RESEARCH ARTICLE

Study of Relationship Between Illness Perception and Delay in Seeking Help for Breast Cancer Patients Based on Leventhal's Self-Regulation Model

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Abstract

One of the major causes of morbidity and mortality in breast cancer patients is delay in seeking help. Leventhal's self-regulation model provides an appropriate framework to assess delay in seeking help. The aim of this study was to investigate the relationship between "illness perception" and "help seeking delay" in breast cancer patients based on Leventhal's self-regulation model. In this correlational descriptive study with convenience sampling conducted in 2013, participants were 120 women with breast cancer who were diagnosed in the last year and referred to chemotherapy and radiotherapy centers in Rasht, Iran. Data collection scales included demographic data, Revised Illness Perception Questionnaire (IPQ-R)and a researcher made questionnaire to measure the delay in seeking help. Pre-hospital delay (help seeking delay) was evaluated in 3 phases (assessment, disease, behavior). The data were analyzed using SPSS-19. The mean (SD) age calculated for the patients was 47.3±10.2. Some 43% of the patients had a high school or higher education level and 82% were married. The "pre-hospital delay" was reported ≥3 months. Logistic regression analysis showed that none of the illness perception components were correlated with appraisal and behavioral delay phases. In the illness delay phase, "time line" (p-value =0.04) and "risk factors"(p-value=0.03) had significant effects on reducing and "psychological attributions" had significant effects on increasing the delay (p-value =0.01). "Illness coherence" was correlated with decreased pre-hospital patient delay (p-value<0.01). Women's perceptions of breast cancer influences delay in seeking help. In addition to verifying the validity of Leventhal's self-regulation model in explaining delay in seeking help, the results signify the importance of the "illness delay phase" (decision to seek help) and educational interventions-counseling for women in the community

Keywords: Breast cancer - illness perceptions - delay in seeking help - self-regulation - Leventhal's model

Introduction

Breast cancer is the most common cancer, the leading cause of cancer death among females, accounting for 23% of the total cancer cases and 14% of the cancer deaths (Jemal et al., 2011). The age incidence of this disease in Iran is almost one decade younger than that of the developed countries (Afsharfard et al., 2013; Rezagholi et al., 2015). Breast cancer diagnosis is one of the most devastating incidents that may occur during a woman's life. Women with breast cancer often face severe psychological distress as a result of awareness of their diagnosis and it may last during the entire treatment period (Shields and Rousseau, 2004; Yusuf et al., 2013).

Studies have shown that negative perceptions of illness are associated with increased future disability and a slower recovery, independent of the initial medical severity of the condition (Pearman, 2003; Montazeri, 2009).

Some behavior interventions designed to change the perception of patients, resulted in significant positive changes in patient's belief during hospitalization, earlier return to work, adhering to screening and treatment programs, better quality of life and longer survival (Shabahang et al., 2011). Petrie and Weinman in their study revealed that evaluation and perception of symptoms are crucial since they affect future behavior of a patient. It is also one of the most important variables in predicting help-seeking delay in patients with breast cancer symptoms (Petrie and Weinman, 2003). Thus, interpretation of symptoms, as the most important step, has a significant impact on patient's delay in seeking treatment (Khakbazan et al., 2014a).

One of the major causes of morbidity and mortality in breast cancer patients is delay in seeking help and consultation (Norsa'adah et al., 2012). Nearly 70 percent of Iranian women are in the advanced stages of

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the disease at the presentation time (Harirchi et al., 2005) when many of whom die within a short period of time (Behjati et al., 2005; Mohebbi et al., 2013). Therefore, delay in diagnosis and treatment is an important issue that can lead to disease progression, reduced survival rate, and eventually increased morbidity and mortality (Yip et al., 2006; Akhtari-Zavare et al., 2013; Yip et al., 2014).

Patients' delay (Pre-hospital delay) is said to the interval between first detection of sign or symptom and initial medical consultation (Leventhal et al., 2001; Bish et al., 2005; Yusoff et al., 2011; Khakbazan et al., 2014b).

Andersen et al (1995), pointed out 3 phases of patient's delay according to Psycho-physiological comparison theory: 1- appraisal delay: once the detection of symptoms and disease (time interval between symptom detection and illness inference); 2- Illness delay: the time interval between illness perception (as breast cancer) and decision to seek help(seek medical care); 3- Behavioral delay: the time interval between decision to seek help and implementation of decision (Andersen et al., 1995).

Delay in seeking help for patients with symptoms of breast cancer in phase "pre-hospital delay" influenced by 3 factors listed: 1) social and demographic factors: age, ethnicity, family history, socio-economic status; 2) clinical factors such as type and nature of the symptoms of breast cancer; 3) psycho-behavioral factors: one of the psychological and behavioral variables in patients' delay is "the perception of symptoms". The perception of the consequences of disease symptoms led to coping reactions in form of seeking help (Leventhal et al., 2001; Macleod et al., 2009).

Leventhal's self-regulation model provides a proper framework to assess pre-hospital delay (patient delay) and help seeking related decisions. According to the self-regulation model, internal stimuli (e.g. experiencing symptoms) and the stimuli from the environment (e.g. information about the risks and observation of the illness in her or his relatives) may cause cognitive and emotional representation, and a person, based on the representation, adopts an action plan to deal with the threat is perceived (Leventhal, 1979). Leventhal believes that any component of illness perception can affect help seeking behavior of women regarding breast cancer symptoms. In fact, women's decision, when evaluating breast cancer symptoms, is affected by Perceived symptoms of illness (Cognitive representation of the disease) and emotional characteristics (emotional representations) (Leventhal et al., 2003).

According to Leventhal et al, individuals develop their experiences in illness conditions within 5 content domains (Leventhal et al., 1997):

1) Identity: statements regarding beliefs about the illness label and knowledge about its symptoms.

2) Cause: beliefs regarding the factors that are responsible for the disease or illness (medically, it may not be completely accurate).

3) Time lines: beliefs regarding the course of the illness. Belief forecasts about this disease on how long it will occur, progress or last).

4) Consequences: beliefs regarding the impact of illness on quality of life and functioning.

5) Cure /controllability: the sensation of empowerment regarding performance of coping behaviors or efficacy of treatment.

Then, the measure was revised to include measures of perceptions regarding duration of illness ('acute/chronic') and fluctuation in illness over time ('time line cyclical'). In addition, the revised version distinguishes perceptions of 'treatment control' and 'personal control' over illness. The revised version includes a new measure of 'illness coherence' – how clear and comprehensive an individual feels her illness to be. A new measure of 'emotional representations' is also included (Moss-Morris et al., 2002).

Illness perception is different from one patient to another. Even in cases where patients have the same condition, their viewpoints about the illness may be very different (Petrie et al., 2007). Khan et al (2015) reported that Significant number of women with breast cancer in North Pakistan experience presentation delay due to their misconceptions about the disease. Yusuf et al (2011) in a study in 2011 stated that delay in presentation of early treatment of breast cancer is actually influenced by a complex interaction of demographic, clinical, cognitive, behavioral and social factors. In a study in 2009, Macleod et al (2009) concluded that non-recognition of symptom seriousness is the main patient-mediated factor resulting in increased time of presentation. Fear of cancer is a contributor to delayed presentation (Macleod et al., 2009; Rastad et al., 2012). In Masoudnia's study (2008), there was a direct correlation between emotional representations and appraisal delay (p<0.05), and a reverse correlation between illness consequences and appraisal delay (p<0.05). He concluded that women's illness perceptions of breast cancer symptoms have significant effects on seeking help, particularly, in the symptom appraisal phase (Masoudnia, 2008).

We need to better understand the factors that might lengthen or shorten the time taken by patients to seek help for symptoms (Macleod et al., 2009). The aim of this study determine the relationship between "illness perception" and "help seeking delay" and also to identify factors contributing to "help seeking delay" in patients with breast cancer symptoms based on Leventhal's self-regulation model. Understanding current status will help designing interventions such as educational and treatment programs, in order to reduce barriers to seeking help and eventually no delay in seeking help.

Materials and Methods

This is a correlational descriptive study with Convenience Sampling, conducted in the private sector (Gil oncology and radiotherapy center) and public centers (Razi hospital and Besat clinic) in Rasht, Iran in 2013.

Eligibility to participate was based on:

1) Iranian nationality.

2) Breast cancer confirmed by tissue diagnosis (stage 1 to 4).

3) Maximum of one year had passed since cancer diagnosis by pathological test.

4) Orientation to time, place and person.

5) Be able to speak Persian.

Proper sample size was 120 women.

To observe ethical issues in this study, explanations about the importance and objectives of the study were given to participants before signing written consent form for research. Also they were informed that, if desirable, they could be notified of the results.

Data collection scales included the following:

a)   Demographic data questionnaire, to gather the date regarding age, marital status, education, job, the average income, number of pregnancy terms, family history of breast cancer, history of benign breast diseases, any other disease, and the first symptoms detected.

b)   Revised Illness Perception Questionnaire (IPQ-R).

c)   A researcher made questionnaire to measure the delay in seeking help (by using existing resources).

IPQ-R questionnaire was used to measure three domains: cognitive representations of illness (part of cognitive questionnaires, emotional representations of illness (emotional part of the questionnaire) and causal attributions of the illness. The questionnaire consists of 12 components of cognitive domain (representational perception of illness), including seven components: illness identity, Timeline acute / chronic, Timeline cyclical, Serious Consequences of the disease, treatment control, personal control, illness coherence (a clear understanding of the illness). Representations of the emotional component of the illness to assess the patients' emotional reactions to the disease (relatively independent of the patients'mood state) are used. Domain of "illness causal beliefs" includes four components: psychological attributions, factors related to the immune system (Immunity), risk factors and accident or chance. All Scales Questionnaire IPQ - R (other than illness identity component is a Yes / No type),were based on a five-point Likert scale (strongly agree, agree, neither agree nor disagree, disagree, strongly disagree.

Illness Perception Questionnaire constructors (Moss-Morris et al., 2002) reported a validity of ≥ 0.8 for all subscales using Cronbach alpha. Different versions of the questionnaire "illness perception" were used according to the research objectives of the study and the type of disease (Moss-Morris et al., 2002). This tools have been translated to Persian by Qhasemzadeh and colleagues at the Center for Science in cognition- behavior and culture, and has a total of 94 items (Qhasemzadeh). Several studies have demonstrated the validity of the IPQ-R questionnaire (Bish et al., 2005; Masoudnia, 2008; Shabahang et al., 2011). Masoudnia's study (2008) used the 43-item version of the questionnaire for breast cancer, and its reliability has been examined (Masoudnia, 2008). In the present study, regarding the purposes of this research and later confirmed by the faculty and examine the validity (CVI and CVR), we used the version with 62 items derived from the questionnaire that included 8 questions about the illness identity as Yes or No answer given, 38 items with the general title "view of the illness ", and 16 items on the "Causes" are defined as a 5-point Likert .

In this study, reliability of the questionnaire was assessed using test-retest method in 15 days for 10 patients. These 10 patients were excluded in the final stage of sampling. Interclass Correlation Coefficient (ICC) for all items in the Questionnaire obtained from $r = 0.8$ (at least) to $r=1$ (maximum). Thus, consistency and reliability in all fields of questionnaire were verified (ICC> 0.7).

In the present study, according to Studies (Leventhal, 1979; Andersen et al., 1995; Masoudnia, 2008), evaluation of patient delay (pre hospital delay) Was examined in 3 phases:

Table 1. Demographic Characteristics of the Study

Demographic item	Value	percentages
Age (mean±SD)	47.3±10.16	
Income (mean±SD)	6,800,000± 2,500,000 Rial	
Education		
Primary school	23.0	19.0
Secondary Level	31.0	26.0
High school and University degree	51.0	43.0
Marriage status		
Single	6.0	5.0
Married	98.0	82.0
widow	9.0	7.0
Divorced	7.0	6.0
Employment		
Employed	16.0	13.0
Household	88.0	74.0
farmer	16.0	13.0
Number of term pregnancy		
zero	13.0	11.0
3 ≥	81.0	67.5
≥ 4	26.0	21.5
Family history of breast cancer (yes)	29.0	25.0
History of benign breast disease (yes)	18.0	15.0
History of other diseases (yes)	32.0	27.0

Table 2. Distribution of Participants in the Study Based on Triple Phases of Patient Delay

Frequency of Delay Phases (≥3month)	No	Percentages
Appraisal delay	22.0	18.0
Illness delay	26.0	22.0
Behavioral delay	15.0	12.5
Total of patient delay (pre hospital delay)	63.0	52.5

Table 3. Regression of Demographic Variables and Illness Perception Domains, with Illness Delay Phase

Variables and components correlated			*p-value	"The odds ratio (OR)"	"95% confidence interval for OR (CI)"
domains of illness perceptions	Cognitive representations	Timeline cyclical	0.04	1	0.93 - 1
	Emotional representations	-	-	-	-
	Causal beliefs	Psychological attribs	0.01	1.1	1.01 – 1.12
		Risk factors	0.03	0.9	0.88 – 1
Demographic variable		Education	<0.001**	0.0	0.01 – 0.19

Only variables that were statistically significant, are shown in the table ;* (p-value < 0.05); ** (p-value < 0.001)

Table 4. Regression of Demographic Variables and Illness Perception Domains, with "Pre-Hospital Delay" Phase

Variables and components correlated			*p-value	"The odds ratio (OR)"	"95% confidence interval for OR (CI)"
domains of illness perceptions	Cognitive representations	Illness coherence	0.01	1.0	0.95 - 0.99
	Emotional Representation	_	_	-	-
	Causal beliefs	_	_	-	-
Demographic variable		Marriage status	0.02	6.7	1.3 – 33.1

*Only variables that were statistically significant, are shown in the table (p-value < 0.05).

1) Appraisal delay: How long did it take to find out if this is a sign of breast cancer since you found the first sign?

2) Illness delay: How long did it take to seek medical care since you found the first sign?

3) Behavioral delay: How long did it take to make an appointment and see a physician since you decided to seek medical care?

Delays of 3 months or more adversely affect survival (Richards et al., 1999; Bish et al., 2005). Therefore, patients were divided into two groups of less than 3 months and more (or equal) than 3 months delay in seeking help. Content validity of questionnaire has been evaluated based on opinions of ten professors and professionals from Giulan University of Medical Sciences and Shahid Beheshti University of Medical Sciences.

Data were analyzed using SPSS software (19th version). Descriptive statistics and analysis were used to determine mean of: age, income and perception component scores. Average scores for each of the components were calculated in percentages. Pearson and Spearman correlation were used to investigate the correlation between demographic variables and illness perception components with triple delay phases. T-test was applied to determine the relationship between demographic variables and the components of "illness perception" with triple phases of patient delay and The Mann-Whitney - U test was usedto check the correlation between education and triple phases of patient delay.

Pre-hospital delay (help seeking delay) was evaluated in 3 phases (assessment, illness, behavioral) .In order to predict the delay in seeking help, logistic regression was used. Therefore, each of triple phases of patient delay, separately, with demographic variables and illness perception components entered into the regression. Then, logistic regression was used to evaluate the impact of perception components on patient delay phase. Each of triple phases of "patient delay" as a binary codes (0 and 1) entered into the regression (Code = zero : delay less than 3 months, code 1 = delay equal to or more than 3 months).

Results

A total of 120 breast cancer patients constituted the study sample. Table-1 shows demographic characteristics. As Table 1 illustrates that the mean (SD) age calculated for the patients was 47.3 ± 10.2 82% of the patients were married, and 43% of them had a high school diploma and university degree. 52.5 % of participants reported ≥3 month patient delay in pre hospital phase (Table 2).

As Figure 1 demonstrates they had poor understanding of the illness (illness coherence= 40%). The majority of participants believed that there is a low chance of disease recurrence (Timeline cyclical= 39%). They also reported a lot of worry and emotional representations along with depression, anxiety and fear (Emotional representations=71%). Most of the patients strongly believed in the effect of dietary habits (risk factors = 67%), stress and family troubles (Psychological attributions=61%) in developing breast cancer.

Logistic regression analysis showed that none of the components were correlated with appraisal and behavioral delay phases (p-value <0.05).

Results illustrated in Table 3 revealed that in illness delay phase, each one unit increases in the mean score of "Timeline cyclical" on a scale of 0 to 100 delay risk decreases by 4%. In other words, patients who perceived breast cancer as a disease with a low chance of disease
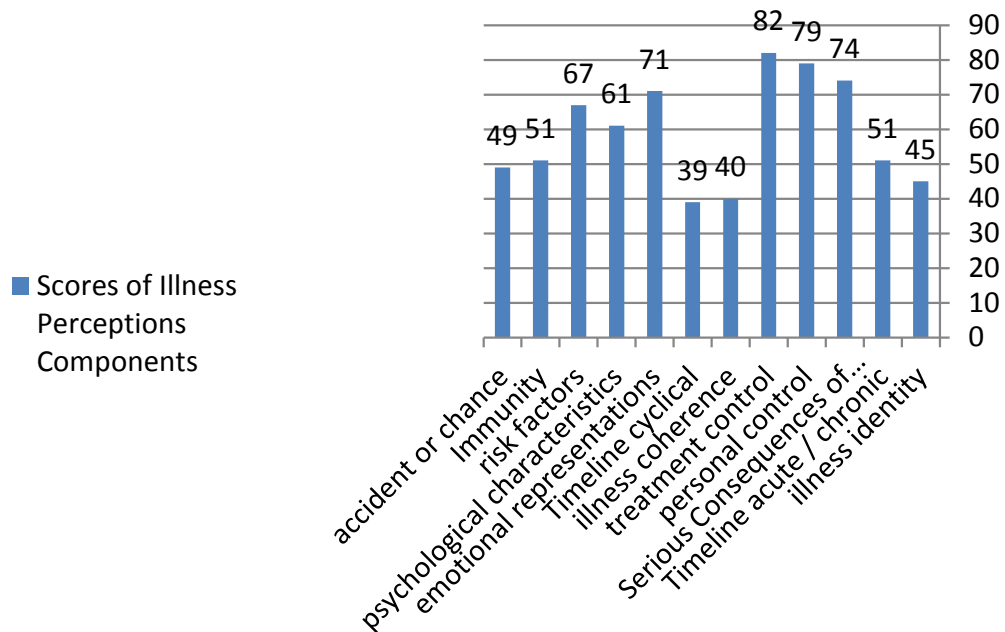
Figure 1. Distribution of "Illness Perception" in Patients (Percent).
0-19% (none or very low), 20-39% (moderate), 60-79% (high), 80-100% (severe, very much).

recurrence had less delay in this phase. Each single unit increase in the mean score of "Psychological attributions" on a scale of 0 to 100, delay risk increases by 6% and with each single unit increase in the mean score of "risk factors", delay risk decreases by 7%. It means that patients who had regarded" Genetics, dietary habits, smoking and tobacco" as breast cancer risk factors, had less delay in this phase.

The results of Table 4 show with each single unit increase in mean score of "Illness Coherence", pre-hospital delay risk reduces by 3%, which means that patients who had higher mean score in "Illness Coherence" (had better understanding of breast cancer), had less delay than other patients.

Discussion

In the present study, pre-hospital delay (help seeking delay) was evaluated in 3 phases (appraisal, disease, behavioral). The mean (SD) age calculated for the patients was 47.3±10.2، 43% of the patients had a high school or higher education and 82% of them were married. The frequency of "pre-hospital delay" was reported to be ≥3 months. Results of Logistic regression analysis showed none of the illness perception components were correlated with appraisal and behavioral delay phases. In illness delay phase, "Timeline"(p-value =0.04) and "risk factors"(p-value=0.03) had significant effect on reducing and "psychological attributions" had significant effect on increasing the delay (p-value =0.01)."Illness coherence "was correlated with the decreased pre-hospital patient delay (p-value = 0.01).

In the present study, the majority of patients had high school or college education (43%). In a study by Masoud-nia (2008) the highest frequency (42%) belongs to patients with primary education. Similarly other studies reported

an association between low education level and patient delay (Harirchi et al., 2005; Macleod et al., 2009; Ermiah et al., 2012; Mohaghegh et al., 2015). Ebrahimi et al (2008) reported that education level is the most effective factor influencing referral time of patients after appearance of the first symptom. Also, low education is associated with low social support and lack of awareness of health (Macleod et al., 2009; Monfared et al., 2013). Lack of awareness and knowledge about the symptoms and risk factors for breast cancer, leading to delay presentation (Khakbazan et al., 2014b; Yu et al., 2015).

Casual beliefs can affect the adaptation of the patient to the illness (Aspinwall and MacNamara, 2005; Büssing and Fischer, 2009). In the present study, patients who perceived factors, such as stress and family troubles as a cause of disease, had increased risk of delay in illness phase. This is consistent with the findings of Nielsen and his colleagues (2005). They reported that women at risk of breast cancer believe that psychological factors influence on the development of breast cancer which may lead to lack of participation in early detection and screening programs. Moreover, breast cancer patients who attribute their disease to psychological factors may experience more difficulty in adaptation with disease (Nielsen et al., 2005). Also, those who believe that stress cause cancer, may not considered themselves at risk because they have not experienced much stress in their life (Leventhal et al., 1984). Mental Stress interact with the endocrine gland's operation, so it seems that the stress is related to breast cancer more than any other cancer (Butow et al., 2000). Depressed mood and disappointment are significantly associated with breast cancer (Montazeri et al., 2004).

Petralia et al (1999) Showed that exposure to passive smoking increases the risk of breast cancer. In some other investigations, lifestyle, nutrition, reproductive and genetic factors have been mentioned as risk factors

for breast cancer (Yip et al., 2006; Peltzer and Pengpid, 2014; Noreen et al., 2015). Also, poor knowledge of risk factors among women in Malaysia (Che et al., 2014) has led to the delay in presentation (Yip et al., 2014; Yu et al., 2015). In the present study, patients who regarded factors such as genetics, dietary habits, smoking and tobacco as a cause of breast cancer (risk factor) experienced less delay in "illness delay" phase. The probable explanation could be lack of awareness of the risk factors; also environmental and cultural poverty, for early diagnosis (FathiNajafi et al., 2005; Macleod et al., 2009) will lead to delay in seeking help.

Generally in pre hospital delay phase: in the present study, patients with clearer perception about the disease (illness coherence) experienced less delay in help seeking. The results are consistent with results of the studies by Masoudnia (Masoudnia, 2008) and Burgess et al. (Burgess et al., 2001). Patients who have a greater understanding of their disease were able to care for themselves better than other patients and they get information required to treat their disease (Asadi et al., 2012), so they will have less delay (Taib et al., 2011; Yusuf et al., 2013).

Bhosai et al (2011) found no statistically significant correlation between marital status and patients' delays. Ghazali et al (2013) reported that unmarried women delayed more than married women. Mohadesi et al (2013) stated that social and emotional support by spouse and family members of breast cancer patients can relatively reduce mental distress causing from diagnosis and treatment process. Meanwhile, single people receive less protection than married people (Asadi et al., 2012). In present study, 82% of participants were married, so we expected less delay, but the results of regression test revealed that delay risk in pre hospital delay phase in married patients was 7 times more than unmarried ones(p=0.02). Taleghani et al (2006), in their study illustrated that breast cancer patients were worried about self-mental image (Sajadi Hezaveh and Khademi, 2009). Factors such as impaired self-concept, body image disturbance, followed by mastectomy and hair loss, impaired sexual (wife and mother) roles, and Threat in marital status (Sajadi Hezaveh and Khademi, 2009) can be effective in patients delay.

Women's perception of breast cancer and their casual beliefs have significant effects on delay in seeking help specifically in "illness phase". According to this study, any behavioral interventions and clinical medicine to reduce patient delay, without focusing on the perceptions and beliefs of women with breast cancer are impossible. The results of this research can provide information for authorities of health care organizations to identify medical problems, and needs as well as helpful for guidelines Codification. So along with reducing the "patient delay", medical expenses resulting from illness of breast cancer will reduce too, while the quality of life in these patients will increase.

This result signify the importance of "decision to seek help" and "implementation of seeking help decision" phases and educational interventions - counseling for women in our community, in addition to verifying the validity of Leventhal's self-regulation model in explaining the pre-hospital delay in seeking help.

Regarding strong points of study: 1-To minimize errors related to data collection, interviews and data collection were conducted by one researcher.2-To reduce recall bias among the subjects, the criterion of time "up to one year of diagnosis of breast cancer pathology tests" were taken into consideration.3- Research environments were chosen in the private sector (Golsar and Gil oncology -radiotherapy center) and public health centers (Razi hospital and Besat clinic) in Rasht. These centers are the largest reception centers for cancer patients across the Gilan province.

The method of sampling and limited generalizability of patient samples and the difficulty of working with them were some restrictions of this study. A convenience sample was used in the study and therefore the results are not necessarily representative of the wider breast cancer population.

Acknowledgement

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