4
21–30	14	13.3
>30	17	16.2
Approximate percentage covered by health insurance plans (%)		
None	44	41.9
1–9	13	12.4
10–19	3	2.9
20–29	4	3.8
30–49	7	6.7
>50	34	32.4

Table 2. *Socio-demographic data for patient and public.*

	Public		Patient	
	Frequency	%	Frequency	%
Number of participants	1085		102	
Age				
18–24	426	39.26	9	8.82
25–29	292	26.91	14	13.73
30–39	243	22.40	23	22.55
40–49	84	7.74	26	25.49
50 Above	39	3.59	30	29.41
Gender				
Male	445	41.01	61	59.80
Female	639	58.89	41	40.20

(*Continued*)

Table 2. *(Continued)*

	Public		Patient	
	Frequency	%	Frequency	%
Education level				
High school	26	2.40	20	19.61
High school	278	25.62	24	23.53
Bachelor	489	45.07	33	32.35
Post-graduate	165	15.21	7	6.86
Bachelor Degree-Medical	89	8.20	2	1.96
Other	35	3.23	15	14.71
Province of origin				
Central	630	58.06	69	67.65
East	105	15.68	7	6.86
West	167	15.39	7	6.86
South	121	11.15	12	11.76
North	61	5.62	6	5.88
Marital status				
Never married	614	56.59	21	20.59
Married	425	39.17	73	71.57
Widowed	11	1.01	2	1.96
Separated	7	0.65	1	0.98
Divorced	27	2.49	5	4.90
Children				
Yes	374	32.97	71	69.61
No	111	8.96	22	21.57
Do not show	600	52.04	9	8.82
Employment status				
Student	468	43.13	9	8.82
Un-employed	143	13.18	36	35.29
Employed	448	41.29	42	41.18
Retired	25	2.30	14	13.73
Employed				
Self-employment	72	6.64	6	5.88
Admin/office work	165	15.21	12	11.76
Education	135	12.44	14	13.73
Military	57	5.25	1	0.98
Health professionals	114	10.51	6	5.88
Engineering	22	2.03	3	2.94
Not employee	383	35.30	42	41.18
Other	111	23.10	16	15.69
Not answer	25	2.30	2	1.96
Income				
<SR 2,999	164	15.12	9	8.82
3,000–5,999	118	10.88	10	9.80
6,000–9,900	185	17.05	16	15.69
>10,000	277	25.53	26	25.49
No salary	340	31.34	41	40.20

(*Continued*)

Table 2. *(Continued)*

	Public		Patient	
	Frequency	**%**	**Frequency**	**%**
Religiosity				
Very religious	118	10.88	27	26.47
Moderate religious	532	49.03	53	51.96
Low religious	400	36.87	21	20.59
Non religious	34	2.99	0	0.00
Family history of cancer				
No family history	328	30.23	42	41.18
First degree relative	129	11.89	16	15.69
Second degree relative	305	28.11	29	28.43
Third degree relative	185	17.05	18	17.65
Far relative	226	20.83	14	13.73
I dont know	139	12.81	5	4.90

Table 3. *Percentage of correct knowledge responses for public and patients.*

		Public responses (%)	**Patient responses (%)**
1	Car accidents mainly caused by environmental factors	88.2	75.5
2	Eye color is entirely determined by a person's genes	81.8	68.6
3	Measles mainly caused by environmental factor	52.7	64.7
4	A daughter of women with faulty breast cancer gene has 50% risk of transmit it.	50.7	40.2
5	Sickle cell anemia caused by genetic factors	49	42.2
6	Mother with two daughters has breast cancer, then there is an equal chance to pass the faulty gene to each one of them.	46.5	36.3
7	Gene test must be repeated every year as the results may change with age	45.7	20.6
8	Lung cancer caused by environmental and genetic factors	45.2	29.4
9	Strokes caused by both environmental and genetic factors	45.0	24.8
10	Genetic tests are always 100% accurate	44.3	27.5
11	Breast cancer caused by environmental and genetic factors	43.9	37.3
12	Down syndrome caused by genetic factors	41.2	21.6
13	G6PD caused mainly caused by genetic factors	35.4	27.5
14	Father can pass down a faulty breast cancer gene to his daughter	32.4	15.7
15	Spina bifida caused by environmental and genetic factors	13.4	6.9