5-2015

Knowledge and Attitude of Physicians, Cancer Patients and Public about Cancer Related Genetic Tests in Saudi Arabia

Lamia Fahad Alsubaie
Sarah Lawrence College

Knowledge and Attitude of Physicians, Cancer Patients and Public about Cancer Related Genetic Tests in Saudi Arabia

By

Lamia Fahad Alsubaie

Submitted for Partial Completion of Master of Science in Human Genetics

Sarah Lawrence College

2015

Abstract

Due to the unique religious and cultural characteristics of Saudi Arabia, evaluating knoweldge and exploring attitudes toward cancer genetic tests (CGT) are important for bolstering currently underdeveloped CGT services. This cross sectional study was carried out in the form of a survey, targeting three different populations: physicians (n=105), cancer patients (n=102) and public participants (n=1087). The public cohort recorded a knowledge score (M=7.16, Mdn=7.00,SD=2.58) higher than patients cohort (M=4.98,Mdn=5.00,SD=2.95). Both patient and public participants expressed interest in CGT. Willingness to undergo CGT correlated with high knowledge in the public cohort (r (1083)= .12, p<.001), while the patient cohort was only willing in the context of a positive family history of cancer (r (100) =.29, p<0.01). Attitudes toward CGT were not correlated with religiosity, fear of stigma, or privacy in the public cohort. Out of these variables; religiosity was coorelated with positive attitude toward genetic services in patient cohort (e.g. willingness to see a genetic counselor (Chi-square(4)=10.33, p<.05). Despite the unavailability of cancer genetic clinics in the area; 79.1% of physicians reported expectations in increasing the number of patients who will be interested in CGT, 63.8% strongly agreed that patients should not undergo CGT without counseling, and 100% said they would refer some or all of their applicable patients should a clinic open up. Physicians' self-reported qualifications, attitudes toward CGT, and confounding factors were also investigated, and showed significant amounts of uncertainty regarding many aspects of CGT amongst the respondents; including clinical utility, cost effectiveness, discrimination and

patient confidentiality. To conclude, there is an overall positive attitude toward cancer genetic services in Saudi society. Public health actions to enhance cancer genetic services should be implemented to recognize and improve care for high-risk families.

Keywords: Cancer genetic counseling, genetic counseling, Saudi Arabia, attitude.

Background

Cancer incidence in Saudi Arabia has remained relatively steady with approximately 2,500 new cases diagnosed annually in Riyadh (Tumor registry, 2012). In 2011, the most frequent cancers in males were colorectal, leukemia & Non-Hodgkin's lymphoma. In females, breast cancer, thyroid cancer and leukemia were the most common (Tumor registry, 2012). Public awareness of cancer and cancer related care is low in the kingdom (Amin et al, 2009; Ravichandran et al, 2010; Ravichandran et al, 2011; Khayaat & Ibrahim 2013; Eldeek et al, 2014).

The nature of Saudi society may affect the use of genetic tests and counseling services. Certain social norms around religiosity, sharing of information, and stigma could dictate practice as it pertains to uptake of genetic services and testing. Our study did ask participants in the public and patient cohorts to self-report their level of religiosity; however the researchers did not provide set definitions around the categories for the participants to identify (such as mosque attendance and prayer rituals). Previous studies in Saudi Arabia either investigated one aspect of attitude and/or knowledge toward cancer genetic services, or focused on one population. (Amin et al, 2009; Milaat, 2000; Ravichandran et al, 2011).

Ravichandran, Mohammed and Al-hamdan (2010) found that younger, single females had a higher overall knowledge about cancer when compared to their counterparts. Additionally, knowing someone with cancer or having personal experience with cancer screening (e.g. mammogram, occult blood test, breast exam or PAP smear) were also associated with

increased knowledge about cancer. In a different study (Ravichandran, Al-hamdan and Mohamed, 2011) about attitudes and behaviors of Saudis with respect to cancer prevention, 95.8% of participants acknowledged the importance of early detection. 55.1% stated they would definitely participate in a cancer detection program in the future, 32.1% were less sure and 12.8% said they would not. When surveyed on their current behaviors, only 23.1% reported that they administered self-breast exams, 14.2% went for clinical breast exams and 8.1% had undergone a mammogram. Barriers to seeking clinical breast exams among women include cultural traditions about modesty and 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 (Amin et al, 2009).

Even among family members of cancer patients, overall knowledge of cancer was low. Eldeek et al. (2014) surveyed 846 healthy individuals who attended an outpatient cancer clinic in Jeddah, Saudi Arabia with their sick relatives. While genetics and diet were identified by a large percentage of participants (44.9% and 30.1% respectively) as causes of cancer, other unfounded factors, such as envy (26.9%), black magic (17.6%) and sadness (12.8%) were also mentioned. 32.5% of participants either did not know or were unsure if cancer was contagious. As previously established, a lack of public awareness is a barrier to cancer prevention and care. In a cross sectional study of the general population, 65.1% of participants attributed their knowledge about cancer to information provided by radio/television, 55.4 % cited friends/relatives and 52.9% pointed to newspapers/magazines. While 29.4% mentioned their physicians and 7.9% mentioned primary healthcare providers as source of knowledge (Ravichandran et al, 2011).

Clinical genetics in Saudi Arabia is a growing field, with approximately 30 board certified clinical geneticists (Alkuraya, 2014) and 10 genetic counselors (Qari et al, 2013). A majority of the physicians were trained in clinical genetics abroad; however a domestic program was recently developed and accredited (Alkuraya, 2014). Four of the genetic counselors graduated with a Master's-level degree from the United Kingdom and one (non-Saudi) graduated from the United States of America. The remaining five counselors graduated with a high diploma-level degree from the recently established genetic counseling training program at KFSH&RC (Qari et al, 2013).

With hereditary cancer accounting for 5-10% of all cancer case, cancer risk counseling has grown rapidly in recent years to become a major area of specialization within genetic counseling (Mendes, 2013). However, it is still immature in Saudi Arabia, regardless of the development of different oncology centers. As of now, there is no cancer genetic counseling clinic in Saudi Arabia; however, some health institutes have expressed interest in having this service as part of the services provided to their patients. (Qari et al, 2013). Acceptance of cancer genetic counseling services depends upon the awareness, attitudes, and social influences (i.e. ethics, religion, economics, culture, law, education, etc.) of both physicians and the public. (Kinney et al, 2010; Bando, 2013).

A cross sectional study (Amin et al, 2012) of 599 women in the Eastern Province found that almost 20% of participants believed themselves to be at higher risk for breast cancer than their peers. With regards to genetic testing for breast cancer genes, knowledge was highest among employed, college educated women between the ages of 30 and-40. 42.8% of women

expressed a general interest in undergoing genetic testing for breast cancer genes, while 11.9% would undergo testing if certain conditions were met, such as no fee, geographic convenience, physician recommendation, reputable laboratory, family/husband consent and pretest counseling to alleviate anxiety.

At this time no studies have been performed to broadly assess cancer genetics knowledge, attitudes and behaviors among the general public, cancer survivors or physicians in Saudi Arabia. The goals of this study are to: 1) get a better understanding of how cancer genetic services are perceived in the general public, among cancer survivors and among physicians; 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; 3) to explore the acceptance of genetic counseling services in Saudi soceity, as it relates to awareness, attitudes, and social influences (i.e. ethics, religion, economics, culture, law, education, etc…) of both physicians and the public.

Materials and Methods

This is cross sectional study carried out in the form of a survey. This study survey was directed toward three different populations: 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 serves from the following organizations: Saudi Oncology Society (SOS), Saudi Cancer Society, Saudi American Cultural Mission (SACM) and Hospitals intra-email systems to reach physicians (National Guard Health Affairs, King Fahad Medical City and Security Forces Hospital). Participation in the online

anonymous survey was voluntary.

The three surveys were designed based on a comprehensive review of the literature. The survey used to collect information from the respondent consisted of four broad categories: 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 was: 1) Saudi nationality; and 2) Age of 18 years or older.

This study was approved by the King Abdul-Aziz Medical City in Riyadh, Saudi Arabia on August 15, 2013, with a renewal issued on August 21, 2014, the Julia Dykman Andrus Memorial's Institutional Review Board on September 30,2013, with a renewal issued on October 28, 2014, and King Fahad Medical City in Riyadh, Saudi Arabia on March 1st, 2014.

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 a 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 SPSS 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 current literature. The knowledge score was computed by totaling the number of correct answers. The expected maximum total score was 15 points. Then the score

was recoded 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 in to ordinal categories to facilitate inclusion in the multiple logistic regression analysis. Analysis of variance (ANOVA) used to measure knowledge scores with different independent variables.

Results

Physicians Survey

A total of 516 physicians from different specialties were invited to participate in the study, of whom 105 (20.35%) returned a completed questionnaire. 15.4% of respondents were oncologists. The other specialities represented included gynocologists, surgeons, and family medicine practitioners. 91.4% worked in a government hospital, 4.8% in private practice and 3.8% were self-employed. 38.1% of physicians in our sample ordered predictive genetic testing for cancer in the previous year. (Appendix A-Table-1)

When physicians asked if they felt qualified to recommend genetic testing themselves, 34.3% felt they were very well qualified, 38.1% were somewhat qualified, 19% were not very well qualified, 4.8% reported they were not qualified at all, and 3.8% were not sure. 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, $p < .001$). Almost all, 96.6%, of those who thought they were not

qualified or were unsure of recommending genetic tests had not ordered genetic testing for inherited cancer susceptibility.

Feeling qualified to recommend genetic testing for inherited cancer susceptibility was positively correlated with having ordered the genetic testing for patients ($r(102) = .40$, $p < .001$) and with having referred a patient to another health care facility for genetic testing ($r(100) = .24$, $p < .01$). Feeling qualified was positively correlated with agreeing that there is strong scientific evidence to support the use of genetic testing in predicting recurrence risk and benefit from chemotherapy ($r(103) = .27$, $p < .01$). Feeling qualified was also correlated with agreeing that the negative result can help in reassuring the patient and their family members that cancer is definitely not inherited ($r(103) = .24$, $p < .01$), agreeing that patients should not undergo testing unless they get genetic counseling about the risks, benefits, and consequences of the test ($r(103) = .24$, $p < .01$) and agreeing that it is difficult to insure that the patients' test results will remain confidential ($r(103) = .17$, $p < .05$). Referring a patient to another health care facility for testing was positively correlated with agreeing that there is strong scientific evidence to support the use of genetic testing in predicting recurrence and risk and benefit from chemotherapy ($r(100) = n.23$, $p < .01$), and with thinking that genetic testing services are not readily available or difficult to access ($r(99) = .19$, $p < .05$).

Three questions on clinical utility concerned the issues of risk analysis, cost-effectiveness, accuracy and availability of guidelines. Almost 40% of physicians believe that the risk of cancer in patients who have a positive genetic test is not clear, while 55.3% disagreed with

this statement, and 4.8% were unsure. More than one-third of physicians believe that genetic testing of patients with family history is not cost-effective (11.4% strongly agree, and 24.8% somewhat agree), while 36.2% strongly disagree, and 7.6% were unsure. Almost 39% of physicians indicated that genetic tests for cancer susceptibility have too many false positives, false negatives, or ambiguous results and 26.7% of physicians were unsure.

Physicians who more frequently asked new patients to provide a family history of cancer among first degree relatives and those who asked more frequently about second degree relatives were more likely to agree that there is strong scientific evidence to support the use of genetic tests in predicating the recurrence risk and benefit from chemotherapy ($r(102) = .33$, $p < .001$ and $r(102) = .20$, $p < .05$). They were also more likely to request genetic testing to enable them to recommend appropriate management strategies to their patients, which include intensive surveillance, prophylactic surgery, or chemoprevention ($r(102) = .19$, $p < .05$ and $r(102) = .17$, $p < .05$). Additionally, they were more likely to agree that patients should not undergo testing unless they underwent counseling about the risks, benefits, and consequences of the test ($r(102) = .26$, $p < .01$).

Three questions concerned the issues of insurance discrimination for patients with positive test results, health insurance coverage for genetic tests for cancer susceptibility, and confidentiality of test results. 46.7% of all physicians thought that patients with positive genetic test results were at risk for insurance discrimination. 32.3% disagreed with this

statement, and 21% were unsure. Almost 40.9% of physicians believed that ordering genetic tests for cancer susceptibility was influenced by coverage of their patient's health insurance plans, although 32.3% said it is not important factor when they order genetic testing. Almost half of physicians (45.8%) thought that it was difficult to ensure the confidentiality of patient test results.

38.1% of physicians reported that they expected the number of their patients who undergo genetic testing for cancer susceptibility to increase substantially and more 41% agreed that the number would be somewhat increasing during the next 5 years. Two access questions covered the issues of genetic counseling and the availability of genetic testing services. More than 63.8% of physicians strongly agree that patients should not undergo testing unless they obtain counseling about the risks, benefits and consequences of the test. 24.8% somewhat agree with this statement, and 3.8% are not sure about this.

On exploring factors that influence recommending genetic testing for hereditary cancer syndromes, 80% reported that the patient's attitude and also his/her family's attitude is important to somewhat important in recommending such tests. On the other hand, about 17.1% thought that the attitude toward this service was not important, and 1.9% were unsure. In addition, physicians were asked if they do not support cancer genetic testing because of concerns regard psychological impact of cancer genetic testing on patients; 41.9% agreed, compared to 50.5% who disagreed, 7.6% were unsure. Although 96.2% of physicians recognize the need for guidelines for genetic testing for inherited cancer

susceptibility, only 62.37% of them reported being very interested in receiving continuing medical education courses in genetic risk assessment for cancer susceptibility. And 8.91% of physicians who agreed on the importance of guidelines said they are not interested in such training.

Public and patients surveys:

A total of 1187 participants completed the survey; 1085 members were general public and 102 were cancer survivors. (Appendix B -Table 2) Amongst the public participants, there were 640 males (59%) and 445 females (41%). Nearly 40% of public participants were 18-24 years old, 53% were between 25 and 50 years of age, and 7.7% were above 50 years of age. The median age was 32. Patients were voluntarily participating in this study. The majority of patients were females 59.8%, while 40.2% were males. Nearly 8.8% of patients were 18-24 years old, 61.7% were between 25 and 50 years of age, and 29.4% were above 50 years of age. The median age was 41.9 years.

Relatives with cancer and exposure to testing

Nearly, 58.7% of the public cohort reported having a relative with cancer; the majority (79.74%) were first-degree relatives. However, public experience with genetic testing was limited to only 17.3%, and 13.3% of the cohort was aware that their friends or family members had ever received cancer genetic testing. The same percentage of respondents from the patient cohort (58.8%) reported having a relative with cancer. Patient experience with genetic testing

in general was again limited to 11.8%, while 16.7% of patients were aware that their friends or family members had ever recieved cancer genetic testing.

Public & Patient reported knowledge

On asking public participants to rate their knowledge level in genetics, most (60.6%) reported knowing the same as most people, and approximately one fifth (21.1%) reported knowing more than most people about genetic testing; 18.4% reported knowing less than others or nothing at all about genetics. In addition, more than half of the patients (56.9%) rate their knowledge as the same as most people. Fewer patients (12.7%) reported knowing more than most people about genetics, and 21.6% reported knowing nothing at all about genetics.

Public & Patient knowledge index

A knowledge index is 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), the median was 7.00. On the other hand, the mean total knowledge score for patients was 4.98 out of 15, the median was 5 out of 15 (SD=2.95). This finding consisted with a previous study from Saudi Arabia, where patients scored lower knowledge scores compared to doctors, nurses and public participants regarding GI cancers. (Parvez et al., 2004). Out of the 15 knowledge-related items, only two public participants answered all knowledge questions correctly, and only 19.3% answered 10 of the 15 questions correctly. No one in the patient cohort answered all knowledge questions correctly and only 3 people

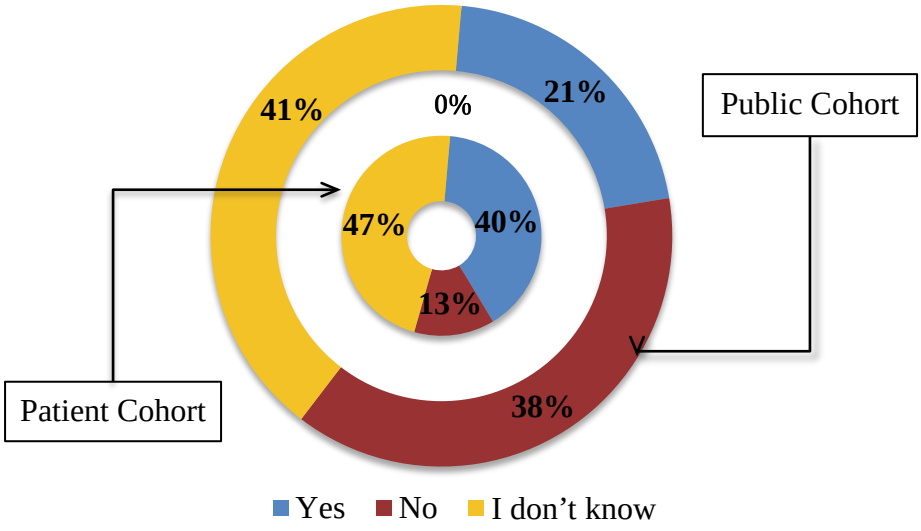
(2.9%) answered 10 questions correctly. Almost half of responders answered correctly that breast and lung cancers are multifactorial in nature (44.9% and 46.2%, respectively). The question most often answered incorrectly in both focused groups was whether spina bifida was caused by genetic factors, environmental factors, or both. Only 13.4% of public and 6.9% of patients answered correctly. (Appendix C- Table 3)

Public and patient correlations for knowledge index

In public cohort, only four demographic variables were significantly correlated with the knowledge index. These were income ($r(1083) = .58$, $p<.001$), being female ($r(1083) = .26$, $p<.001$), education ($r(1083) = .23$, $p<.001$) and age ($r(1083) = .15$, $p<.001$). In the patient cohort, significant correlations with knowledge scores were found for three demographic variables: education ($r(86) = .36$, $P<0.001$), gender (being female) ($r(100)$ .33, $p<.001$), and income ($r(99)$, =.22, $p<.05$). Knowledge was not correlated with age, region, city, marital status, having children, or level of religion.

There was a significant correlation between knowledge and learning about the genetic explanation of cancer from their own experience with cancer ($r(100) = .32$, $p<0.01$), having friends or family members who had a hereditary cancer disease ($r(100) = .25$, $p<0.01$), having family or friends who had a genetic test ($r(100) = .24$, $p<0.05$), not refusing a cancer genetic test because of stigma ($r(100) = .22$, $p<0.05$) by their doctors. Knowledge was related to perceiving genetic tests for cancer to be accurate ($r(100) = .27$, $p<0.01$).

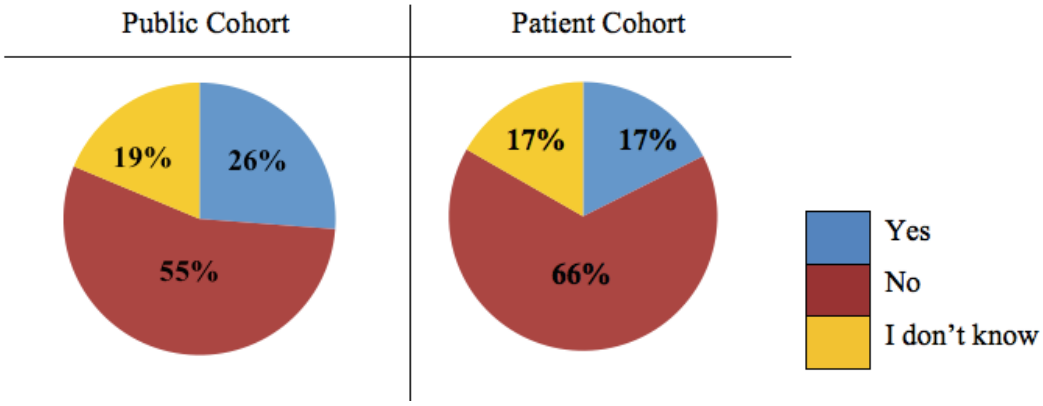
Figure1: Is genetic testing for hereditary cancer syndrome accurate?



Public and patient predictive genetic testing for cancer

Several confounding factors were assessed in the study regarding genetic testing. The majority of participants, patients and public, were interested in predictive cancer genetic testing in general, 72.5% (SD=0.737) and 58.4 %(SD=0.73) respectively. Both focused groups that declined testing, expressed further interest in testing if there was a family history indicating a need for testing. However, in the absence of treatment, the interest in testing dropped to half in the case of public respondents and almost a quarter in the case of patients. Participants were asked whether or not they would refuse genetic testing due to perceived stigma. (Figure 2)

Figure 2: Participants view on refusal genetic testing due to perceived stigma.



A substantial majority of public and patient participants (74.6% and 84.3%) agreed that physicians are entitled to share genetic test results with family members, even if it violated the test candidate's privacy. However, 75% of respindents perceived that secrecy could be a barrier for cancer genetic testing. While in public population, knowledge was significantly related to willingness to undergo genetic testing for risk of developing cancer before the age of 65 ($r (1083)= .12$, $p<.001$). Knowledge was also related to perceiving genetic tests for cancer to be accurate ($r (1083)= .11$, $p<.001$). Patients knowledge on the other hand was not related to willingness to undergo genetic testing about person's risk for developing cancer before age of 65 but was significantly related to wanting to test for a higher cancer risk if they had a family history ($r (100) = .29$, $p<0.01$).

Public and patient attitude about genetic counseling

Overall, public (62.4%) and patient (70.6%) respondents were interested in cancer genetic counseling services, compared to 18.6% of public and (12.73%) of patients who were definitely not interested in this service. Interestingly, 24.75% of public who declined genetic

counseling service considered visiting a psychologist if their cancer genetic test result showed a higher predisposition to develop cancer. While patients didn't express significance interest in visiting a psychologist if their cancer genetic test result showed higher predisposition to develop cancer.

The effective of religiosity

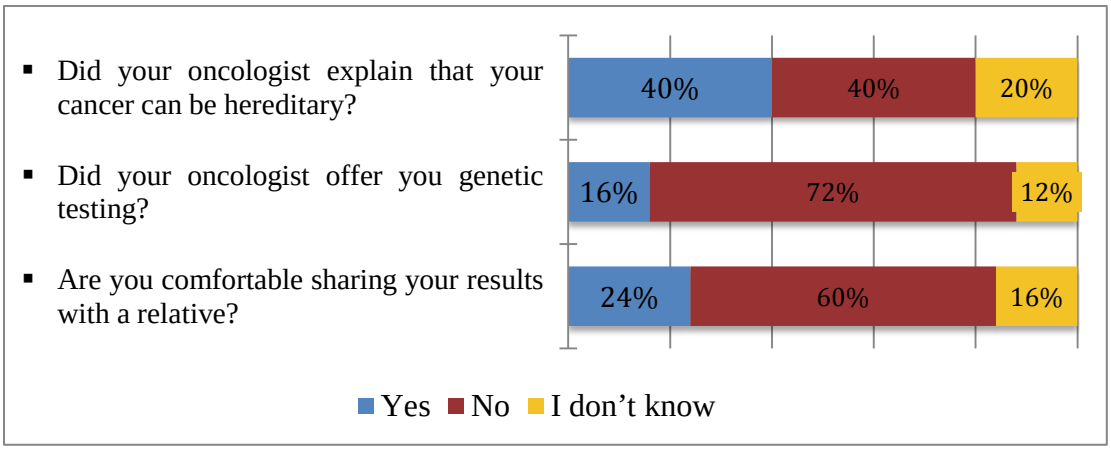
Crosstabular analysis was done between the level of religiosity of the person and their willingness to undergo genetic testing, willingness to see a genetic counselor, willingness to see a psychologist, willingness to share genetic cancer information with relatives, and refusing a genetic test because of stigma. In public population, level of religiosity was not significantly associated with any of the above variables. However, in the patient population, level of religiosity was significantly associated with willingness to see a genetic counselor (Chi-square (4) = 10.33, $p < .05$). 81.0% of those with "average" religiosity would see a genetic counselor, and 73.6% of those with a conservative background would see a genetic counselor, and 55.6% of those with a strict religious background would see a counselor.

Level of religiosity was also significantly associated with refusing to take a genetic test because of stigma (Chi-square (4) = 11.40, $p < .05$). While 66.7% of those with "average" religiosity would not refuse a test because of stigma, and 73.6% of those with a conservative background would not refuse a test because of stigma, only 51.9% of those with a strict religious background would not refuse a test because of stigma. For patient cohort, level of

religiosity was not willingness to see a psychologist, or willingness to share information with relatives.

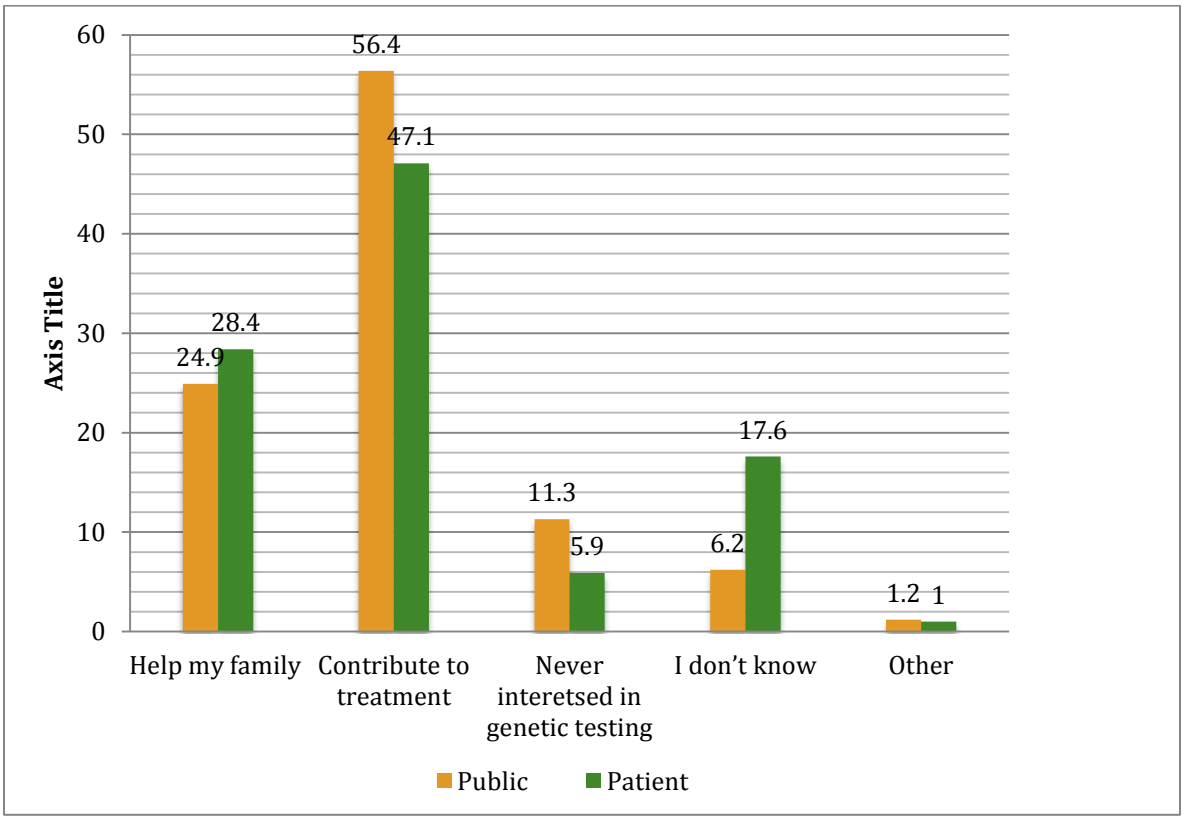
The patient experience is summerized in figure 3.

Figure 3: Patient experience:



On investigating the reasons behind interest in genetic testing for hereditary cancer syndrome; the main reason for both cohorts was as it may help treatment.

Figure 4: Reasons behind interest in genetic testing for hereditary cancer syndrome.



Discussion

The present study is the largest observational cancer genetic services study in Saudi Arabia to date. In the present study, both patient and public participants expressed interest in genetic testing for hereditary cancer syndrome, 72.5% and 58.4% respectively. This was similar to previous studies where almost half (42.8%) of the participants expressed interest in genetic testing for breast cancer. (Amin et al, 2012). In the public cohort; high income, being female, higher education and age were the variables that had the highest correlation with knowledge index. In the patient cohort; higher education, being female, and high

income had significance correlations with knowledge scores. In this study, higher knowledge scores in the public cohort correlated with a greater willingness to undergo genetic testing overall. In the patient cohort, higher knowledge scores were correlated with a greater willingness to undergo genetic testing only in the context of a positive family history of cancer.

Predicting uptake of genetic testing is a complicated proposition. Sweney et al. (2014) completed a qualitative systematic review of the literature in which they analyzed 115 studies in an attempt to identify what factors, if any, influenced people's decision to pursue testing. Sweeny categorized their findings into subjective (perceived risk of disease, disease- specific worry, perceived control, perceived disease severity, perceived benefits to testing, perceived barriers to testing, subjective norms, attitudes toward testing, knowledge and perceived risks of testing) and objective (family health history, personal health history, general health motivation, monitoring, positive outlook, discomfort with uncertainty, decisional preference, gender, education, employment status, income, age, marital/parental status, and religiosity) predictors. The researchers concluded that people are more likely to undergo genetic testing when they perceive the benefits of the testing to be high and the risks to be low; when the tests are accessible and when the testing is regarded in a positive light. Knowledge did not prove to be a consistent predictor of uptake.

79.1% of physicians in this study reported they expected an increase in the number of patients who will be willing to undergo genetic testing for cancer. The reported interest captured by this study refutes previous studies who propose that the high rate of interest among female participants may not adequately reflect the genuine demand for testing, but instead a generic interest in modern laboratory procedures (Bruno et al, 2004) or misunderstanding of the impact genetic testing can have on breast cancer risk analysis (Amin et al, 2012).

More than half of physicians (63.8%) strongly agree that patients should not undergo testing unless they obtain counseling about the risks, benefits and consequences of the test. On the availability of facilities that can provide genetic counseling and testing for inherited cancer susceptibility in the geographic area from which you draw your patients, 45.7% of physicians reported there is available facility, 24.8% said there is no available facility and 28.6% were unsure of the availability. 12% of those who referred thier patient to seek genetic testing referred them to genetic counselors, while 56.25% referred them to geneticists. This finding is consistent with a 2012 study of physician attitudes toward genetic counseling services in Pakistan (Ashfaq et al, 2012). While there are no genetics clinics in the area, 100% of the physicians surveyed would refer some or all of their applicable patients should one open up. 41.9% of physicians reported concerns regarding the psychological impact of cancer genetic testing on patients. This is exactly the area where genetic counselors can be best utilized.

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” (Resta et al, 2006). There was a significant amount of uncertainty surrounding many aspects of cancer genetic testing amongst the physician respondents; including clinical utility, cost effectiveness, discrimination and patient confidentiality. 28% of respondents reported that they were unqualified to recommend genetic testing. 90.5% reported that they are interested in received continuing education in genetic risk assessment and testing for inherited cancer susceptibility; and 96.2% felt there is a need for physician guidelines to inform practice. Consequently, this may affect cancer risk communication and the decision making process and/or medical management for cancer patients. (Schneider, 2011)

62.4% of public participants were interested in cancer genetic counseling. Of those who would not see a genetic counselor, 24.75% considered visiting a psychologist if their cancer genetic test result showed higher predisposition to develop cancer. 70.6% of patient participants were interested in genetic counseling. Those who declined genetic counseling didn’t express significance interest in visiting a psychologist if their cancer genetic test result showed higher predisposition to develop cancer. The decision to outright decline genetic counseling services or the preference for a psychologist may indicate a low understanding of the role of a genetic counselor among public cohort. The slightly higher acceptance of genetic cousneling services in the patient cohort may reflect a greater appreciation for the role, especially if their oncologist did not discuss genetics as part of their care. Additional education is required for both populations as genetic counseling improves knowledge of

cancer genetics and uptake of testing without an adverse effect on cancer-specific worry, general anxiety, distress, and depression. (Braithwaite et al, 2004)

Previous studies tried to connect a relationship between religiosity and attitude toward genetic testing. While some of the studies indicate negative correlation (Botoseneanu et al, 2011, Bowen et al, 2003), other studies show the opposite (Warner, Curnow, Polglase, & Debinski, 2005). This is consistent with Sweeny et al. (2014) conclusions that socio-demographic information and religiosity were objective predictors that were not consistent and sometimes contradictory in terms of testing uptake.

With regard to stigma and privacy, our study found that more than 84.4% of the patient respondents and 57.7% of the public respondents thought that doctors are entitled to share genetic tests results information with relatives if there is impact on their lives. The patient respondents were specifically asked about willingness to share their genetic results with relatives, given their experience; 59.8% were definitely willing to share, 24.5% refused and 15.7% did not know if they will share their information. The next generation of physicians in Saudi Arabia also embraces the idea of disclosure (Al-Amri, 2011), hopefully helping to alleviate some of the stigma previously discussed.

Earlier study suggested poor cancer risk communication on the behalf of physicians with their patients, (Kelly et al, 2009) present study findings regard patient experience (Figure 3) support these findings. Overall, current study results demonstrate a seemingly harmonious

picture between physician's self-reported qualifications and patient experience. Review the hereditary component of cancer diagnosis with patients not only considered a professional role (Worthern et al, 1999), but empower the patient with necessary information in order to maintain their autonomy (Schneider, 2011)

Conclusion

In conclusion the study found a broad interest for and positive attitude towards genetic services for hereditary cancer syndromes in Saudi Arabia. Greater education is needed across all populations. Further areas of research include some barriers to access (perceived or real) to genetic services as well as further exploration into factors that influence uptake in Saudi society as the vast majority of this data exists for patients of Western origin.

Acknowledgements

The authors acknowledges the following for their support in data collection: Omniah Abdulrehim, Genetic coordinator, National Guard Health Affairs, Mr. Mofarrej Almofarrej, Saudi Oncology Society, Dr. Mushabbab Asiri, Cancer Center – KFMC, Dr. Aziza Alswayyed, King Fahad Medical City, Dr. Khayal Alkhayal, department of surgery, King Saud University. Also, Prof. Michael J. Smith for his continues support in evaluation this study. Special thanks and appreciation go to Dr. Abdulrahman Alswaid from National Guard health affairs in Riyadh for his cooperation and extra effort in collecting the data for this study.

References

Al-Amri, A. (2011). Attitudes of Saudi medical students toward the disclosure of information on cancer in eastern Saudi Arabia. *J Fam Cimmunity Med,*18(2):54-58.

Alkuraya, F. S. (2014), Genetics and genomic medicine in Saudi Arabia. *Molecular Genetics & Genomic Medicine*, 2: 369–378.

Amin, T. T., Al Mulhim, A. R., & Al Meqihwi, A. (2009). Breast cancer knowledge, risk factors and screening among adult Saudi women in a primary health care setting. *Asian Pac J Cancer Prev,*10(1):133–138.

Amin, T.T., Al-Wadaani, H.A., Al-Quaimi, M.M. Aldairi, N.A., Alkhateeb, J.M., & Al-Jaafari, A.A., (2012) Saudi Women's Interest in Breast Cancer Gene Testing: Possible Influence of Awareness, Perceived Risk and Socio-demographic factors. *Asian Pac J Cancer Prev,* 13(8):3879-3887.

Ashfaq, M., Amanullah, f., Ashfaq, A., & Ormond K.E., (2013) The Views of Pakistani Doctors Regarding Genetic Counseling Services – Is there a Future? *J Genet Counsel,* 22:721–732

Bando, H. (2014). Issues of concern in risk assessment, genetic counseling, and genetic testing of younger breast cancer patients in Japan. *Breast cancer,* 21(6):656-63.

Botoseneanu, A., Alexander, J. A., & Banaszak-Holl, J. (2011). To test or not to test? The role of attitudes, knowledge, and religious involvement among US adults on intent-to-obtain adult genetic testing. *Health Education and Behavior*, 38(6), 617–628. doi:10.1177/1090198110389711

Bowen, D. J., Singal, R., Eng, E., Crystal, S., & Burke, W. (2003). Jewish identity and intentions to obtain breast cancer screening. *Cultur Divers Ethnic Minor Psychol*, 9(1):79-87.

Braithwaite, D., Emery, J., Walter, F., Prevost, A.T., & Sutton, S. (2004). Psychological impact of genetic counseling for familial cancer: a systematic review and meta-analysis. *J Natl Cancer Inst,* 96(2):122-133.

Bruno, M., Tommasi, S., Stea, B., Quaranta, M., Schittuli, F., Mastropasqua, A., Disrantie, A., Di Paola, L., & Paradiso A. (2004). Awareness of breast cancer genetics and interest in predictive genetic testing: a survey of a southern Italian population. *Annals of Oncology*, 15, SUP1:48–54.

Eldeek, B., Alahmadi, J., Al-attas, M., Sait, K., Anfinan, N., Aljahdali, E., Ajaj, H. & Sait, H. (2014). Knowledge, perception, and attitudes about cancer and its treatment among healthy

relatives of cancer patients: single institution hospital-based study in Saudi Arabia. *J Cancer Educ.* 29(4):772-80.

Kelly, K.M., Ferketich, A.K., Sturm A.C., Porter, K., Sweet, K., Kemp K., Schwirian, P., & Westman J.A. (2009) Cancer risk and risk communication in urban, lower-income neighborhoods. *Prev Med.* 48:392–396.

Kinney A.Y., Gammon, A., Coxworth, J., Simonsen, S., & Arce-Laretta, M., (2010). Exploring attitudes, beliefs, and communication preferences of Latino community members regarding BRCA1/2 mutation testing and preventive strategies. *Genet Med,* 12(2):105–115.

Khayyat Y.M., & Ibrahim EM. (2014) Public awareness of colon cancer screening among the general population: A study from the Western Region of Saudi Arabia, *Qatar Med J,* vol(2014):3

Mendes, A., Sousa, L., & Paneque, M. (2013). From constraints to opportunities? Provision of psychosocial support in Portuguese oncogenetic counseling services. *Journal of genetic counseling*, 22(6), 771–83.

Milaat WA. (2000). Knowledge of secondary-school female students on breast cancer and breast self-examination in Jeddah, Saudi Arabia. *East Mediterr Health J,* 6(2-3): 338-344.

Qari AA, Balobaid AS, Rawashdeh RR, & Alsayed M.D. (2013). The development of genetic counseling services and training program in Saudi Arabia. *J Genet Couns,* 22(6):835-838.

Ravichandran, K., Mohamed, G., & Al-hamdan, N.A. (2010). Public Knowledge on Cancer and its Determinants among Saudis in the Riyadh Region of Saudi Arabia. *Asian Pac J Cancer Prev*, 11(5):1175-1180

Ravichandran, K., Al-Hamdan, N. a, & Mohamed, G. (2011). Knowledge, attitude, and behavior among Saudis toward cancer preventive practice. *Journal of family & community medicine*, 18(3), 135–42.

Resta, R.G. (2006). Defining and redefining the scope and goals of genetic counseling. *Am J Med Genet C Semin Med Genet* 142C(4): 269-275.

Schneider K. A. (2011). Counseling about cancer: strategies for genetic counseling (3rd edition. p. 12) Wiley-Blackwell

Sweeny, K., Ghane, A., Legg., A.M., Huynh H.P., & Andrews., S.E. (2014). Predictors of Genetic Testing Decisions: A Systematic Review and Critique of the Literature. *J Genet Couns*, 23(3):263–288.

Parvez, T., Gumgumji, A.A., Anwar, M.S., & Al-Ahmadi, S.S., (2004). Awareness about causes of gastroinstestinal tract (GIT) malignancies. *J Coll Physicians Surg Pak,* 14(2):98-101.

King Faisal Specialist Hospital and Research Center - Oncology Center Research Unit (2013). *2012 Tumor Registry annual report.* Retrieved from http://www.kfshrc.edu.sa/oncology/2012_Tumor_Registry_Annual_Report.pdf

Warner, B. J., Curnow, L. J., Polglase, A. L., & Debinski, H. S. (2005). Factors influencing uptake of genetic testing for colorectal cancer risk in an Australian Jewish population. *J Genet Couns*, 14(5), 387-394.

Worthen, H. G. (1999). Inherited cancer and the primary care physician. *Cancer*, 86: 2583–2588.

Appendix

A. Physician demographic: Table-1

		Frequency	%
Nationality			
	Saudi	63	60%
	Non-Saudi	42	40%
Affiliation with academic institution			
	Yes	68	64.8%
	No	37	35.2%
Prcatice management			
	Govermental	96	91.4%
	Commercial owned	5	4.8%
	Self-employeed	4	3.8%
Total phyiscian 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%

B. Socio-demographic data for patient and public: Table-2

		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%
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/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%
	Office work/Admin	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	10.23%	16	15.69%
	Not answer	25	2.30%	2	1.96%
Income					
	< 2999 SR	164	15.12%	9	8.82%
	3000 – 5999	118	10.88%	10	9.80%
	6000-9900	185	17.05%	16	15.69%
	> 10,000	277	25.53%	26	25.49%
	No salary	340	31.34%	41	40.20%
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%

C. Percentage of correct knowledge responses for public and patients: Table-3

		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 a 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, there is 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%