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Young women perceptions towards genetic testing of breast cancer

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Abstract

The objective of this study was to explore the perceptions of young women towards genetic testing for breast cancer. An in-depth interview was conducted among 26 young women who were chosen randomly from the Faculty of Health and Life Sciences (FHLS), Management and Science University (MSU), Shah Alam, Malaysia. Writing the answers of the participants was used with participant permission to make notes about her answer and the interview took approximately 40–60 minutes. The majority of the study participants (85%) knew about the genetic test of breast cancer. Regarding the source of the information, 8 (30.8%) reported that they knew about the genetic test of breast cancer from the internet, followed by 7 (26.9%) from lecturer, 4 (15.4%) from textbooks, 3 (11.5%) from newspapers, 2 (7.6%) from magazines, and 1 (3.8%) from her friend. Most of the participants 23 (88.5%) mentioned that they would introduce the genetic test of the breast cancer to their families and friends. However, 3 (11.5%) mentioned that they would not recommend breast cancer genetic test to their families and friends. In conclusion, majority of participants knew about the genetic test of breast cancer. The majority of the young women were willing to perform breast cancer genetic test because they were concerned about their health, considering the genetic test of the breast cancer as a prevention measure, positive family history of breast cancer and for early detection. About quarter of participants reported that they would not perform any genetic test in the future because of the cost of the test, no family history of breast cancer, knowing the future diseases would make the life miserable, impact of the genetic test on quality of life, and the test had not been recognized yet.

Keywords: Perceptions; young women; genetic testing; breast cancer.

Introduction

Breast cancer is the most prevalent cancer worldwide with about 1 million new cases annually (Parkin *et al.*, 2005). In Malaysia, the second report of the National Cancer Registry indicated that the incidence rate of breast cancer in Malaysian women was 46.2 per 100,000 populations (Lim and Halimah, 2004). This is low compared to 130 per 100,000 populations in USA. Despite a low incidence when compared to other countries, breast cancer is one of the most common cancer among Malaysian women constituting 31% (3,738 cases) of all cancers in women, in 2003. Breast cancer in Malaysia could be considered as the leading cause of cancer deaths among women (Yip and Ng, 1996). Overall, 1 in 20 women of Malaysia will have breast cancer in their lifetime.

Genetic testing to predict breast cancer by means of *BRCA1* and *BRCA2* is quite new. In September 1994, scientists isolated a breast susceptibility gene, known as *BRCA1*, on chromosome 17 (National Cancer Institute, 2002). About 5–10% of cancers are due to heredity and single gene mutations. Women born with mutations in either *BRCA1/2* are at significantly higher risk of developing breast cancer than women in the general population (King *et al.*, 2003). The presence of the *BRCA1/2* genes does not state that an individual will develop breast cancer but only she/he possesses the gene. Carriers of *BRCA1/2* mutations have an probability of 80% breast cancer by the age of 70 years (Ford *et al.*, 1998). The officials of the Human Genome Project and the National Cancer Institute discourage public use of the *BRCA1/2* genetic test. Such officials recommend only the clinical

use of a genetic test that predicts a disease with a proven cure; whereas breast cancer has no proven cure yet. Because nothing is known yet about the sensitivity, specificity, and reliability of the genetic tests and a little is known about the effectiveness of genetic or psychological counseling. In this context, genetic screening should only be available to individuals who agree to join peer review (National Cancer Institute, 2002). Use of genetic testing for individuals with high risk for developing breast cancer is increasing which helps in the prevention of development of cancer with control strategies. Genetic testing is now clinically available, and may identify cancer patients with a hereditary predisposition who may be at risk for second malignancies and may benefit from additional surveillance or preventive options. In the last decade, a number of distinct hereditary cancer syndromes and their causative genes have been defined, including the hereditary breast cancer syndrome due to the *BRCA1/2* genes (Miki *et al.*, 1994; Wooster *et al.*, 1994). In addition, predictive testing may be carried out for the cancer-free family members of proven mutation carriers to determine their risk status and accord appropriate surveillance or preventive recommendations (American Society of Clinical Oncology, 2003; Burke *et al.*, 1997; Meijers-Heijboer *et al.*, 2001; Rebbeck *et al.*, 2002). Studies from different countries have shown that genetic testing is being accepted by the general public (Berth *et al.*, 2002; Human Genetics Commission, 2001; Shaw and Bassi, 2001). One of the barriers among Asian women is Asian culture. A study has shown that traditional Chinese family beliefs may influence attitude towards health care and create barriers to optimal service utilization (Eisenbruch *et al.*, 2004). Evidence-based primary prevention strategies for high risk women include chemoprevention with paclitaxel or other selective estrogen receptor modulators (SERMs) and prophylactic surgeries such as bilateral oophorectomy and/or bilateral mastectomy, which entail 50–90% risk reduction for new primary breast cancers (Robson, 2002; U.S. Preventive Services Task Force, 2002; Grann *et al.*, 2002; Schrag *et al.*, 2000). No previous study conducted about the perceptions of young women towards genetic testing for breast cancer in Malaysia. The objective of this study was to explore the perceptions of young women towards genetic testing for breast cancer.

Methods

An in-depth interview was conducted among 26 young women. The convenience sampling from the Faculty of Health and Life Sciences (FHLS) during the academic year 2009 at Management and Science University (MSU), Shah Alam, Malaysia to explore the young women's opinion about the genetic test of breast cancer. They were chosen randomly from the FHLS during the study period by going to the different departments in the faculty namely: Medical Science, Pharmacy, and Biomedicine and chosen randomly by waiting for them to finish their classes and introducing them to the study and its purpose. The inclusion criteria were young women older than 20 years, can speak English, and Malaysian citizen. This study was approved by the ethics committee of MSU. The exclusion criteria were women younger than 20 years old and foreign students. Those who were willing to participate were invited to the library or food court of the university campus to conduct the interview with her. Writing the answers of the participants was used with participant permission to make notes about her answer and the interview took approximately 40 minutes. The main questions asked were: Do you know breast cancer genetic test? What is the source of information about breast cancer genetic test? Are you willing or not willing to perform breast cancer genetic test in the future? If yes please give the reason(s); if no please give the reason(s). Are you going to introduce the genetic test of breast cancer to your family and friends or not? (Please specify the reason(s)). The interviewers followed the standardized protocol to ensure that all the interviews conducted in a similar manner with an identical set of questions were discussed. The obtained data were sorted into various categories based on content analysis. Due to the small sample size, the data was analyzed manually.

Results

The total study participants include 26 young women, with ages ranging from 18 to 30 years. Half of the participants 13 (50%) were less than 23 years old. The majority of the participants were Malay 11 (42.3%), followed by Indian 9 (34.6%), Chinese 5 (19.2%),

Table 1: Socio-demographic characteristics of the study participants (n = 26).

Variable		Frequency (F)	Percentage (%)
Age (years)	<23	13	50
	≥23	13	50
Race	Malay	11	42.3
	Indian	9	34.6
	Chinese	5	19.2
	Others (Iban)	1	3.9
Marital status	Married	1	3.9
	Single	25	96.1
Family residence	Urban	20	76.9
	Rural	6	23.1
Family monthly income (RM)	<5000	16	61.5
	≥5000	10	38.5
Father's job	Professional	18	69.2
	Non-professional	8	30.8
Mother's job	Professional	7	26.9
	Non-professional	19	73.1

and others 1 (3.9%). Most of the participants 25 (96.1%) were single and 1 (3.9%) was married. The majority of the participants 20 (76.9%) were from the urban areas and 6 (23.1%) were from the rural areas. Most of the participants 16 (61.5%) had monthly family income less than RM 5000 and 10 (38.5%) of them had monthly family income more than RM 5000. The majority of the participants 18 (69.2%) stated that their fathers were professionals and 8 (30.8%) participants stated that their fathers were not professionals. The majority of the participants 19 (73.1%) stated that their mothers were not professionals and 7 (26.9%) stated that their mothers were professionals (Table 1).

Knowledge about breast cancer genetic test?

The majority of the study participants 22 (85%) knew about the genetic test of breast cancer and 4 (15%) of the study participants did not know about the genetic test of breast cancer.

The source of the information about breast cancer genetic test

Eight (30.8%) participants reported that they knew about the genetic test of breast cancer from the internet, followed by 7 (26.9%) who knew from their lecturer, 4 (15.4%) from the textbooks, 3 (11.5%) from the newspapers, 2 (7.6%) from the magazines, and 1 (3.8%) from

her friend. Below are some quotations from the participants' answers regarding their source of the information:

"I learned about genetic test from the genetic disorder class." (Malay, 20 years old, Urban, Single)

"I learned about the genetic test during my course subjects and through the internet especially from the YouTube." (Indian, 24 years old, Rural, Single)

"I have learned about genetic test through my lecturer and during my assignments." (Indian, 24 years old, Urban, Single)

"I read about the breast cancer genetic test from the internet." (Chinese, 25 years old, Urban, Single)

"I learned about breast cancer genetic test in breast cancer awareness campaign." (Indian, 30 years old, Urban, Married)

Attitudes towards performing breast cancer genetic test

Regarding the willingness of the young women to perform breast cancer genetic test in the future, 19 (73.1%) reported that they were willing to perform the genetic test in the future. However, 7 (26.9%) reported that they were not willing to perform any genetic test in the future.

The reasons given for those willing to perform the genetic test in the future were: concern about their health, considering the genetic test of the breast cancer as prevention measures, positive family history of breast cancer, and for early detection. Below are some quotations from the participants' answers regarding their willingness to perform the genetic test:

"It is important for my good health." (Chinese, 25 years old, Urban, Single)

"Nowadays, many women are prone to breast cancer therefore safety precaution in order to detect the possibilities of getting breast cancer." (Indian, 24 years old, Rural, Single)

"Because my aunt was diagnosed with breast cancer so I am afraid." (Chinese, 23 years old, Urban, Single)

"I will do the breast cancer genetic test to detect breast cancer at early stage." (Malay, 24 years old, Urban, Single)

"I would like to do the breast cancer genetic test to know whether I am a cancer patient or not." (Indian, 19 years old, Urban, Single)

The reasons given for those who were unwilling to perform the genetic test in the future were: the cost of the test, no family history of breast cancer, knowing the future diseases would make the life miserable, impact of the genetic test on quality of life, and as the test had not been proven yet. Below are some quotations from the participants' answers regarding their unwillingness to perform the genetic test:

"I am not willing to do such test in the future because it is expensive." (Malay, 25 years old, Urban, Single)

"I am not going to do the breast cancer genetic test in the future because there is no family history of breast cancer in my family." (Malay, 20 years old, Urban, Single)

"I do not prefer to perform breast cancer genetic test in the future because the life will become miserable; better to live your life without knowing any kind of diseases you will have in the future." (Indian, 22 years old, Urban, Single)

"If the breast cancer genetic test positive this will affect quality of life and living with

depression." (Malay, 20 years old, Urban, Single)

"Because the breast cancer genetic test still not recognized yet as a 100% confirmation of getting breast cancer even after going through the analysis." (Chinese, 24 years old, Rural, Single)

Introduce breast cancer genetic test to the family

When the participants were asked whether they would introduce the genetic test of breast cancer to their families and friends, most of them 23 (88.5%) mentioned that they would recommend the test to their families and friends, and 3 (11.5%) mentioned that they would not recommend the test to their families and friends.

The reasons given by those who were ready to recommend the breast cancer genetic test to their families and friends were: prevention, awareness, and responsibility to share knowledge regarding the health. The test can save and prolong life and reduce the death rate. Below are some quotations from the participants' answers who were ready to recommend the genetic test for breast cancer to their families and friends:

"To help them identify their health condition and the prevention." (Indian, 25 years old, Urban, Single)

"For prevention, since there are older members in my family who might be at the risk of getting breast cancer." (Indian, 24 years old, Rural, Single)

"I will recommend the breast cancer genetic test for my family and friends to make them conscious and aware about the disease." (Chinese, 23 years old, Urban, single)

"It is my responsibility to share my knowledge with my family and friends about our health status among women." (Indian, 24 years old, Urban, Single)

"I would like to know if in the future any one of my family and friends will have breast cancer." (Indian, 19 years old, Urban, Single)

"Sure I will recommend the breast cancer genetic test to my family and friends because it could save life and prolong lives." (Malay, 22 years old, Urban, Single)

"I will recommend the breast cancer genetic test to my family and friends to reduce the rate of death among my family members

and friends.” (Indian, 30 years old, Urban, Married)

The reasons given by those who were not ready to recommend the breast cancer genetic test to their families and friends are: the cost of the test and as it was not recognized as an accurate test. Below are some quotations from the participants' answers who were not ready to recommend the genetic test for breast cancer to their families and friends:

“I will not recommend this test either to my family nor friends due to the high cost of the test.” (Malay, 20 years old, Single)

“I will not recommend this test to my family and to my friends because it is not accurate test.” (Chinese, 24 years old, Rural, Single)

Discussion

Eight (30.8%) participants reported that they knew about the genetic test of breast cancer from the internet. This may be due to internet as one of the main sources of information nowadays. Regarding the willingness of the young women to perform breast cancer genetic test in the future, 19 (73.1%) stated that they were willing to perform the genetic test in the future. This may be due to the fact that the participants in this study had a health science background. A similar finding reported by Lerman *et al.* (1994) stated that 91% of the participants said that they would want to be tested for susceptibility to breast cancer, 4% would not, and 5% were uncertain. A similar finding by Chaliki *et al.* (1995) reported that in a study at the National Cancer Institute, 23 (79%) indicated that they want to be tested and 7 (26.9%) that they would not perform any genetic test in the future. This may be due to the culture and traditional family beliefs aspects such as cancer being taboo which may create significant barriers to cancer risk predictions (Eisenbruch *et al.*, 2004; Glanz *et al.*, 1999).

The reasons given for those who were not willing to perform the genetic test in this study were: the cost of the test, no family history of breast cancer, knowing the future diseases makes the life miserable, impact of the genetic test on quality of life, and the test had not been recognized yet. A similar finding was reported by Durfy *et al.* (1999) found that Caucasian women mistrust medical professionals and feel

that genetic tests are not accurate. Similar finding reported that all women stressed the importance of cost of genetic counseling as a potential inhibiting the decision to receive it (Ford *et al.*, 1998). Furthermore in other studies, the issue of cost was cited to be an important possible barrier (Salant *et al.*, 2006; Lee *et al.*, 2002; Durfy *et al.*, 1999).

The finding of this study showed that the reason of participants not willing to perform breast cancer genetic test was due to anxiety and depression. A similar finding reported by Phelps *et al.* (2007) that the main concern of individuals regarding genetic test is fear of how they would cope with being at risk. Hence, interventions designed to improve an individual's perceived ability to cope with cancer genetic risk assessment and its implications may help to reduce distress (Berkenstadt *et al.*, 1999; Codori *et al.*, 1999; Vernon *et al.*, 1999).

Willingness to inform the family about the availability of testing and the decision to contact relatives and friends about the cancer family risk rated very high in this study. A similar finding was reported by Julian-Reynier *et al.* (1996).

Conclusion

Majority of the study participants knew about the genetic test of breast cancer. The majority of the young women were willing to perform breast cancer genetic test because they were concerned about their health, consider the genetic test of breast cancer as a prevention measure, and a positive family history of breast cancer. About 26.9% of the participants reported that they would not perform any genetic test in the future because of the cost of the test, no family history of breast cancer, knowing the future diseases would make the life miserable, impact of the genetic test on quality of life, and as the test had not been recognized yet. Educating the young women and the public regarding genetic test is crucial. Further studies among women from general population are required in the future.

Ethical Approval

This study has been approved by the ethics committee of Faculty of Health and Life Sciences (FHLS), Management and Science University

(MSU), Shah Alam, Malaysia. Every student has been informed about the purposes, tasks of the research, and agreed to take part in it.

Conflict of Interests

None declared.

Authors' Contributions

Both authors contributed equally to this study.

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