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Early detection of breast cancer: the role of risk perception and family history

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Abstract. Background: Breast cancer is the neoplasm with the highest mortality rates among Brazilian women. Family history plays an important role in tracking the illness because its analysis reveals possible genetic risks. Objective: The aim of this study is to compare the risk perception and self-care for breast cancer among healthy women with and without family history. Method: The study included 211 women (mean age = 59.11 years, SD = 8.54) of which 55 (26.4%) had a family history of the illness. The instruments used were a sociodemographic and health behavior questionnaire and a risk perception questionnaire. Results and Conclusions: The results showed no significant differences in risk perception and self-care behavior among women with and without breast cancer history, signaling the need of guidelines for psychologists to act in breast cancer prevention among women with a family history, encompassing understanding of the risk factors and causes of the illness as well as women's responsibility in tracking.
Keywords: Cancer; breast cancer; self-regulation; self-care; illness prevention.

[en] Detección precoz del cáncer de mama: el papel de la percepción de riesgo y la historia familiar

Resumen. Introducción: el cáncer de mama es el segundo tipo de neoplasia con más mortalidad entre las mujeres brasileñas. La historia familiar tiene un papel importante, pues su análisis permite identificar posibles riesgos genéticos. Objectivo: comparar la percepción de riesgo y el autocuidado del cáncer de mama en mujeres sanas con y sin historia familiar de la enfermedad. Método: Participaron 211 mujeres (edad media = 59,11 años, DT= 8,54), de las cuales 55 (26,4%) tenían historia familiar de la enfermedad. Los instrumentos utilizados fueron un cuestionario sociodemográfico y de conductas de salud y un cuestionario de percepción de riesgo.

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Resultados y Conclusiones: Los resultados mostraron que no existían diferencias significativas en la percepción de riesgo y conductas de autocuidado entre mujeres con y sin historia familiar de cáncer de mama, lo que señala la necesidad de protocolos de trabajo para los psicólogos en la prevención del cáncer de mama en mujeres con historia familiar de enfermedad oncológica, lo que incluye la comprensión de los factores de riesgo y las causas de la enfermedad, así como su responsabilidad en el seguimiento.
Palabras clave: cáncer; cáncer de mama; autoregulación; autocuidado; prevención de enfermedades.

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1. Introduction

Breast cancer (BC) is the most common cancer among women, even in Brazil, accounting for approximately 25% of new cases of cancer each year[1] . The incidence of BC increases significantly from the age of 50 and, besides the age, early menarche (before eight years of age), late menopause (after the age of 50), the occurrence of the first pregnancy after 30 years of age, and/or not having had children are risk factors. Behavioral factors such as, for example, overweight and smoking, also increase the chances of the occurrence of BC. Family history (hereditary genetics) is an important risk factor for the illness. It is estimated that about 10% of cases of breast cancer are hereditary[2].

The analysis of BC family history reveals the existence of specific characteristics that may indicate genetic risk, namely: families affected by BC for three consecutive generations, two or more relatives diagnosed in the premenopausal period, diagnosis of bilateral BC and even breast cancer in men[3,4]. The occurrence of mutations in BRCA1 and BRCA2 genes increases susceptibility to BC and is also related to ovarian cancer. The mutation in BRCA1 shows a risk of 57% of women developing breast cancer throughout their life, while the mutation in BRCA2 increases the risk by 49%. Also, if the woman has mutation of these genes and has the diagnosis of BC, it has increased risk of developing the illness in the other breast, especially if the woman is young[1,2,4–6].

Genetic predisposition can only be confirmed by conducting genetic testing. This test is not carried out in Brazil by the Unified Health System, it is expensive and is, therefore, inaccessible to women (Brazil, 2013). Furthermore, there is controversy among experts about the usefulness of having the confirmation of gene mutation since the indication of invasive procedures such as mastectomy and ovary removal for preventive purposes is questionable[8]. However, for women at increased risk of breast cancer, there are some recommendations: 1) women should be familiar and aware (‘breast cancer self-awareness’) of their breast and report any changes to the doctor; 2) women should have the breasts examined by a clinician every 6-12 months from 25 years of age on and alternately perform breast ultrasound

and mammography (annual MRI and alternating mammography) from 30 years every six months. To reduce the risk, bilateral prophylactic mammography and preventive chemotherapy have shown a reduced incidence of BC of up to 90% for women who have alterations in BRCA1/2[2].

In face of these issues, women with BC family history may show exacerbated concern regarding their health[9], which can significantly interfere in their risk perception (RP) of developing the illness[10–12]. The risk perception concerns the individual understanding of the probability of being affected by an illness (vulnerability beliefs)[13,14]. In general, women with a family history tend to overestimate their risk for BC because of negative emotions related to the experiences with the family member who had the illness[12,15].

Through their representations or perceptions, individuals model their health behavior both for illness prevention and for treatment compliance[16]. Therefore, it is understood that the perceptions of individual illnesses are modifiable. Through psychoeducation, for example, you can change the mindsets and erroneous beliefs about the illness[17].

Women with a family history of the illness can be confronted with complex information on the risk of family members developing the illness, such as sisters and daughters[11,12]. Through routine consultations and also the media, women are exposed to plenty of information about the personal risk of developing BC, especially those with a family history of the illness[2]. In some cases, these women can be consulted about this by their family members and also about ways of screening and prophylaxis. The challenge to process such information becomes even greater considering the vulnerability of women with a family history of breast cancer of developing the illness[9,18]. Although the experience of having had a very close family member with BC might have a negative effect on processing of information related to cancer, knowledge of being at risk could be an invitation for a woman to have a project for her health to be followed, in collaboration with the health system[9]. Women can, thus, be urged to take greater responsibility for their own health, which may have implications in self-care[19].

Self-care is characterized by actions that people take deliberately to prevent illnesses and promote their health[19]. In the case of breast cancer, self-care is related to performing screening tests (mammography and breast ultrasound), gynecological consultations(clinical examination) and self-examination, in addition to maintaining a healthy lifestyle (not using drugs, regular practice of physical activities, etc.). Women with exacerbated RP, as a result of family history of breast cancer,when compared to women who have no family history, have higher repetition rates of screening tests[12]. Thus, this study was designed to compare the risk perception of breast cancer and self-care among healthy women with and without family history of the illness (first and second-degree kinship). It was hypothesized that women with a family history of breast cancer had a greater perception of risk of having the illness and, therefore, greater self-care.

2. Method

2.1. Participants

The study included 211 women over 40 years of age, users of primary care health service of a large city in the south of Brazil (mean age = 59.11 years, SD = 8.54).

Of these, 55 women (26.4%) had a family history of breast cancer of first and/or second degree, and had not done tests to confirm genetic risk. The sample was selected consecutively among those who were waiting for checkup consultations at the women's and pediatrics clinic of a health center. Women with a personal history of breast cancer were excluded (n = 4).

2.2. Instruments

a) Sociodemographic, clinical and health behavior questionnaire: instrument developed by the authors to evaluate information regarding age, marital status, education, labor activity, medical history, and health behaviors (e.g. frequency of consultations and exams);
b) Risk perception questionnaire (adapted from Figueiras, 2014)[20]: analogue questionnaire ranging in intensity from zero (no risk) to 10 (high risk). The questionnaireincludes four questions about breast cancer, namely: 1) To what extent do you think you can help reduce the risk of breast cancer?; 2) To what extent do you think you are at risk of having breast cancer?; 3) Compared to a person of your age and gender, to what extent do you believe that you are at risk of getting breast cancer?; 4) To what extent is breast cancer a serious illness?; For the evaluation of the answers, the mean of the scores of each item and the total mean are used.

2.3. Ethical Procedures

The research project was approved by the Research Ethics Committee of the Universidade do Vale do Rio dos Sinos - UNISINOS and the Health City Secretariat of Porto Alegre (Proceeding number 180/2014), in accordance with Resolution 466/2012 of the National Health Council, Brazil. Participants signed the informed consent form and the confidentiality of the information was assured.

2.4. Data collection Procedures

Women were invited to participate in the survey in the waiting rooms of the health center. They were informed about the objectives of the study and those who chose to participate in the study signed the Informed Consent Form - ICF. The instruments were applied by trained researchers, and answered individually in an appropriate place. After filling, the instruments were placed in envelopes with code numbers, separated from the ICF, without any personal identification. This procedure assures the secrecy and confidentiality of the information obtained.

2.5. Data Analysis

Data were tabulated and exported to the statistical program SPSS version 22.0. Initially, descriptive analyzes were performed (mean, standard deviation, frequency, percentages). Then inferential analyses of sociodemographic and health behavior variables were made. Mann-Whitney's test was performed to assess differences between the groups in the scores in the risk perception questionnaire. To examine

associations between family history and self-care (questionnaire assessing health behaviors), the Chi-square test was conducted. The value of $p \leq 0.05$ was used in the comparison analyses.

3. Results

Both the group of women with a family history of breast cancer (n = 55) and the group without the family history (n = 156) had a mean age of 59 years (SD = 8.23 and 8.66, respectively). In the group of women with a family history, among the family members who had had breast cancer, 43.6% (F = 24) of them had died, 36.4% (F = 20) had survived without sequelae, 7.3% (F = 4) survived with sequelae (total mastectomy) and 20% (F = 11) were still in treatment at the time of data collection. The family members were diagnosed on average 14.55 years before the interview (SD = 12.94). The demographic data of the sample are described in table 1.

Table 1. Sociodemographic data.

		With family risk of BC N=55		Without family risk of BC N=156	
		F	%	F	%
Marital Status	Single	13	23.6	28	17.9
	Married /Living with a partner	19	34.5	72	46.2
	Separated	14	25.5	36	23.1
	Widowed	09	16.4	20	12.8
Education	Illiterate	2	3.6	2	1.3
	Elementary School	12	21.8	54	34.6
	High School	25	45.5	81	51.9
	College	16	29.1	19	12.2
Work	Yes	20	36.4	58	37.2
Children	Yes	45	81.8	140	90.3

Regarding the indication of preventive examinations by gynecologists in their last routine consultation, 85.5% (F = 47) of women with a history reported having received the indication for mammography, and 74.5% (F = 41) reported receiving indication for breast ultrasound. In the group of women with no family history, 90.4% (F = 141) said they had received indication for mammography and 63.5% (F = 99) for ultrasound.

Health self-care data in the group of women with and without a family history of the illness are described in Table 2. The chi-square test indicated that there were no significant associations between the health behaviors investigated (mammography, ultrasound, self-examination and routine gynecological consultations) and family history of breast cancer. Most women in both groups usually perform the indicated examinations and attend health services regularly.

Regarding the risk perception of developing breast cancer, the data showed that there are no significant differences between the groups in any of the questions of the questionnaire and on the overall score of risk perception (Table 03), showing that risk perception of women with and without family risk is similar. Moreover, there was no significant correlation between the time the family member had the illness and the risk perception of the participants.

Table 2. Health self-care data.

		With family risk of BC N=55		Without family risk of BC N=156			
		M	SD	M	SD		
Age of the first mammogram		37.02 years	8.3	40.94 years	8.82		
		F	%	F	%	x^2	p
Frequency of the mammogram**	Does not perform	6	10.6	8	5,1		
	Within one year	37	67.3	117	75.0	2.526	0.28
	Beyond one year	9	16.4	30	19.2		
Frequency of the ultrasound***	Does not perform	16	23.6	54	34,6		
	Within one year	30	29.1	70	44.9	1.097	0.58
	Beyond one year	9	54.5	26	16.7		
Frequency of the self-examination	Does not perform	12	21.8	51	32.7		
	Seldom	22	40	52	33.3	2.331	0.312
	Regularly	21	38.2	53	34,0		
Consultation with a gynecologist*	Does not perform	0	0	7	4,5		
	Within one year	46	83.6	133	85.3	3.401	0.183
	Beyond one year	8	14.5	15	9.6		

*one participant did not answer

** four participants did not answer

*** six participants did not answer.

Table 3. Score in the Risk Perception Questionnaire.

	With family risk of BC N=55		Without family risk of BC N=156				
	M	SD	M	SD	U	*z*	p
Risk Perception							
RP 1 – Contribution to reduce the risk of having BC	8.01	2.23	7.93	2.44	4132.5	-0.348	0.727
RP 2 – Being at risk of having BC	3.96	3.35	5.05	3.67	3572.5	-1.744	0.81
RP 3 – Being at risk of having BC compared to another person	4.78	3.08	5.18	3.12	3952	-0.742	0.458
RP 4 – Severity of the BC	9.17	1.8	9.42	1.41	3898.5	-1.251	0.211
Total Risk Perception	4.98	1.64	5.43	1.74	3609.5	-1.627	0.104

4. Discussion

The aim of this study was to compare BC risk perception and self-care of healthy women with and without family history of the illness (1st and 2nd degree kinship). The findings revealed that women with a family history had self-care behaviors similar to women with no history and did not perceive themselves at greater risk of having BC.

Regarding self-care, the fact that women in both groups perform preventive BC exams regularly and see the doctor regularly is very positive, indicating self-care with their health and autonomy[19]. It is observed that both women with and without history had similar self-care behaviors, which was a different result from another study[12]. However, the fact that the sample of this study was collected at the health center itself might have caused this result bias, since all the women attended the health care service. Perhaps if the sample had been collected at the women's own homes, the result would be different.

Women with a family history did not realize greater overall risk of having BC compared to women with no history. Despite possible personal risk and the experience of a close relative having had the illness[12], this perception of higher risk might not have shown up clearly by lack of information from the participants, and by the fact that none of them has had genetic testing and counseling. Nevertheless, they do not consider their personal contribution in reducing the risk in the same way that women without a family history. This aspect deserves attention because it is from the perception of personal contribution to reducing the risk of the illness that preventive measures can be activated[21]. Therefore, it is important that the health psychologist can intervene in personal control beliefs to promote self-care and breast cancer prevention.

The literature indicates that patients with higher risk perception levels related to cancer may have more concerns and general distress[22,23]. In some cases, this distress cannot achieve clinical relevance. Nevertheless, chronic distress has been associated

with increased health behaviors (e.g. screening) and biological responses that may be relevant to the risk of developing the illness in women with FH (e.g. impaired immune function, increased levels of cortisol, etc.)[13]. Therefore, further studies can be developed to investigate variables that may be related to therisk perception of breast cancer, such as distress.

Women with FH of BC may believe they cannot do anything about the illness prevention because of heredity or the belief that the illness is hereditary and there is not much to be done[21]. In practical terms, the result of this study shows that in general women should be educated to realize their own contribution to the control of risk factors (e.g. healthy diet, regular physical exercise, etc.) The adoption of healthy lifestyle habits depends largely on how women perceive illness[19,21]. This may include beliefs about risk factors, personal vulnerability and the etiology of the illness. Further studies should explore the relationship between BC family history, risk perception, illness perception and their implications for self-care.

The present study had a number of limitations. Our sample was composed of public health service users and, therefore, people who have some care and concern for their health. Moreover, none of the women with a family history had had genetic testing, which can have an impact on the perception of individual woman's risk since there is no confirmation of this specific vulnerability.

New studies on the subject are important to clarify the phenomenon of preventive behaviors against breast cancer with family history. There is a clear need to raise awareness among women about the importance of breast cancer prevention and the consequences of lack of care based on their personal view of risk, and not on information about the illness and statistical data.

5. Conclusion

No significant differences in risk perception and self-care behavior among women with and without breast cancer history were found, signaling the need of guidelines for psychologists to act in breast cancer prevention among women with a family history, encompassing understanding of the risk factors and causes of the illness as well as women's responsibility in tracking. These results are relevant to guide the actions of the health psychologist in the prevention of breast cancer, given that healthy women with or without a history should be educated to realize their personal risk and their own contribution to the control of illness risk factors. Women with a family history of BC may believe that they have nothing to do about the prevention of the illness by virtue of heredity and, therefore, do not have adequate preventive behaviors of early detection (self-examination, doctor visits, imaging). Adopting healthy lifestyle habits (e.g. healthy diet, regular physical exercise, etc.) will depend largely on how the woman understands the risk factors and the etiology of the illness.

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