



Knowledge and views about genetics: a public-based cross-sectional study

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Abstract

This study aimed to explore the knowledge, factors affecting knowledge, and views of the Jordanian population on genetics-related issues. A cross-sectional questionnaire study was conducted in Jordan. The questionnaire was administered by face-to-face interview to the participants who were recruited from different public places. In total, 5000 questionnaires were collected from public population in Jordan and 43.4% (2171/5000) of them were knowledgeable. The public's knowledge was found to be associated with female gender (OR = 1.493, 95% CI = 1.280–1.741, $p < 0.001$), bachelor degree (OR = 1.853, 95% CI = 1.592–2.157, $p < 0.001$), having children (OR = 1.433, 95% CI = 1.162–1.768, $p = 0.001$), and having first-degree relatives with comorbid conditions (OR = 1.669, 95% CI = 1.431–1.946, $p < 0.001$). Although public in Jordan had positive genetic attitudes, they raised several concerns about the applications of genetics in clinical practice. Genetic knowledge was significantly associated with all positive public attitudes and most of their concerns ($p < 0.001$). These findings suggested that female gender, educational level, having children, and having first-degree relatives with comorbid conditions were good predictors for public's knowledge about genetics-related issues. Public education about the value of participation in genetic research as well as educational and training programs for healthcare professionals are recommended to assist in establishing genetics-related services in Jordan.

Introduction

In many societies, people are concerned about the cultural fear of being associated with a genetic disease and the following possible stigmatization within the community [1]. Indeed, the frequency and the consequences of genetic diseases in Arab populations are high due to the degree of consanguinity between parents [2]. This could raise ethical, social, and legal issues that are related to a certain population, community, or society. Societies and cultures are extremely dynamic and changing with time, therefore, evaluating people's acceptance of sharing genetic information is of a great value to meet the public prediction about the services. Previous studies revealed different factors that affect public attitudes towards

genetics, such as age, gender, and educational level among others [3, 4].

The attitudes and beliefs of public toward genetics were investigated in non-Arab populations [5, 6]. In Jordan, the attitudes of public toward establishing biobanks were investigated [7]; however, their knowledge and views about genetic information are largely unknown. It has been suggested that assessing the knowledge is the first step in the decision making process for adopting or rejecting any innovation [8]. Understanding public views will help to identify the potential barriers in implementing genetic services into clinical practice. The public opinion about the genetic matters might change over time with the advances in genetic research to detect many diseases, accompanied with media attention. The main goal of the current study was to explore the knowledge, factors affecting knowledge, and views of Jordanian population on genetics-related issues. In addition, evaluating the intention to change the behavior in a group of healthy adults was assessed. To the best of the authors' knowledge, this is the first study in Jordan and Middle Eastern countries that elucidated the knowledge and views of public about genetics in the medical field.

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Materials and methods

Study design

A cross-sectional questionnaire-based study was conducted in Jordan between August 2017 and June 2018. The questionnaire was administered by face-to-face interview by the researchers in Arabic language. The research assistants ($n = 8$) were trained to ensure consistent interview and avoid any missing information in answering the questionnaire. Implied consent was obtained if the participants were willing to participate in the survey and the data were completely and irreversibly anonymized. A convenience sampling approach was adopted in the current study and the participants were recruited from different public places such as malls ($n = 7$), community pharmacies ($n = 15$), and blood banks ($n = 3$) from north, middle, and south Jordan. The ethical approval to conduct this research was granted by the institutional review board in Jordan University of Science and Technology (study number 156/2017) and has been performed in accordance with the Declaration of Helsinki and its later amendments.

Development of the questionnaire

To cover all aspects of interest in this project, a bespoke questionnaire was designed. The questions of the questionnaire were selected from the literature [3, 9] and some of them were newly developed after thorough discussion with the research team. In addition to the demographic details of participants, the questionnaire consisted of four sections that addressed four different themes: (i) knowledge, (ii) attitudes, (iii) concerns, and (iv) potential to change behavior. The latter section assessed the behavior of a group of public healthy adults (age 20–50 years old) to change their lifestyle utilizing a hypothetical clinical case scenario. The questions were adapted from previous study [10]. The case scenario focused on receiving the results of a genetic test that revealed their risk of developing common diseases in Jordan, such as cardiovascular disease or diabetes mellitus [11, 12].

The content of the questionnaire was reviewed for face validity and content validity by the members of the research team. In addition, a pilot study was conducted prior to the study ($n = 20$). Feedback from the pilot study was used to enhance the clarity of the questionnaire and collected data was not included in the final analysis. All sections in the questionnaire were comprised of closed-ended questions. The knowledge section consists of eight items that had three possible answers (true, false, I do not know). The attitude section consists of six statements with (yes, no) options and the concern section consists of seven statements with a 5-points Likert scale (ranging from “very nonconcerned” to

“very concerned”). The internal consistency of the relevant sections in the designed questionnaire was tested using the Cronbach’s α (alpha) measure. The results ranged between 0.552 and 0.623, which indicated good reliability [13].

Statistical analysis

Following data collection, the responses were coded and entered into Statistical Package for Social Sciences (SPSS Inc., Chicago, IL) version 20. Continuous variables were presented as median (Interquartile range), while categorical variables were presented as numbers and percent. Univariate analysis was conducted using Mann–Whitney U test for continuous variables and Chi-square test for categorical variables. In order to determine factors that were independently associated with level of knowledge, multivariate analysis using binary logistic regression was performed including all variables with $p < 0.2$ on univariable analysis. Odds ratio (OR) values and their 95% confidence intervals (95% CI) were calculated. Statistical significance was set at p value < 0.05 .

The main outcome in the study was the public knowledge which was dichotomized as knowledgeable and non-knowledgeable. For this purpose, the answers to the eight different questions of knowledge for each participant were labeled as categorical variables using a cutoff point for cumulative scores of correct answers. To calculate the knowledge score, all respondents who gave the wrong answer or stated “do not know” were coded “incorrect.” A participant was categorized as knowledgeable if the sum of the scores was > 5 (out of 8) and nonknowledgeable if the sum of the scores was ≤ 5 (out of 8). For the purpose of analysis, we restricted response options for the concern section. For example, we combined both “very nonconcerned” and “nonconcerned” as one category and both “very concerned” and “concerned” as one category.

Results

Demographics

In the present study, a total of 5644 persons were approached and 5000 of them were enrolled with a response rate of 88.6%. The median age of participants was 32 years old and more than half of them were female (58.5%). About 60% of the participants were married and the majority of those had children (84.1%). Approximately half of the public had university degree (51.5%). In addition, about half of the respondents were recruited from the middle area of Jordan (50.5%). Demographic details of participants are presented in Table 1. Almost half of the participants reported gaining their knowledge through media ($n = 2360$, 47.2%)

Table 1 Demographic details of the study participants

Characteristics ^a	All participants
Age (years) ^b	32 [24–42]
Gender	
Male	2085 (41.7)
Female	2915 (58.3)
Education	
School education	2424 (48.5)
Bachelor degree	2573 (51.5)
Marital status	
Single	1926 (38.5)
Married	3074 (61.5)
Have children ^c	
No	489 (15.9)
Yes	2585 (84.1)
Consanguinity with spouse ^c	
No	2107 (68.7)
Yes	960 (31.3)
Comorbidity in first-degree relatives	
No	3123 (65.4)
Yes	1651 (34.6)

^aAll data expressed as *n* (%) of participants unless otherwise indicated

^bData described as median [Interquartile range]

^cFor married participants

rather than other sources: healthcare providers (*n* = 839, 16.8%), people (*n* = 672, 13.4%), or the newspaper (*n* = 142, 2.8%).

Public knowledge

In the present study, 43.4% (2171/5000) of public were knowledgeable and the mean number of correct answers was 5.02 ± 1.791 (range 0–8). Only 5.8% (290/5000) of participants answered all questions correctly and few respondents (1.2%, *n* = 61) reported knowing nothing at all about genetics (knowledge score = 0). An overview of the questionnaire items and answers is presented in Table 2. Question one “There is a relation between consanguinity and genetic disease” was the one that was answered correctly by most respondents (*n* = 4134, 82.7%) (the correct answer was “true”). On the other hand, question eight “Genetic information will not help in predicting drug response to some therapies” had the lowest number of correct answers (*n* = 1467, 29.3%) (the correct answer was “false”).

As shown in Table 3, the results of univariate analysis showed that participants’ gender, level of education, having children and comorbidity in first-degree relatives were significantly associated with the public’s knowledge (*p* < 0.001). In addition, the results of multivariate analysis

identified the independent factors that predicted a higher level of knowledge. Females were knowledgeable compared with males (OR = 1.493, 95% CI = 1.280–1.741, *p* < 0.001) and participants who had bachelor degree were knowledgeable compared with those who had school education (OR = 1.853, 95% CI = 1.592–2.157, *p* < 0.001). Furthermore, participants who had children (OR = 1.433, 95% CI = 1.162–1.768, *p* = 0.001) and those with comorbid conditions in their first-degree relatives were more likely to be knowledgeable (OR = 1.669, 95% CI = 1.431–1.946, *p* < 0.001).

The knowledge of participants was also investigated by asking them about the methods that could be used for genetic testing. The majority of respondents were aware that genetic testing can be carried out using blood samples (*n* = 4415, 88.3%) as compared with other methods: tissue (*n* = 1778, 35.6%), saliva (*n* = 1158, 23.2%), urine (*n* = 1109, 22.2%), and swab (*n* = 882, 17.6%).

Public attitudes

About 70% of participants showed their willingness to use their genetic data in medical research. In addition, 75.7% of participants stated that they will be happy to inform their families about the results of genetic test for a specific disease. Furthermore, 66.9% of participants were willing to store their blood samples and health-related data in a biobank for long-term use. Importantly, the majority of participants were enthusiastic for genetic neonatal screening programs (86.2%) and premarital genetic test to the most common genetic diseases (88.3%). The analysis indicated that genetic knowledge was significantly associated with all positive public attitudes (*p* < 0.001).

Public concerns

Figure 1 reveals the potential concerns to genetic service implementation in Jordan regarding different issues that are related to genetic testing. Almost 60% (56.6%) of respondents were concerned that genetic testing would increase the complexity of providing healthcare. In addition, a half (49.3%) of participants were concerned that the cost of testing would be a barrier to the genetic service implementation. Importantly, about a quarter (27.9%) of respondents believed that stigmatization could affect the acceptance of genetic service in Jordan. Furthermore, a third of all participants were concerned that genetic test would affect their health insurance and employment. It is worth mentioning that approximately a sixth of participants were undecided (stated “neutral”) regarding all potential concerns. The analysis indicated that genetic knowledge was significantly associated with most public concerns (*p* < 0.001) except for stigmatization where knowledgeable

Table 2 Overview of knowledge points

Items in the questionnaire	Correct answers <i>n</i> (%)
There is a relation between consanguinity and genetic disease (True)	4134 (82.7)
You do not have the right to refuse genetic testing (False)	2493 (49.9)
Healthy parents can have a child with a hereditary disease (True)	3650 (73)
The carrier of a disease gene may be completely healthy (True)	3434 (68.7)
All serious diseases are hereditary (False)	3139 (62.8)
A gene is a molecule that controls hereditary characteristics (True)	3454 (69.1)
Genetic information will help in predicting susceptibility of some disease (True)	3307 (66.1)
Genetic information will not help in predicting drug response to some therapies (False)	1467 (29.3)

Table 3 Univariate and multivariate analysis of factors affecting the participants' knowledge

Factors ^a	Univariate analysis			Multivariate analysis	
	Not knowledgeable <i>n</i> = 2829	knowledgeable <i>n</i> = 2171	<i>p</i> value	OR (95% CI)	<i>p</i> value
Age (years) ^b	31 [24–42]	32 [24–42]	0.894		
Gender					
Male	1306 (46.2)	779 (35.9)	<0.001	Ref	<0.001
Female	1523 (53.8)	1392 (64.1)		1.493 (1.280–1.741)	
Education					
School education	1536 (54.3)	888 (40.9)	<0.001	Ref	<0.001
Bachelor degree	1291 (45.7)	1282 (59.1)		1.853 (1.592–2.157)	
Marital status					
Single	1105 (39.1)	821 (37.8)	0.371		
Married	1724 (60.9)	1350 (62.2)			
Have children ^c					
No	311 (18)	178 (13.2)	<0.001	Ref	0.001
Yes	1413 (82)	1172 (86.8)		1.433 (1.162–1.768)	
Consanguinity with spouse ^c					
No	1172 (68.1)	935 (69.5)	0.418		
Yes	549 (31.9)	411 (30.5)			
Comorbidity in first-degree relatives					
No	1866 (69.7)	1257 (59.9)	<0.001	Ref	<0.001
Yes	811 (30.3)	840 (40.1)		1.669 (1.431–1.946)	

^aAll data expressed as *n* (%) of participants unless otherwise indicated

^bData described as median [Interquartile range]

^cFor married participants

Bold values indicate statistical Significant $p < 0.001$

public were significantly less concerned regarding this issue ($p < 0.001$).

Potential to change behavior

A total of 3824 adult healthy participants from the public answered the questions related to the potential to change behavior. The majority of public participants showed their willingness to change their lifestyles if they received genetic results that indicate their potential risk to develop

cardiovascular disease or diabetes mellitus. Most of the participants would increase their physical activity ($n = 3455$, 90.4%) and change their eating behavior ($n = 3354$, 87.7%). In addition, more than three quarters ($n = 2930$, 76.6%) of smoker participants would quit smoking (cigarette or argileh). The univariate analysis showed that genetic knowledge was significantly associated with the motivation of participants to change their lifestyle behaviors by improving their diet, physical activity and smoking cessation ($p < 0.001$).

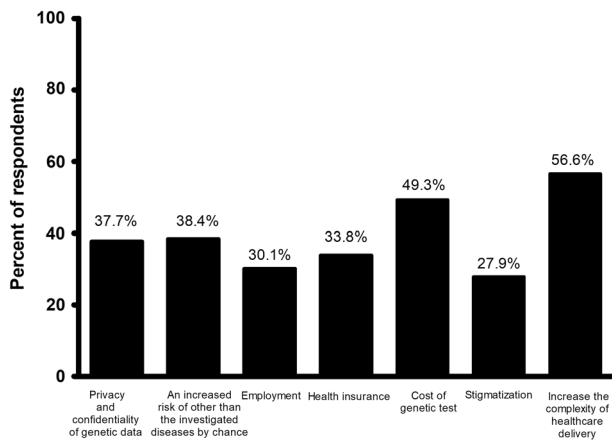


Fig. 1 Public concerns regarding implementation of genetic service in Jordan

Discussion

Genetics is a rapidly growing field of science all over the world that aims to enhance the overall human health. Nevertheless, for practical implementation of genomics in clinical fields, perspectives of public toward this issue is a major constituent. In the current study, we explored the knowledge and views of Jordanian population on genetics-related issues. Female gender, participants who had bachelor degree, participants who had children and those with comorbid conditions in their first-degree relatives were independently associated with public's knowledge about genetics. In spite of positive genetic attitudes addressed by the participants, there were several concerns about the application of genetics in clinical practice. The high number of participants who were recruited from different regions of the country rendered our study findings representative of the Jordanian situation. Therefore, the findings of the current national study could be generalized and give an overview about public knowledge and views. The total number of Jordanian populations is 10,248,069 with about half females and half males. The highest percentage for those aged 25–64 and the lowest for those aged between 65 and over [14]. The numbers and percentages of the current study are consistent with Jordanian statistics. In our study, 58% of participants were females and 42% of them were males. The highest percentage was for participants (70.2%, $n = 3510$) aged between 25 and 64 years old and only 1.3% ($n = 65$) of participants aged ≥ 65 years old.

Overall, the findings of the current study showed that less than half of public (43.4%) were knowledgeable about genetics. Previous studies reported varying percentages for the knowledge about genetics [3, 9]. However, it is difficult to compare the percentage in the current study with that in previous studies as other populations were studied and different questionnaires and methods of knowledge

calculation were used. The knowledge of our population could be explained by several reasons. First, most participants were highly educated with more than half of them had a bachelor degree. The same finding was reported by Etchegary et al. [3]. Second, about two-thirds of the participants were females who were more knowledgeable than males as shown in previous studies [15–17]. Third, the knowledgeable participants were mainly young adults who are consistent with previous reports [15–18]. Although the mean number of correct answers was relatively high (5.02), only a small percentage of the participants could correctly answer all the questions. This could be explained by the fact that the lay public might have general basic information about genetics but they are unfamiliar with precise genetic details. For example, previous studies reported a misconception among public regarding the specific area of genetic testing that is related to pharmacogenomics [19–22]. In addition, there is a limited or negligible enrollment of geneticists in the healthcare team in health settings in Jordan. A study by Ahram et al. revealed a lack of knowledge about genetic counselors among Jordanian population [23]. Hence, there is an urgent need to adopt educational and training programs for healthcare professionals to enhance the clinical application of genetics in Jordan.

It is noteworthy to mention that about 83% of the participants realized that there was a relationship between consanguinity and genetic diseases. A recent published study reported a declining level of consanguineous marriage in Jordan [24]. We have shown in the current study that there was a positive relationship between public's knowledge and having first-degree relatives with comorbidities. Consistent finding was reported by Calsbeek et al. where they showed a positive relationship between having a chronic disease and the patient's knowledge [18]. This could be due to the knowledge seeking behavior of participants with chronic or hereditary diseases. Moreover, participants who had children were more knowledgeable than others. This could be explained by the parents' interest to understand the health status of their children especially their susceptibility to develop a genetic disease.

The knowledgeable participants in the present study reported an increased likelihood of improving their diet, physical activity, and quit smoking. This highlights the importance of educational programs to enhance public awareness, especially young adults, to motivate their health lifestyle behavior improvement for preventing the development of chronic diseases. A previous study showed that knowledge of genetic susceptibility might change the behavior of healthy adults who were at risk to develop chronic diseases [10]. Knowledge alone might not be sufficient to change the health behavior. Other factors, such cultural imperialism, powerlessness, and socioeconomic status, are also important and should be assessed in a future qualitative study. In

addition, further studies are recommended to examine whether disclosing the genetic risk information would interact with their potential to improve their lifestyle behavior.

In the present study, the participants showed high levels of positive genetic attitudes which are consistent with previous reports among several populations [4, 9, 15, 16, 22, 25]. More than two-thirds of the participants appeared to be in favor with the importance of genetic testing for short- (i.e., use of their genetic data in medical research) and long- (store their blood samples and health data in biobank for future use) term purposes. Importantly, more than 85% of the respondents showed interest in neonatal screening and offering premarital genetic test to the most common genetic diseases. Different neonatal genetic screening tests (e.g., glucose-6-phosphate dehydrogenase deficiency, phenylketonuria, and congenital hypothyroidism) and premarital testing (e.g., thalassemia, sickle cell anemia, and familial Mediterranean fever) are available in Jordan upon request. However, no national genetic screening or premarital programs are currently adopted for all public in Jordan due to the limited financial resources. Allum et al. in their meta review analyzed 193 nationally representative surveys on public understanding of science and identified a positive correlation between general attitudes towards science and general knowledge of scientific facts [26], which goes in parallel with the findings of our study.

Despite the positive attitudes, the participants had many concerns regarding the clinical application of genetic testing. The major concern was the increased complexity of the healthcare delivery. To overcome this concern and to ensure the delivery of high quality services, a comprehensive plan should be implemented to improve the healthcare professionals' competencies, attitude, knowledge, and skills of clinical genetics. Most participants had concerns about the cost of genetic testing, consistent with populations of other countries [22, 27, 28]. This could be due to the fact that patients with genetic diseases confronted more difficulty in getting health insurance [9, 15, 16]. Beyond the previously mentioned concerns, about half of the participants were concerned about genetic discrimination or stigmatization, a phenomenon that was widely expressed among several populations [28–31]. Furthermore, it was found in the current study that a third of the respondents were concerned that genetic testing might reveal, by chance, the susceptibility to other diseases. This additional information might be unwanted and stressful for the individual, could result in the development of discrimination in obtaining life insurance and may lead to psychological problems [32]. The knowledgeable public in the current study appeared to have more concerns compared with nonknowledgeable group. This could be explained that knowledge has the potential to affect the opinion as knowledgeable people would be more realistic about the current situation of genetic application. In

addition, low level of knowledge makes it difficult for participants to comment on any genetic related issues as there would be a difficulty in opinion formulation.

The current study has some limitations. First, all sections in the questionnaire were comprised of closed-ended questions. Although closed-ended questions are easier to answer, they can guide the respondents in a certain direction and hence limit the respondents' abilities to express their values and concerns. Second, there is a potential of response bias as participants interested in genetics could have participated more than others. A previous study argued that excluded participants were from under-represented backgrounds and that structural inequalities should be taken into account rather than participants' interest/attitude as the reason for declined participation [33]. However, our study included participants from different regional areas of Jordan with a high response rate. A future qualitative study that investigates factors affecting participants' exclusion is recommended. Third, there is a gap between "knowledgeable" and "nonknowledgeable" categorization that potentially might lose a lot of nuance in the response. This could have been reduced by using different answer options, such as low, moderate, and high. However, this was performed to simplify the analysis as eight questions in knowledge section were examined. In addition, previous studies which investigated the level of knowledge on other medical topics divided the participants into two groups [34, 35].

In conclusion, the current study represented a national survey that investigated the knowledge of public and views toward genetics related-issues among Jordanian population. Our results suggest that female gender, educational level, having children, and having first-degree relatives with comorbid conditions were good predictors for public's knowledge about genetics. In spite of positive genetic attitudes addressed by our participants, they were concerned about application of genetics in clinical practice. The results of the current study will help to strengthen the importance of public education regarding the value of participation in genetic research in order to establish genetic related service in Jordan. As the culture background in Jordan is close to other countries in Middle East, the present results could be generalized to other Arab countries in the region.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

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