

## RESEARCH ARTICLE

# Saudi Women's Interest in Breast Cancer Gene Testing: Possible Influence of Awareness, Perceived Risk and Socio-demographic Factors

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### Abstract

**Background:** Development of effective educational strategies should accompany increases in public awareness and the availability of genetic testing for breast cancer (BC). These educational strategies should be designed to fulfill the knowledge gap while considering factors that influence women's interest in order to facilitate decision making. **Objective:** To determine the possible correlates of Saudi women's interest in BC genes testing including socio-demographics, the level of awareness towards BC genes, the family history of BC and the perceived personal risk among adult Saudi women in Al Hassa, Saudi Arabia. **Subjects and methods:** This cross-sectional study was carried out during the second BC community-based campaign in Al Hassa, Saudi Arabia. All Saudi women aged  $\geq 18$  years ( $n=781$ ) attending the educational components of the campaign were invited to a personal interview. Data collection included gathering information about socio-demographics, family history of BC, the perceived personal risk for BC, awareness and attitude towards BC genes and the women's interest in BC genes testing. **Results:** Of the included women ( $n=599$ ), 19.5% perceived higher risk for BC development, significantly more among  $< 40$  years of age, and with positive family history of BC before 50 years of age. The participants demonstrated a poor level of awareness regarding the inheritance, risk, and availability of BC genetic testing. The median summated knowledge score was 1.0 (out of 7 points) with a knowledge deficit of 87.8%. The level of knowledge showed significant decline with age ( $> 40$  years). Of the included women 54.7% expressed an interest in BC genetic testing for assessing their BC risk. Multivariate regression model showed that being middle aged (Odds Ratio 'OR'=1.88, confidence intervals 'C.I'=1.14-3.11), with higher knowledge level (OR=1.67, C.I=1.08-2.57) and perceiving higher risk for BC (OR=2.11, C.I=1.61-2.76) were the significant positive correlates for Saudi women interest in BC genetic testing. **Conclusion:** Saudi women express high interest in genetic testing for BC risk despite their poor awareness. This great interest may reflect the presence of inappropriate information regarding BC genetic testing and its role in risk analysis.

**Key words:** Breast cancer - genetic testing - awareness - perceived risk - interest - Saudi women

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### Introduction

Breast cancer (BC) is the most common of cancer among Saudi females and accounted for more than 24% of all newly diagnosed cancer among them (Saudi Cancer Registry, 2005). Moreover, it is estimated that by year 2025, the incidence will reach to 350% and mortality of 160% (Ibrahim et al., 2008). Furthermore, data on female patients with invasive BC reported from different regions

in Saudi Arabia showed that most patients were in the age group of 40 to 50 years and were predominantly pre-menopausal (Amin et al., 2009; El Saghier et al., 2006; Akhtar & Nadrah, 2005) with advanced stage where ductal carcinoma in situ represented fewer than 5% (Ibrahim et al., 2008; Amin et al., 2009). In many developed countries, the incidence and mortality of BC have reached a plateau level and even decline (Peto et al., 2000; Jemal et al., 2009). This decline has been attributed

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to several factors including early detection through the use of screening mammography and appropriate use of systemic adjuvant therapy (Hortobagyi, 1998). Promotion of mammography screening and other breast health practices and public awareness campaigns have heightened women's concern about BC (Mogilner *et al.*, 1998). Consequently, women often seek information about their individual risk for BC (Bottorff *et al.*, 1997; Brain *et al.*, 2000) and BC genes testing presents a new avenue for obtaining individualized risk information and has attracted the attention of increasing numbers of women, regardless their risk profile (Bottorff *et al.*, 2002). An estimated 5–10% of breast and ovarian cancers are attributed to deleterious BRCA1/2 mutations, which account for ~20–40% of familial BC and for the majority of familial ovarian cancers (Frank *et al.*, 2002; Pal *et al.*, 2005). El-Harith *et al* concluded from their study that BRCA1 and BRCA2 mutations are likely to contribute to the pathogenesis of familial BC in Saudi Arabia (El Harith *et al.*, 2002). Women at high risk would benefit from genetic counseling that helps patients or family members make informed decisions about genetic testing and that enhances selection of early cancer detection and/or risk-reduction strategies (The United States Preventive Services Task Force 2005 and the National Comprehensive Cancer Network 2008; Schwartz GF *et al* 2008; Gronwald J *et al* 2006).

Awareness of hereditary cancer risk and genetic testing for cancer susceptibility can enhance informed decision making (Schwartz *et al.*, 2005). However, this awareness varies by socio-demographics, family history, access to information through the health care system (Meischke *et al.*, 2001; Benjamin-Garner *et al.*, 2002; Wideroff *et al.*, 2003; Vadaparampil *et al.*, 2006) and the perceived personal risk (Bottorff *et al.*, 2002; Bruno *et al.*, 2004). Also, individual's decision regarding whether or not to seek clinical cancer genetic services may also be influenced by knowledge, cognitions, emotions, family communication, and socio-demographic and clinical characteristics (Bottorff, 2002; Kinney *et al* 2006; Ropk *et al.*, 2006). To enhance informed decision making about cancer genetic counseling or testing, it has become increasingly important to gain a better understanding of cultural, access, and psychosocial contexts related to factors influencing the use of these health services (Bottorff, 2002; Kenny *et al.*, 2010).

Moreover, it is imperative that all segments of the population be educated about hereditary cancer risk, the availability of genetic counseling and testing services, and cancer prevention strategies to facilitate informed decisions (Bottorff, 2000; Ropka *et al.*, 2006; Kinney *et al.*, 2010). In Saudi Arabia, the awareness regarding BC genes, the interest in BC genetic testing and factors that may influence this interest is lacking despite the expected wide spread implementation of these tests in the clinical practice. Subsequently, it is important to understand factors that contribute to interest and utilization of cancer genetic services. The objective of

this study was to determine the possible correlates of Saudi women's interest in BC genes testing including socio-demographics, the level of knowledge, the family history of BC and the perceived personal risk.

#### *Setting and design*

This was a cross-sectional survey study carried out in Al Hassa Governorate, Eastern Province of Saudi Arabia; located 50 km from the Arabian Gulf, 450 km from the capital Riyadh, populated by about one million and half. Al Hassa is comprised of three regions; urban, populated by about 60% of the total population, rural consisting of 23 villages (35% of the population) and "Hegar" Bedouin scattered communities making up the remaining 5%. The Ministry of Health provides primary care through 54 primary health care centers, while the rest of the population provided primary care through other sectors e.g., National Guard, ARAMCO, and others.

#### *Subjects and Methods*

This study was carried out during 2nd breast cancer campaign which was held in one of the biggest mall in Al Hassa, between 5th and 21st October 2011, and sponsored by the Saudi Cancer Foundation. The campaign included several activities; clinical breast examination, mammography screening unit, breast cancer fair and health education sessions. During this period, 5533 women have visited the different functions of the campaign, breast self examination corner attended by 3437 women, mammography was done for 119 women by a mobile unit and 781 women have attended the series of lectures on BC early detection and prevention. Women interested in clinical breast examination were referred to specialized consultants at King Fahd Hospital. All Saudi women aged  $\geq 18$  years attended the BC awareness lectures were targeted for the study. All women were approached personally to participate following proper orientation about the objectives and potential impact of the study.

## **Materials and Methods**

Women who agreed to participate were invited to personal interview by trained interns for the purpose of data collection.

#### *Data collection tool*

A questionnaire form was designed and used for data collection and it was composed of the following components:

- Socio-demographic characteristics: Age in years, educational stage, occupational status, family income in Saudi Riyals, and marital status.
- Family history of BC: Number and degree of relation (if any), age at diagnosis with emphasis on the occurrence of BC among relatives before the age of 50 years.
- BC screening practices in the last two years in the form of clinical breast examination and mammography

and the reasons for screening.

- The history of any tests to screen or diagnose genetic conditions among family and relatives and the nature of the conditions pertained.

- Two closed ended questions were employed to assess the woman's personal perceived risk for the development of BC compared to a woman of the same age (Hopwood et al., 2001; Bruno et al., 2004). One question with yes/no option regarding ever heard/read about BC genes and their role in BC development was added and the sources of their information.

- Knowledge about BC genes and their risk in BC development and attitude toward BC genes screening: The knowledge part composed of seven closed ended questions with three options (true, false and I do not know), adopted from the available literature (Lerman et al., 1996; Lerman et al., 1997; Bruno et al., 2004). Correct responses were given one point each while incorrect and do not know responses were given nil. The attitude questions were adopted from the available literature (Bluman et al., 1999; Kenny et al., 2010) and included two closed ended with five options ranged from strongly agree to strongly disagree. Interest in BC genes testing was also assessed using a closed ended with five options (yes definitely, probably, definitely no, probably no and non-decided), the reasons for interest/none in genetic testing were probed by open ended questions as well as the need for more information about BC genes, their role in BC development and genetic testing using two more closed ended questions.

#### *Pilot testing*

A field pre-testing of the designed questionnaire form was carried out on 49 women attended a nearby primary care center. The original questionnaire included the terms BRCA 1 and BRCA 2, which was omitted as many of the included women found difficulty in recognizing these terms and instead we used the term breast cancer genes, the knowledge sections originally included 10 questions with a reliability coefficient (Cronback's Alpha) of 0.546, removal of three questions assessing specific aspects of breast cancer genes (prevalence of breast cancer genes, the size of risk pertained if having BRCA 1 and BRCA 2 mutations, and mode of inheritance of breast cancer genes) improved the reliability coefficient to 0.817. The attitude section was originally composed of five Likert scaled questions with an alpha coefficient of 0.498; omitting three questions (related to advantages and disadvantages to BC genetic testing and steps taking if BC genes positive) and improved the alpha reliability coefficient to 0.631. The original questionnaire was in English for which translation into Arabic by two faculties with back translation to English was done to preserve the original construct. Training of the interviewers (three female interns) was also carried out during the pilot.

#### *Data analysis*

Data were processed and analyzed using SPSS

version 13.0 (SPSS Inc. Chicago IL). Of the total Saudi women attended the BC educational lectures (n=781), 637 agreed to participate with a response rate of 81.6%. Questionnaire forms with missing of two or more items were discarded (n=38), hence the total subjects included in the final analysis accounted to 599 women.

Both descriptive and inferential statistics were applied as appropriate. Categorical data were expressed using frequency, proportions and percentage, Chi square test of significance, and estimation of Odds ratio (OR) with 95% confidence intervals were also used to report univariate analysis. Numerical data including knowledge scores were reported using median, mean and standard deviation. The median summated score for knowledge section (total of 7 points) was 1.0 with 75th percentile of 3.0, a cut off of  $\geq 3.0$  was employed to classify the included participants as less knowledgeable ( $\leq 2$  points) and more knowledgeable ( $\geq 3$  points).

Non-parametric tests of significance including Mann Whitney and Kruskal Wallis were used for statistical comparison. A multivariate binary logistic regression model was generated to determine the potential correlates of women's interest in BC genes testing (dependent variable) out of the significant independent variables at the univariate analysis (socio-demographics, perceived personal risk, family history of BC and level of knowledge). P value of  $< 0.05$  was applied as a level of significance.

#### *Ethical considerations*

Permissions were obtained from the local Health Authorities as well as our institution after approval of the study proposal and data collection tools. Participants were provided with full explanation of the study with the emphasis on the right of the subject not to participate. Informed consent forms were obtained from those agreed to participate; data confidentiality was maintained.

## **Results**

#### *Socio-demographic and participants characteristics*

The age ranged from 18 to 66 years, 67 (11.2%) were illiterates, 76 (12.7%) had primary/preparatory level of education. Working females represented 42.2%, most of them were occupying governmental jobs (n=172, 82.7%) or self employed (n=36, 17.3%). Out of 599 participants, 122 (20.4%) had a positive family history of BC among  $\geq 3$  relatives before the age of 50 Family members of immediate family were mentioned to be affected in 26.2% (mothers n=14, sisters n= 12, brother n=1, grandmother n=7). Clinical breast examination in the last two years was mentioned by 24.5% of participants (91 of cases for reasons related to BC detection), while 13.9% underwent screening mammography in the last two years.

#### *Perceived BC risk*

Of the included women, 117 (19.5%) mentioned their

**Table 1. Responses of the Included Saudi Women Regarding Breast Cancer Gene Knowledge**

| Knowledge items  | Correct         | %    | In correct | %    | Do not know | %    |
|--|-----------------|------|------------|------|-------------|------|
| All women with breast cancer genes will be affected with breast cancer (False)                             | 77              | 12.9 | 92         | 15.3 | 430         | 71.8 |
| All women without breast cancer genes have a chance to develop breast cancer (True)                        | 106             | 17.7 | 77         | 12.9 | 416         | 69.5 |
| Women with breast cancer genes have a higher chance of getting ovarian cancer (True)                       | 74              | 12.4 | 133        | 22.2 | 392         | 65.4 |
| A father can pass breast cancer genes to his daughters (True)  | 37              | 6.2  | 92         | 15.4 | 470         | 78.4 |
| Breast cancer genes are responsible for the development of breast cancer before the age of 50 years (True) | 92              | 15.4 | 89         | 14.6 | 418         | 69.8 |
| Only those women with family history of breast cancer have breast cancer genes (False)                     | 87              | 14.5 | 83         | 13.9 | 429         | 71.6 |
| There are tests available to detect breast cancer genes (True)   | 39              | 6.5  | 85         | 14.2 | 475         | 79.3 |
| Total knowledge score: Range   | 0-7             |      |            |      |             |      |
| Median (mean±SD)   | 1.0 (2.02±1.71) |      |            |      |             |      |

likelihood of being at higher risk for BC development compared to women of their age. Perceived higher risk for BC demonstrated by 19.5% of participants and it was significantly more among those < 40 years (23.0% vs. 14.6% for those > 40 years, Odds ratio (OR) =1.75, confidence Intervals, C.I.=1.11-2.70, P=0.010), with positive family history of BC (41.8% vs. 13.6% of those without, OR=4.58, C.I.=2.87-7.32, P=0.0001). The perceived personal risk was not significantly affected by other socio-demographic variables (20.4% with > secondary education vs. 16.8% with < secondary education, P=0.341), working condition (21.1% vs. non working 20.7%, P=0.908), and family income (20.9% in lower income of < 10,000 SR vs. 16.7% with higher income, P=0.224). Only 24.5% of participants have heard about the role of BC genes and their risk in the development of cancer, among them, health-related sources were acknowledged by 18.4%, school and college curricula in 10.9%. The main sources for information among our participants were friends, relatives and television (63.5%).

#### BC gene awareness

Table 1 depicts the responses of the included participants towards the knowledge items of BC genes. Of the included women, 12.9% have responded correctly about the statement that all women with BC genes will be affected by the disease, 17.7% correctly responded about the statement that all women without BC genes have a chance to develop BC, 12.4% agreed about the role BC genes in increasing the risk for ovarian cancer, the role of father in passing the breast cancer genes to his daughters received the least correct responses (only 6.2%), BC genes and their role in BC development before the age of 50 years was correctly stated by 15.4%, 14.5% of women stated correctly that BC genes can be found irrespective of the presence of family history of BC, and 6.5% of women agreed about the availability BC genes testing. Overall a mean knowledge deficit of 87.8% (those with incorrect/do not know responses) was found among the participants (ranged from 82.4 to 93.8%). The median of the summated knowledge score was 1.0, mean of 2.02±1.71. The 25th percentile was 0.0 and 3rd quartile was 3.0, 329 (53.6%) scored 0.0, 163

scored 1-2 points and 107 scored 3 or more points. Age category of 18-<30 years scored higher than the other age groups (2.25±1.52 vs. 1.63±1.39 for those < 40 years of age, Kruskal Wallis, P=0.02). Those with < secondary education scored significantly less (1.80±1.47) compared to ≥ secondary education of 2.08±1.74 (Mann Whitney, P=0.033), while it was not significantly affected by the presence of positive family history of BC (2.04±1.73 among those without family history vs. 1.96±1.49 for those with).

More than 60% of women agreed that screening for BC genes should be done to all women irrespective of their family history of the disease, while 40.4% mentioned their agreement that BC genes testing should only be carried out to those with risk factors including positive family history.

#### Influence of participants' characteristics on awareness:

Table 2 displays the results of univariate analysis of socio-demographics and family history of BC as

**Table 2. Influence of Sociodemographics on the Level of Knowledge towards Breast Cancer Genes among the Included Saudi Women**

|                                       | Knowledge levels ≤ 2 (N=492) | ≥ 3 (N=107) | Odds ratio (95% CI) |
|---------------------------------------|------------------------------|-------------|---------------------|
| Age groups                            |                              |             |                     |
| 18- <30                               | 134(79.8)                    | 34(20.2)    | Reference           |
| 30- <40                               | 132(71.7)                    | 52(28.3)    | 1.79(1.13-2.83)**   |
| 40- <50                               | 122(92.4)                    | 10(7.6)     | 0.31(0.15-0.64)**   |
| ≥ 50                                  | 104(90.4)                    | 11(9.6)     | 0.43(0.21-0.86)*    |
| Monthly income (Saudi Riyals)         |                              |             |                     |
| < 5000                                | 92(85.2)                     | 16(14.8)    | Reference           |
| 5000- <10000                          | 229(83.3)                    | 50(16.7)    | 0.97(0.62-1.51)     |
| ≥ 10000                               | 151(78.6)                    | 41(21.4)    | 1.32(0.83-2.09)     |
| Education:                            |                              |             |                     |
| < Secondary                           | 123(86.2)                    | 20(13.8)    | Reference           |
| Secondary                             | 145(86.7)                    | 22(13.3)    | 0.66(0.38-1.12)     |
| College or higher                     | 244(77.5)                    | 65(22.5)    | 1.92(1.22-3.01)**   |
| Working                               |                              |             |                     |
| No                                    | 324(87.5)                    | 49(12.5)    | Reference           |
| Yes                                   | 150(72.1)                    | 58(27.8)    | 2.56(1.63-4.01)*    |
| Breast cancer among family < 50 years |                              |             |                     |
| No                                    | 401(82.3)                    | 86(17.7)    | Reference           |
| Yes                                   | 91(81.3)                     | 21(18.0)    | 1.08(0.61-1.88)     |

**Table 3. Multivariate Regression Model of Correlates of Interest in Breast Cancer Genes Screening Among Saudi Women**

| Variables                      | Interest No. (%) |                         | OR (95.0% C.I)  | P value | Multivariate logistic regression model |       |                  |         |
|--------------------------------|------------------|-------------------------|-----------------|---------|--|-------|------------------|---------|
|                                | Yes (N=325)      | No <sup>1</sup> (N=274) |                 |         | B                                      | S.E.  | OR (95.0% C.I)   | P value |
| Age categories:                |                  |                         |                 |         |  |       |                  |         |
| 18 - <30                       | 70(21.5)         | 98(35.8)                | Reference       |         |  |       | Reference        |         |
| 30- < 40                       | 120(36.9)        | 64(23.4)                | 1.92(1.32-2.80) | 0.003   | 0.687                                  | 0.349 | 1.88 (1.14-3.11) | 0.013   |
| 40 - < 50                      | 74(22.8)         | 58(21.2)                | 1.10(0.73-1.65) | 0.661   | -0.212                                 | 0.339 | 0.81 (0.42-1.57) | 0.532   |
| ≥ 50                           | 61(18.8)         | 54(19.7)                | 0.92(0.61-1.18) | 0.771   | 0.152                                  | 0.350 | 1.16 (0.59-2.31) | 0.665   |
| Income:                        |                  |                         |                 |         |  |       |                  |         |
| < 5000                         | 53(16.3)         | 55(20.1)                | Reference       |         |  |       | Reference        |         |
| 5000- <10000                   | 156(48.0)        | 143(52.2)               | 0.85(0.60-1.13) | 0.306   | -0.230                                 | 0.273 | 0.79 (0.47-1.36) | 0.401   |
| ≥ 10000                        | 116(35.7)        | 76(27.7)                | 1.45(1.01-2.08) | 0.037   | 0.321                                  | 0.295 | 1.38 (0.77-2.46) | 0.277   |
| Breast cancer among relatives: |                  |                         |                 |         |  |       |                  |         |
| None                           | 247(76.0)        | 230(83.9)               | Reference       |         |  |       | Reference        |         |
| Yes                            | 78(24.0)         | 44(16.1)                | 1.65(1.07-2.54) | 0.016   | 0.123                                  | 0.246 | 1.25 (0.87-1.78) | 0.081   |
| Education:                     |                  |                         |                 |         |  |       |                  |         |
| < Secondary                    | 63(19.4)         | 80(29.2)                | Reference       |         |  |       | Reference        |         |
| Secondary                      | 90(27.7)         | 77(28.1)                | 0.98(0.67-1.42) | 0.911   | -0.233                                 | 0.304 | 0.79 (0.44-1.44) | 0.443   |
| College or higher              | 172(52.9)        | 117(42.7)               | 1.51(1.08-2.11) | 0.012   | 0.413                                  | 0.229 | 1.41 (0.91-2.17) | 0.062   |
| Knowledge: < 3                 |                  |                         |                 |         |  |       |                  |         |
| Knowledge ≥ 3                  | 252(77.5)        | 237(86.5)               | Reference       |         |  |       | Reference        |         |
| Knowledge ≥ 3                  | 73(22.5)         | 34(13.5)                | 1.90(1.23-3.13) | 0.002   | 0.342                                  | 0.379 | 1.67 (1.08-2.57) | 0.041   |
| Perceived breast cancer risk:  |                  |                         |                 |         |  |       |                  |         |
| Less/similar                   | 235(73.3)        | 247(90.1)               | Reference       |         |  |       | Reference        |         |
| Higher                         | 90(27.7)         | 27(9.9)                 | 3.50(2.15-5.71) | 0.001   | 0.441                                  | 0.343 | 2.11 (1.61-2.76) | 0.009   |

<sup>1</sup>or Undecided; OR, odds ratio; S.E, Standard error; C.I, Confidence Intervals; Chi-square for the model = 27.968; percent predicted = 69.2; -2 Log likelihood= 676.175; Hosmer and Lemeshow test=11.368, P=0.182.

influential factors on the level of BC genes knowledge among the included women. Women aged 30- <40 years, working, and with college education were significantly more knowledgeable regarding BC genes and their role in BC development, those aged > 40 years showed a significantly lower level of knowledge. Higher family income (≥10,000 SR) and those with positive family history of BC had higher but non significant knowledge level.

#### Women's interest in BC genes testing:

Of the included women 42.8% expressed their interest in BC genetic testing for assessing their BC risk, 11.9% expressed their conditional interest for testing, examples included that genetic testing should be free of charges, in a nearby hospital, in quality laboratory, recommended by the treating physicians, properly explained to overcome test related anxiety and/or fear of positive results, and the presence of husband/family consent. Also, 90.3% of participants expressed their need for more information regarding BC genes and their role in the development of BC. Only 2.3% stated that they have discussed BC gene risk, testing and their implications with their physicians and the stated reason for consultation was due to affection of close family relatives with the disease.

Correlates of women's interest: Table 3 demonstrates the results of univariate and multivariate analysis for the dependent variable (interest in BC genetic testing) through inclusion of the different independent variables including socio-demographics, the presence of family history for BC and the perceived risk for the development

of the disease. Univariate analysis showed that woman interest in genetic testing was significantly influenced by age (30 to <40 years, OR=1.92, P=0.003), higher income (> 10,000 SR, OR=1.45, P=0.037), college education (OR=1.51, P=0.12), the presence of family history of BC (OR=1.65, P=0.016), higher level of awareness about BC genes (OR1.90, P=0.002) and the perceived higher risk for the development of BC (OR=3.50, P=0.001). The effects of income, education and family history of BC were attenuated in the multivariate regression model while being middle aged women (30- <40 years) with more knowledge (score ≥ 3) and perceiving higher risk for BC were the significant positive correlates for Saudi women's interest in BC genetic testing.

## Discussion

The results of the current study should be cautiously interpreted in the lights of the following limitations: Community-based studies considering the interest in BC genetic testing were not conducted in any Arab country, and yet there is no screening program launched for the purpose of testing and individual risk estimation using BC genes. This a preliminary study to determine the level of awareness, interest and educational gap regarding BC genetic testing for the sake of better understanding of the appropriate methods of education tackling the role, the availability, personalized risk, implications of test results in Saudi community and similar countries in the Middle East. Furthermore, there are no yet sufficient studies that explored the

prevalence of BC genes mutation among Saudi women; hence the risk attributed to these markers can not be estimated. The sampled women were included using non-probability rather than random sampling method which may influence the generalizability of the results taking in mind the possible factor of curiosity among those accepted participation and the missing data of the non-respondents which may differ from the participants in the context of awareness, risk perception, interest and socio-demographic characteristics. Additionally, the awareness portion of the questionnaire was based on true/false options with high probability of guessing which we did not control. Also, the potential cultural/psychological factors that may influence the women's interest were not studied. It is believed that the high rate of interest in genetic testing of the women may not adequately reflect the actual demand for testing, since it may only be the expression of their generic interest in modern laboratory procedures or probably reflects their inappropriate knowledge of the information that genetic testing can provide for breast cancer risk analysis (Bruno *et al.*, 2004). Some authors proposed that due to the great attention in the media and the increasing availability of information on the potentialities of genetic approaches may have created expectations regarding genetic tests for determining BC. This does not necessarily imply that the women know the specific test indications, technical limits and, particularly, the uncertainties surrounding the choice of the best post-test preventive clinical options.

This study showed that 19.5% of women had perceived a higher risk to be affected with BC compared to their peers and this perceived risk was significantly more among those < 40 years and with the presence of positive family history of BC.

The perceived risk among included Saudi women is higher than those reported by similar study in Italy where it had been reported that only 9% of participants had higher personal risk compared to their peers and the percentage was higher in women with a family history of breast/ovarian cancer and 21% of the women were continuously thinking /obsessed about the possibility of having cancer (Bruno *et al.*, 2004). The previous figures are low compared to that reported from an Australian community-based study where 50.3% of the included women with familial BC experience had perceived higher risk than those without (Price *et al.*, 2007). They also stated that some women at increased familial risk of BC experienced elevated levels of cancer-specific worry, which can possibly act as a significant factor in decisions regarding risk-reducing surgery. Furthermore, it was found that risk perception appeared to act independently in formulation and impact on cancer-related worry (Price *et al.*, 2007). Arnadottir *et al* (2000) in Iceland found that the sole drive for genetic testing interest was the presence of higher level of cancer-specific distress. Some authors concluded that the stressful impact of recent cancer-related events among family may contribute to the excessive risk perception among women that could

be augmented by lack of education about genetic risk assessment and chances pertained for being BC genes carrier; points should be considered in counseling women with perceived higher risk (Price *et al.*, 2007; Bruno *et al.*, 2004).

Our study showed a huge knowledge deficit of 87.8% among our participants. Those with > secondary education, working and younger age were significantly more knowledgeable while the state of awareness did not affected by the presence of positive family history of BC. Our study demonstrated a poor level of knowledge among the included Saudi women which is consistent findings from previously conducted studies in Western countries (Mouchawar *et al.*, 1999; Donovan & Tucker, 2000) where they found that women (with or without BC) had poor or limited knowledge about the availability of genetic testing (Mouchawar *et al.*, 1999), the information provided by testing, and the implications of testing (Donovan & Tucker, 2000) irrespective of their BC condition. Studies from the developed countries reported a far less knowledge deficits among the included participants of < 60% among Italian and Canadian women (Burno *et al.*, 2004; Brottorff *et al.*, 2002); they have found that the majority of women reported having a certain degree of awareness about BC-related genes.

This discrepancy in BC genes awareness between developed and developing countries can be partially explained by difference in the socio-economic, cultural and health services provided (health education strategies, availability of genetic testing and counseling) in a transitional country like Saudi Arabia compared to situations in developed countries. Our results are line with those found by Bottorff *et al* where age (< 50 years) was a significant positive predictor for awareness towards BC genetic testing while family history of breast and/or ovarian cancer was not positively associated with a better awareness (Bottorff *et al.*, 2002) On the other hand, MacNew *et al* (2010) reported a conflicting results where participants with a family history of BC were significantly more knowledgeable about BC genes. Also, our results are in agreement with those reported from other studies where low levels of knowledge was found among those with < college education (Bruno *et al.*, 2004; MacNew *et al.*, 2010).

In our study almost two thirds of the participants had demonstrated favorable attitude towards BC genetic testing. Similar finding were reported by others, Kenny *et al* (2010) in their qualitative study found that none of their Latino participants had ever heard of BC genetic testing while all participants expressed favorable attitudes toward genetic testing. Also Halbert *et al* (2005) found similar results among different ethnic groups. The successful translation of genetic discoveries from research institutions to clinical care settings will depend on understanding and influencing patient awareness and attitudes, health care system, and societal factors that contribute to the effective uptake of these discoveries (Kenny *et al.*, 2010).

The availability of molecular assays for individualized BC risk evaluation has generated great expectations in the overall population, with a large number of women potentially seeking genetic testing information regardless of their risk profile (Paradiso et al., 2004). Most of the data concerning the interest of women in genetic testing for BC susceptibility was obtained in North America, with highly variable percentages of women interested in genetic testing (Andrykowski et al., 1996; Bottorff et al., 2002) the majority was found in young age (Tambor et al., 1997; Mogilner et al., 1998), and those with previous diagnosis of BC (Cappelli et al., 1999). In this study, 54.7% of participants have expressed their interest in BC genetic testing for assessing their BC risk, significantly more among relatively younger age (< 40 years), with higher socio-economic and educational status. It was proposed that younger women's interest in testing may reflect the perceived implications of a BC diagnosis during mid-life as well as better understanding of genetics because of exposure to developments in science and genetics during their formal education (Bottorff et al 2002).

Studies on the association between interest in genetic testing and family history of BC (Donovan & Tucker, 2000; Kash et al., 2000) or other demographic factors (educational level and work status) (Lerman et al., 1994; Cappelli et al., 1999; Donovan & Tucker DC 2000; ) reported controversial results. In a Canadian study Bottorff et al (2002) found that interest in testing was significantly higher among those < 50 years of age. Personal history of BC, family history of BC, years of education, and knowledge of genetic testing were positively associated with women's interest, low interest was found among women with low knowledge scores. (Bottorff et al., 2002). The results of the current study showed that the interest in BC testing was significantly associated with presence family history of BC, higher level of awareness about BC genes and the perceived higher risk for the development of BC as revealed by univariate analysis; only perceived risk, awareness level and age were remained to be positively correlated to women's interest in the regression analysis model. In Italy, Bruno et al (2004), have found that being married and the presence of psychological distress were significantly associated with a higher interest while family history of BC was found to have no significant impact. Others found that interest in testing was inversely associated with a family history of BC and increasing age (Armstrong et al., 2000). The association between family history of BC and interest in genetic testing are equivocal. Some researchers have reported that interest in genetic testing is higher among those with a family history of BC (Kash et al., 2000; Bruno et al., 2004), others have reported lower levels of interest in individuals with a family history (Andrykowski et al., 1997), and yet others have found no association between interest in genetic testing and a family history of breast or ovarian cancer (Donovan & Tucker, 2000; Bottorff et al., 2002). Bottorff

et al (2002) found that, after controlling for other factors, women with a family history of breast/ovarian cancer were not more likely to express interest in genetic testing than those without. Some authors believed that the high rate of interest in genetic testing of the women studied did not adequately reflect the actual demand for testing, since it may only be the expression of their generic interest in modern laboratory procedures or the curiosity-driven behavior (Bottorff et al., 2002).

The great attention in the media and the increasing availability of information on the potentialities of genetic approaches may have created expectations regarding genetic tests for determining BC (Bruno et al., 2004; Price et al., 2007), the last notion did not necessarily imply that women know the test indications, technical limits and, the uncertainties surrounding the choice of the best post-test preventive clinical options (Bottorff et al., 2002). Despite the enormous limitations of this study, the results may provide important indications for the development of broad-ranging educational strategies for the public to facilitate the BC risk evaluation and informed decision making. Educational material and medical services especially dedicated to such information will soon be available at a lower level of care with the necessity of meticulous tailoring of proper counseling and screening. Matters including implications of test results, and limitations of the testing, the options for risk estimation without genetic testing, the risk of passing a mutation to children, the technical accuracy of the test, the cost of testing, the psychological distress, the risk of labeling, discrimination and options/limitations of medical surveillance following testing should be clearly discussed and included in any future health education programs.

Saudi women expressing high interest in genetic testing for BC risk despite their poor awareness. This great interest may reflect the presence of inappropriate information regarding the BC genetic testing and their role in risk analysis. High interest in BC genetic testing could be attributed by the presence exaggerated perceived personal risk due to lack of proper health education program and deficiency in health counseling services.

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