J Genet Counsel (2015) 24:1001–1010
DOI 10.1007/s10897-015-9839-3

ORIGINAL RESEARCH

Knowledge, Attitudes, and Practice Regarding Genetic Testing and Genetic Counselors in Jordan: A Population-Based Survey

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Received: 11 July 2014 / Accepted: 24 March 2015 / Published online: 8 April 2015

Abstract Genetic testing has a potential in the prevention of genetic diseases, particularly in communities with high rates of consanguineous marriage. Therefore, knowledge, practice, and attitudes of the public in Jordan regarding genetic testing were investigated. Individuals (N=3,196) were questioned about the concepts of genetic testing and genetic counselors, if they underwent any genetic tests, the type of test, the method of consenting to the test, as well as their level of satisfaction with the privacy of the genetic testing service. The likelihood of pursuing predictive genetic testing for cancer was also investigated. Although almost 70 % of respondents knew the term "genetic testing," only 18 % had undergone genetic testing, primarily the mandatory premarital test. In addition, there was a lack of general knowledge about genetic counselors. Many of those who had genetic testing (45 %) indicated they did not go through a consent process, and a lack of consent was significantly related to dissatisfaction with the privacy of the service. Approximately 55 % of respondents indicated they would potentially pursue predictive genetic testing for cancer. Going for routine health checkups was not significantly correlated with either actual or potential uptake of genetic testing, suggesting health care providers do not play an influential role in patients' testing decisions. Our results show a gap between the knowledge and uptake of genetic testing and may help to guide the design of effective strategies to initiate successful genetic counseling and testing services.

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Keywords Genetic testing · Genetic counselors · Cancer · Jordan · Quantitative research

Introduction

Genetic testing involves the use of molecular methodologies to elucidate mutations or aberrations in a person's genetic material. Different types of genetic testing exist with the differences depending on the purpose of the test itself and the tested subjects. Carrier testing is used to figure out whether a certain individual carries a mutation that may lead to the development of an autosomal recessive disorder in their offspring. The genetic disorders of thalassemia and glucose-6-phosphate (G6PD) deficiency, both of which have high prevalence and unique genetic mutations in the Mediterranean region, can be diagnosed genetically (Ip and So 2013; Minucci et al. 2009). Investigating the risk of developing a disease in asymptomatic individuals with potential high risk, known as predictive gene testing, is usually carried out in families that have a history suggestive of an inherited disease. For example, the U.S. Preventive Services Task Force recommended testing for mutations in the BRCA1 and BRCA2 genes in women whose family history is associated with a specific family history pattern (U.S. Preventive Services Task Force 2005). Accompanying genetic testing is genetic counseling, which is defined as by the Task Force of the National Society of Genetic Counselors (NSGC) as "the process of helping people understand and adapt to the medical, psychological and familial implications of genetic contributions to disease" (Resta et al. 2006). The process aims to integrate interpretation of family and medical histories, multi-level education regarding hereditary diseases, and promotion of informed choices and adaptation to the risk or condition via counseling.

Rare genetic disorders are common in Arab countries with a high frequency of autosomal recessive disorders (Teebi and Teebi 2005). It has been argued that this unique distribution of genetic diseases among Arabs is mainly due to the high rates of consanguineous marriage, which can be as high as 50 % of all marriages (Bittles 2012; Tadmouri et al. 2009). For example, founder mutations and a unique distribution of genetic diseases in addition to a high prevalence of hereditary hemoglobinopathies such as sickle cell disease and thalassemia have been reported In Saudi Arabia, which has one of the highest rates of consanguineous marriages in the world (Al-Owain et al. 2012). In a retrospective study, 6 years following implementation of mandatory pre-marital testing in Saudi Arabia, Memish and Saeedi (2011) found an increased frequency of voluntary cancellation of marriage proposals among those at high risk for β-thalassemia which correlated with marked decline in the frequency of β-thalassemia. These findings suggest a significant reduction in the genetic disease burden in Saudi Arabia in the future (Memish and Saeedi 2011). Like the rest of the Arab population, the rates of consanguineous marriage in Jordan are high; constituting almost one half of all marriages, with first cousin marriage rates reaching more than 30 % (Khoury and Massad 1992). Jordan thus implemented a mandatory pre-marital testing in 2004 in order to facilitate disease prevention, screening, and early diagnosis. The main test offered in this program is for the detection of β-thalasemia, which has an estimated carrier rate of 2–4 % (Hamamy et al. 2007).

The Kingdom of Jordan is a small country situated in central Middle East and has an estimated population size of 6.5 million people. Although the country has limited resources, it has excelled in health care services (World Health Organization 2006). Health care is provided by the Ministry of Health, in addition to military, private, and university teaching hospitals, as well as the United Nations Relief and Works Agency. Although 56 % of the 106 hospitals belong to the private sector, public hospitals provide more beds (38.1 % vs. 32.7 %) (Ministry of Health 2011). Jordan has a rate of 25.5 physicians per 10,000 people (Ministry of Health 2011). According to a recent national-based survey investigating "Knowledge, Attitudes, Practices (KAP) towards Cancer Prevention and Care in Jordan," almost 60 % of the population have health insurance, and of these, 43 % are insured by the Ministry of Health and 35 % have military-based insurance (Ahmad et al. 2011). Of note, the Ministry of Health also provides health care for the uninsured (Hamamy et al. 2007). As for genetics services, there are no official numbers reported yet. Although specialized genetic clinics are non-existent, there are increasing numbers of public and private laboratories offering genetic testing. These tests cover diseases prevalent in Jordan such as β-thalassemia and familial Mediterranean fever, as well as testing for other genetic diseases including cystic fibrosis, phenylketonuria, and some cancer biomarkers (Hamamy et al. 2007). Genetic counseling is scarce and is mainly provided by pediatricians and, to a lesser extent, clinical geneticists (Hamamy et al. 2007; World Health Organization 2006).

Purpose of the Study

The promise of genetic testing for reducing the prevalence of genetic disorders has led to a growing need to assess the knowledge, understanding, and attitudes of populations regarding genetic testing (Blanchette et al. 2014; Lanie et al. 2004; Sanderson et al. 2004). Thus, this study compares the knowledge concerning genetic testing and genetic counseling, practice, and attitudes of different Jordanian subgroups regarding genetic testing, as well as their potential use of genetic testing to learn of the possibility of developing cancer. In addition, the concept of consenting for genetic testing is also investigated. This is the first study of its kind conducted in the Middle East at the national level. Due to the similar cultural background between Jordan and surrounding countries, the data generated herein may be generalized elsewhere in the region.

Methods

Study Design

The questions regarding genetic testing that are the focus of the present study were part of the quantitative, descriptive, cross-sectional survey entitled "Knowledge, Attitudes, Practices (KAP) towards Cancer Prevention and Care in Jordan." The purpose of the survey was to identify participants' knowledge, attitudes, and practices concerning cancer care. The questionnaire was in Arabic, with an available English translation, when needed. The questionnaire included standardized definitions for medical terms to be read by the interviewers. The questionnaire consisted of ten sections of various topics. Items, which were part of a section entitled "New Fields in Cancer Research and Care in Jordan," assess public knowledge and attitudes about genetic testing.

The national survey was prepared by a panel of experts (a committee) from different Jordanian institutions including the Ministry of Health, the Department of Statistics, and the University of Jordan (Ahram et al. 2012). Since the survey was conducted at the national level, the tool was reviewed and modified at the Department of Statistics for ethical and scientific considerations. Ethics approval was obtained from a special committee at the Center of Consultation/the University of Jordan. Biomedical and clinical research conducted in Jordan and involving human subjects are specifically reviewed by an IRB, but epidemiological studies are not.

The questionnaire was piloted and validated by a panel of experts to assure the suitability of the content, clarity, and that items were understandable. The pilot study was first carried out in one area in the capital city, Amman, to test the survey tool, sampling technique, survey methods, and interviewers' performance. The pilot sample consisted of 56 randomly selected subjects. Following the pilot, a 2-day review session was conducted and resulted in implementation of minor modifications. Based on the pilot study, interviewers were trained on how to read and clarify the questions as well as how to respond to inquiries. In addition, issues related to data collection were addressed during pilot testing.

Participants and Procedures

The survey was conducted nationwide in the three regions of Jordan (North, Central, and South) covering the 12 governorates via face-to-face interviews with 3,196 individuals aged 18 and above during the period of January-March, 2011. The survey sample was selected using the 2004 Population and Housing Census as the sampling frame in order to ensure that the final sample reflected the socioeconomic and geographic composition of Jordan. The sampling frame was stratified by governorate, major cities, and urban and rural areas. A 3-stage sampling procedure was employed. First, a total of 300 blocks were selected systematically as primary sampling units (PSUs) with a probability proportional to the size of the PSU. In the second stage, a fixed number of 15 households were selected as final sampling units in each PSU, resulting in a sample size of about 4,500 households. In the third stage, random selection of individual interviewees from each household was carried out using Kish tables (Kish 1965). The response rate of surveys was 93 %.

The interviews were conducted by 18 trained teams, and each team was assigned a number of blocks in the sample area. In order to facilitate entry to the participants' homes, the interviewers were females; all had a baccalaureate degree and had undergone 12 days of training on the interview skills and the questionnaire content. Participants were approached through direct invitation at their homes. The duration of each interview was approximately one hour. Selected houses were re-visited twice before deciding to exclude them. The total percentage of excluded houses was approximately 5 %. Prior to the interview, participants were briefed about the purpose and the outcomes of the study, and their rights to voluntarily participate, withdraw, or refuse to participate. Verbal informed consent was obtained (agreement to host the interview in participants' houses is considered culturally compatible). Since data were collected through face to face interviews by well-trained personnel, there were no missing data. Those who declined to participate comprised less than 2 % of the potential sample, mainly due to being busy or uninterested in participating. Additionally, since the interviews were conducted at the participants' homes, and the majority of respondents had low or moderate income, homes were not large enough to maintain strict privacy for each interview.

Data Collection and Analysis

Data entry and processing were conducted as data were being collected. Double data-entry was performed for 30 % of the data in order to run quality control checks. Data were then exported to Statistical Package for Social Sciences (SPSS), version 17, and frequencies and tabulations were run to check for completeness and consistency of the data. As most of the variables in the study were categorical and were measured on nominal or ordinal levels, descriptive frequencies were used to describe the basic features of the data. In addition, graphs and figures were used to provide a visual summary of the findings. Codes were assigned to each questionnaire to maintain anonymity and confidentiality of the participants.

Instrumentation

The items from the survey that are the focus of the present study were close-ended and completed through a face to face structured interview.

Demographic Data

Participants were asked about their gender, age, education, income (1 Jordanian Dinar=$1.40), and marital status. Respondents were also asked whether they had health insurance and if they performed routine health checkups, which were defined for them as "a general physical exam, not an exam for a specific injury, illness, or condition." Respondents were asked to rate their health in comparison to others of the same age and gender. Five options were provided ranging from "excellent" to "bad."

Knowledge of Genetic Testing and Genetic Counselors

Participants were questioned about their knowledge of the term "genetic testing" by asking them whether they had ever heard of or read about it. Response options of "yes" and "no" were provided. Respondents were then informed of the meaning of the term as follows: "genetic testing is the analysis of the hereditary material as well as proteins and metabolites in order to detect heritable disease-related genotypes, mutations, and phenotypes for clinical purposes. It can also provide lifetime information about a person's genes and chromosomes. Screening can also include checking for a person's risk of developing an inherited disease by doing a genetic test." Afterwards, respondents were asked about their knowledge of the term "genetic counselors."

Practice of Genetic Testing

Participants were asked if they had ever undergone genetic testing and, if they had, the type of genetic testing they had done. Based on the response given by the survey participant, the type(s) of genetic test was selected by the interviewer: premarital testing, diagnostic testing, carrier testing, predictive testing and pre-symptomatic testing, in addition to a "don't know" option. More than one option could be selected. Respondents were asked to recall the party requesting the genetic testing with a possibility of more than one answer.

Consenting for and Satisfaction with Genetic Testing

Respondents were asked if they were consented about the genetic testing and, if they remembered being consented, the type of consent (verbal, written, both), as well as their level of satisfaction with the privacy of the genetic testing service they received. Those attitudes were measured on a 5-point Likert scale with scores ranging from "very satisfied" to "very unsatisfied," in addition to a category of "don't know."

Genetic Testing for Cancer

Participants were asked about their willingness to undergo genetic testing to learn of the probability of developing cancer. Those attitudes were measured on a 4-point Likert scale with scores ranging from "very likely" to "very unlikely."

Statistical Analyses

Data were analyzed using the SPSS software program. Descriptive statistics were used to report sample characteristics in addition to frequencies and percentages. Data were correlated with age, gender, and education level. Pearson correlation coefficient was used to assess the relationship of those demographics and the attitudinal statements. Pearson correlation coefficient was also utilized to assess the relationship between being consented and the level of satisfaction of the received service. A p value of less than 0.05 is considered significant.

Results

Knowledge of Genetic Testing and Genetic Counselors

Knowledge of genetic testing and genetic counselors was investigated among the 3,196 respondents. Although more than two-thirds of respondents knew of the term "genetic testing," less than 25 % had heard of or read about the term "genetic counselors" (Table 1). Knowledge of genetic testing was associated with increasing education and income ($p<0.001$). On the other hand, individuals with the highest educational level, those with middle income, and middle-aged respondents were significantly ($p<0.05$) more familiar with the term "genetic counselor." In addition, those who went for routine health checkups were significantly ($p<0.001$) more likely to be knowledgeable of both terms.

Undergoing Genetic Testing

When assessing the portion of individuals who had undergone genetic testing; only 17.7 % of respondents indicated undergoing genetic testing (Table 2). None of them indicated that they did not know whether they had ever had genetic testing. Undergoing genetic testing was associated with younger age ($p<0.001$), increasing education ($p<0.001$), higher income ($p=0.017$), and perception of having better health ($p<0.001$), but not with gender or having health insurance. Paradoxically, there was a negative association between those who had genetic testing and those who went for routine health checkups ($p<0.001$). As expected, the knowledge and pursuit of genetic testing were significantly associated with each other ($p<0.001$). On the other hand, there was no association between knowledge of genetic counselors and undergoing genetic testing ($p=0.930$).

In addition, married individuals performed genetic testing at a higher rate than others ($p<0001$). The association between being married and performing genetic testing reflected the main purpose of having genetic testing in the form of premarital testing (93.6 %), which ranked first among the reasons to undergo genetic testing. Other reasons for undergoing genetic testing were for diagnosis (3 %), followed by carrier testing (2.8 %), and predictive and pre-symptomatic testing (0.1 %). Only two respondents indicated that they did not know the type of genetic test they had received. Whereas 78 % of individuals who underwent genetic testing did so as requested by court-for-marriage, 11.3 % of requests for genetic testing were made by physicians, 9 % of individuals performed testing on their own, and only 1.6 % underwent testing as requested by either clinical geneticists or genetic counselors. Only one respondent did not know who requested the genetic test.

Consenting and Satisfaction of Genetic Testing

Consenting is an important process of genetic testing. We, therefore, inquired if the 567 individuals who underwent genetic testing were consented prior to the procedure. Whereas 44.5 % of individuals indicated they were not consented at all, 54 % stated they were consented either verbally (27.6 %), in writing (23.2 %), or both (3.2 %). A small minority (1.5 %) did not remember being consented and responded with "I don't know" as an answer to the question. Although the majority (90.7 %) expressed their satisfaction with the privacy they received during the genetic testing procedure, there was a

Table 1 Knowledge of Jordanian population of genetic testing and genetic counselors

Have you ever heard or read about:	Genetic testing?		Genetic counselors?	
	Yes (%)	No (%)	Yes (%)	No (%)
Total responses (3196)[a]	2189 (68.5)	1007 (31.5)	723 (22.7)	2473 (77.37)
Gender				
Males (1647)	1129 (68.5)	518 (31.5)	370 (22.5)	1277 (77.5)
Females (1549)	1060 (68.4)	489 (31.6)	353 (22.8)	1196 (77.2)
χ^2 *(P)*	0.005 (0.487)		0.035 (0.852)	
Age				
18–29 (963)	699 (72.6)	264 (27.4)	182 (18.9)	783 (81.1)
30–39 (916)	640 (69.9)	276 (30.1)	210 (22.9)	706 (77.1)
40–49 (628)	462 (73.6)	166 (26.4)	171 (27.3)	456 (72.7)
50–59 (271)	165 (60.9)	106 (39.1)	74 (27.4)	196 (72.6)
60 and above (418)	223 (53.3)	195 (46.7)	86 (20.6)	332 (79.4)
r (P)	0.120 (<0.001)*		0.036 (0.040)*	
Education				
Elementary or less (614)	280 (45.6)	334 (54.4)	124 (20.2)	490 (79.8)
Preparatory to high school (1638)	1140 (69.6)	498 (30.4)	368 (22.5)	1270 (77.5)
Diploma and above (944)	768 (81.4)	176 (18.6)	731 (77.5)	213 (22.5)
r (P)	0.256 (<0.001)*		0.036 (0.042)*	
Income[a]				
Less than 300 (1494)	902 (60.4)	592 (39.6)	232 (15.5)	1262 (84.5)
300 to 599 (1227)	908 (74.0)	319 (26.0)	247 (43.9)	980 (79.9)
600 and above (452)	360 (79.6)	92 (20.3)	83 (18.5)	369 (81.5)
r (P)	0.164 (<0.001)*		0.039 (0.026)*	
Marital status				
Single (635)	433 (68.2)	202 (31.8)	138 (21.7)	497 (78.3)
Married (2338)	1634 (69.9)	704 (30.1)	534 (22.8)	1804 (77.2)
All others (222)	121 (54.5)	101 (45.5)	51 (23.3)	171 (76.7)
χ^2 (P)	22.263 (<0.001)*		0.410 (0.815)	
Undergoing routine checkups				
Yes (607)	447 (73.6)	160 (26.4)	174 (28.7)	433 (71.3)
No (2589)	1742 (67.2)	847 (32.8)	549 (21.2)	2040 (78.8)
χ^2 *(P)*	9.313 (<0.001)*		15.596 (<0.001)	

[a] The total responses for the Income category were 3173, where 23 respondents refused to declare their income

* Indicates a significant value (*p*)

significant association between being dissatisfied and not being consented ($p<0.001$). There were not significant associations between satisfaction and demographic factors, namely gender, age, education, income, or marital status (data not shown). Only 12 respondents (2 %) indicated a "don't know" option to the question concerning satisfaction.

Genetic Testing for Cancer

In order to investigate the possibility of future prevention of cancer via genetic testing, we asked all respondents about the possibility of undergoing genetic testing to learn of their risk of developing cancer. There was clear division among respondents whereby 55.3 % of respondents indicated they would be likely to pursue predictive genetic testing versus 44.7 % who indicated they were unlikely to undergo such testing (Table 3). Younger, single, and more educated individuals were more likely to perform the cancer predictive genetic test with significant *p*-values of <0.001. Interestingly, there was no association between the likelihood of undergoing genetic testing to know the risk of developing cancer with knowledge of genetic testing ($p=0.083$) or among those who went or did not go for routine health checkups ($p=486$). In addition, although there was no significant trend between the likelihood of undergoing the genetic test to know the risk of developing cancer with income ($p=0.353$) and self-perception of health status ($p=0.185$) according to the Pearson correlation coefficient; the Chi-square tests revealed that those within the highest income

Table 2 Practice of genetic testing

Did you ever undergo a genetic test?[a]	Yes (%)	No (%)
Total responses (3196)[a]	567 (17.7)	2629 (82.3)
Gender		
Males (1647)	279 (16.9)	1368 (83.1)
Females (1549)	288 (18.6)	1261 (81.4)
χ^2 (*P*)	1.494 (0.120)	
Age		
18–29 (964)	282 (29.3)	682 (70.7)
30–39 (916)	230 (25.1)	686 (74.9)
40–49 (628)	48 (7.6)	580 (92.4)
50–59 (271)	5 (1.8)	266 (98.2)
60 and above (418)	3 (0.7)	415 (99.3)
r (*P*)	0.289 (<0.001)*	
Education		
Elementary or less (614)	51 (8.3)	563 (91.7)
Preparatory to high school (1638)	304 (18.6)	1334 (81.4)
Diploma and above (944)	212 (22.5)	732 (77.5)
r (*P*)	52.594 (<0.001)*	
Income[b]		
Less than 300 (1494)	232 (15.5)	1262 (84.5)
300 to 599 (1227)	247 (20.1)	980 (79.9)
600 and above (452)	84 (18.6)	368 (81.4)
r (*P*)	0.043 (0.017)*	
Marital status		
Single (635)	22 (3.5)	613 (96.5)
Married (2338)	536 (22.9)	1802 (77.1)
All others (222)	9 (4.1)	213 (95.9)
χ^2 (*P*)	1.602×10^2 (<0.001)*	
Knowledge of genetic testing		
Yes (2189)	481 (22.0)	1707 (78.0)
No (1007)	86 (8.5)	922 (91.5)
χ^2 (*P*)	85.566 (<0.001)*	
Knowledge of genetic counselor		
Yes (607)	125 (17.3)	599 (82.7)
No (2589)	442 (17.9)	2030 (82.1)
χ^2 (*P*)	0.145 (0.930)	
Having health insurance		
Yes (1902)	338 (17.8)	1564 (82.2)
No (1294)	229 (17.7)	1065 (82.3)
χ^2 (*P*)	0.003 (0.498)	
How would you rate your health status in comparison to others of your same age and gender?		
Excellent (1011)	211 (20.9)	800 (79.1)
Very good (1190)	232 (19.5)	958 (80.5)
Good (807)	113 (14.0)	694 (86.0)
Satisfactory (149)	7 (4.7)	142 (95.3)
Bad (39)	4 (10.3)	35 (89.7)
r (*P*)	−0.097 (<0.001)*	

[a] No respondent indicated the "do not know" option

[b] The total responses for the Income category were 3173, where 23 respondents refused to declare their income

* Indicates a significant value (*p*)

category and those who thought of their health as bad were significantly less likely to undergo the genetic test with *p*-values of 0.001 for both.

Discussion

Overall, the results in regards to genetic testing in Jordan illustrate that despite the decent level of knowledge of genetic testing, uptake of genetic testing is minimal and is directed towards the mandatory pre-marital testing rather than diagnostic or predictive testing. In addition, there is a lack of knowledge of genetic counselors and, consequently, their critical role in educating patients and the public. Consenting for genetic testing is not a common practice and lack of consenting was correlated with dissatisfaction regarding the privacy of the provided service. Another notable finding is the clear division of interest in undergoing genetic testing for the purpose of learning of cancer susceptibility. Better knowledge of genetic testing as well as actual and potential pursuit of genetic testing are associated with younger age and higher education. The latter finding of the association between interest in genetic testing with age and education subgroups has been illustrated in other studies (Aro et al. 1997; Cherkas et al. 2010; Morren et al. 2007).

Knowledge of genetic testing is increasing over time in parallel to increased interest (Henneman et al. 2013). As mentioned earlier, although the rate of knowledge of genetic testing was decent among the public in Jordan, it is not the case in regards to genetic counseling. However, lack of knowledge of genetic counseling does not seem to be unique to Jordan, as a similar trend has been observed in other communities including the USA (Riesgraf et al. 2014), Canada (Maio et al. 2013), and Japan (Osawa et al. 1994).

Identifying patients at risk of certain hereditary malignancies through genetic testing can help provide them with more detailed screening and prophylactic preventive treatment (Demeure 2009; Oseni and Jatoi 2008). In our study, almost half of respondents indicated a willingness to undergo cancer predictive genetic testing. Compared to other countries in the region, our results are similar to the attitudes of Saudi women towards testing for breast cancer and those of Ashkenazi Jewish women (Amin et al. 2012; Lehmann et al. 2002). This percentage is lower than that found in Tunisia, where 72.5 % of respondents indicated they wished to know if they were predisposed to develop cancer (Ben Fatma et al. 2005). This could be due to social and cultural barriers including: embarrassment and fear of stigmatizing the family reputation, especially if the disease is socially perceived as inheritable, fear of getting a cancer diagnosis, or lack of access to health and cancer information (Akhu-Zaheya et al. 2014; Kawar 2013; Othman et al. 2013; Taha et al. 2012, 2013).

Table 3 Probability of undergoing genetic testing for cancer[a]

	Very likely (%)	Likely (%)	Unlikely (%)	Very Unlikely (%)
Total responses (3196)	279 (8.7)	1486 (46.5)	947 (26.5)	584 (18.3)
Gender				
Males (1647)	151 (9.2)	769 (46.7)	431 (26.2)	296 (18.0)
Females (1549)	128 (8.3)	717 (46.3)	416 (26.9)	288 (18.6)
r (P)	0.016 (0.367)			
Age				
18–29 (963)	134 (13.9)	505 (52.4)	199 (20.7)	125 (13.0)
30–39 (916)	76 (8.3)	433 (47.3)	239 (26.1)	168 (18.3)
40–49 (628)	46 (7.3)	283 (45.1)	190 (30.3)	109 (17.4)
50–59 (271)	13 (4.8)	121 (44.6)	71 (26.2)	66 (24.4)
60 and above (418)	10 (2.4)	143 (34.2)	149 (35.6)	116 (27.8)
r (P)	0.196 (<0.001)*			
Education				
Elementary or less (614)	26 (4.2)	241 (39.3)	210 (34.2)	137 (22.3)
Preparatory to high school (1638)	156 (9.5)	803 (49.0)	412 (25.2)	267 (16.3)
Diploma and above (943)	97 (10.3)	441 (46.8)	225 (23.9)	180 (19.1)
r (P)	−0.076 (<0.001)*			
Income[b]				
Less than 300 (1494)	106 (7.1)	706 (47.3)	411 (27.5)	271 (18.1)
300 to 599 (1227)	121 (9.9)	595 (48.5)	321 (26.2)	190 (15.5)
600 and above (452)	47 (10.4)	171 (37.8)	111 (24.6)	123 (27.2)
r (P)	0.16 (0.353)			
χ^2 (P)	42.088 (<0.001)*			
Marital status				
Single (635)	107 (16.9)	344 (54.2)	117 (18.4)	67 (10.6)
Married (2339)	163 (7.0)	1069 (45.7)	645 (27.6)	462 (19.8)
All others (222)	9 (4.1)	72 (32.4)	86 (38.7)	55 (24.8)
χ^2 (P)	1.37×10^2 (<0.001)*			
Knowledge of genetic testing				
Yes (2189)	205 (9.4)	1028 (47.0)	557 (25.4)	399 (18.3)
No (1007)	74 (7.3)	457 (45.4)	290 (28.8)	186 (18.5)
r (P)	0.031 (0.083)			
Do you go to routine checkups?				
Yes (607)	59 (9.7)	284 (46.8)	153 (25.2)	111 (18.3)
No (2589)	220 (8.5)	1202 (46.4)	694 (26.8)	473 (18.3)
r (P)	−0.012 (0.486)			
How would you rate your health status in comparison to others of your same age and gender?				
Excellent (1012)	98 (9.7)	444 (43.9)	262 (25.9)	208 (20.6)
Very good (1189)	107 (9.0)	608 (51.1)	292 (24.6)	182 (15.3)
Good (806)	64 (7.9)	353 (43.8)	232 (28.8)	157 (19.5)
Satisfactory (149)	6 (4.0)	72 (48.3)	39 (26.2)	32 (21.5)
Bad (40)	5 (12.5)	8 (20.0)	22 (55.0)	5 (12.5)
r (P)	0.023 (0.185)			
χ^2 (P)	47.048 (<0.001)*			

[a] Based on responses to the question: How likely is it that you would choose to undergo genetic testing to know your risk of developing cancer?

[b] The total responses for the Income category were 3173, where 23 respondents refused to declare their income

* Indicates a significant value (p)

It is interesting to note that those who went for routine health checkups were less likely to actually undergo genetic testing and were not more likely to undergo cancer predictive testing. These results may suggest health care providers do not play an influential role in patients' testing decisions and/or do not contribute to increasing awareness of genetic testing among the public. This is not only true in Jordan, as it has also been observed in other countries (Henneman et al. 2004; Leighton et al. 2012; Morren et al. 2007). In one study, reasons for not promoting the introduction of genetic testing in primary health care include lack of both guidelines and evidence for the benefits of such testing (McCahon et al. 2009). Another reason could be the lack of knowledge of genetic testing among physicians, as illustrated in different studies conducted in New Zealand (Morgan et al. 2004), USA (Freedman et al. 2003), and England (Fry et al. 1999; McCahon et al. 2009). Although support for genetic susceptibility testing for breast and ovarian cancers was high among physicians of various specialties, only a third of them were knowledgeable of it (Escher and Sappino 2000). In a Finnish study, professionals have noticed that lay people had high expectations regarding genetic testing (Toiviainen et al. 2003). This may additionally make physicians reluctant about recommending genetic testing for the public. Burke (2004) argued for not only increasing educational awareness of the critical role of genetic testing and risk identification among patients, but also for the importance of the partnership between clinicians and medical geneticists in preventing the initiation and progression of genetic diseases.

Of note, other factors may contribute to the lack of interest in genetic testing among those who routinely undergo health checkup. For example, they may have the wrong perception that a routine health checkup and a laboratory test would be sufficient to reveal susceptibility to diseases. Nevertheless, an integration of certain elements of medical genetics into primary health care can be accomplished in line with identification and monitoring of individuals at higher risk of developing diseases by primary care physicians (Emery and Hayflick 2001).

An alarming finding concerns the lack of use of consent forms when performing genetic testing reported by the participants in the present study. This is in support of a previous study extracted from the KAP survey revealing the low interest in signing a consent form when participating in biobanking (Ahram et al. 2013). Although consent forms were not generally provided and were not part of the general legal routine before the genetic screening, 91 % of the sample expressed satisfaction with the level of privacy offered to them during screening. It is noteworthy to observe that dissatisfaction with the service provided correlated with not being consented. The low frequency of use of consent forms could be due to lack of knowledge of patient rights. It is important to note that increasing knowledge of genetic testing and the social and medical implications associated with it does not necessarily increase enthusiasm about genetic testing (Etchegary et al. 2010; Jallinoja and Aro 2000). However, the existence of an informed consent with a privacy clause and commitment would show respect towards the patient, provide comfort and assurance, create a trusting relationship, and, consequently, promote genetic testing.

Study Limitations, Practice and Policy Implications, and Research Recommendations

A number of limitations exist in this study. Firstly, consistent with other self-report interview methods, individuals may be reluctant to explicitly state their views objectively and would rather provide biased answers that are socially acceptable. It is also important to take into account that intentions may not reflect actual behavior. Another limitation in this study is the focus on univariate descriptive analyses; hence, the findings should be interpreted with caution. Further, it is suggested for future studies to examine through bivariate and multivariate statistics how variables affect genetic testing and genetic counselor in Jordan. Nevertheless, one strength of this study is that it evaluated the attitudes of a nationally representative sample of the Jordanian public who were interviewed in their homes, in contrast to studies conducted on individuals visiting health facilities where they might provide more biased answers. Importantly, individuals with familial hereditary diseases may also provide unique insights into the potential practice of genetic testing that could be more relevant for them than for the general public, necessitating the replication and extension of the present survey to this group of individuals. Our results also offer valuable information with regards to the potential initiation of wide range genetic testing in Jordan. Furthermore, future studies could examine the differences between socio-demographic characteristics and the performance of genetic testing and genetic counseling. Moreover, additional studies are needed to identify the awareness of the Jordanian population about the risks, benefits, and limitations of prenatal tests.

We stress the need to initiate public awareness and educational programs about genetic testing whereby the public would develop an appreciation for its value as well as realistic expectations of the outcome. It is also important to increase awareness of individuals' rights and responsibilities and the critical aspect of the informed consent. A recent study has indicated the most effective means for raising awareness is the use of media for reaching and educating the public (Akhu-Zaheya et al. 2014). This can also be accomplished at the governmental level via the introduction of genetic testing services and genetic counselors as part of primary health care services.

Funding This work was supported by the Arab Fund for Economic and Social Development (AFESD). The KAP Survey was implemented by King Hussein Institute for Biotechnology and Cancer (KHIBC) under The National Life Science Research and Biotechnology Promotion (LSR/BTP) Initiative in Jordan.

Conflict of interest M. Ahram, M. Soubani, L. Abu Salem, H. Saker, and M. Ahmad declare that they have no conflict of interest.

Human Studies and Informed Consent All procedures performed in studies involving human participants were in accordance with the ethical standards of the Department of Statistics and a special committee at the Center of Consultation, the University of Jordan, and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Animal Studies No animal studies were carried out by the authors for this article.

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