Breast cancer prevention: what women think about the illness, its risks and self-care

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Abstract

Background: Early detection of breast cancer (BC) is important to reduce mortality rates. To prevent BC, women should adopt self-care behaviors. This study aimed at examining risk and illness perception and self-care of healthy women regarding breast cancer. **Methods:** Participants were 211 women (M=59.11 years, SD=8.54) and with no personal history of the illness, selected by convenience. Measures were a sociodemographic, clinical and health behavior questionnaire, illness perception and risk perception questionnaires. Nonparametric statistics (Spearman) was employed to analyze the relationship between illness perception, risk perception and sociodemographic variables. The open answers to the causes of the illness were classified according to the content analysis. **Results:** We found a relationship between risk and illness perception and self-care in healthy women regarding BC. It was identified that women had reasonable illness coherence (M=3.18) and considered the illness more timeline chronic than timeline acute (M=3.22), reasonable timeline cyclical (M=3.56), with severe consequences for health (M=4.22), and reasonably threatening (M=3.15). **Conclusions:** BC and risk perception and self-care are interrelated variables among healthy women.

Keywords: Neoplasms; Self-regulation; Breast cancer; Self-care.

Prevenção do cancer de mama: o que as mulheres pensam sobre a doença, seus riscos e autocuidado

Resumo

Introdução: A detecção precoce do câncer de mama (CM) é importante para reduzir as taxas de mortalidade. Para preveni-lo, a mulher deve adotar comportamentos de autocuidado em saúde. Esse estudo objetiva examinar a percepção de risco, a percepção da doença e o autocuidado de mulheres saudáveis com relação ao CM. **Método:** Participaram 211 mulheres (M=59,11 anos; DP=8,54) sem histórico de CM selecionados por conveniência. Os instrumentos foram questionário de dados sociodemográficos, clínicos e de comportamento em saúde, questionários de percepção da doença e percepção de risco. Estatística não paramétrica (Spearman) foi utilizada para analisar a relação entre percepção da doença, percepção de risco e variáveis sociodemográficas. As respostas abertas sobre as causas da doença foram classificadas segundo análise de conteúdo. **Resultados:** Observou-se que existe relação entre a percepção de risco e da doença, e autocuidado em mulheres saudáveis. Identificou-se que as mulheres têm razoável percepção de entendimento da doença (M=3.18), a consideravam mais crônica que aguda (M=3.22), razoavelmente cíclica (M=3,56), com consequências graves à saúde (M=4,22), e relativamente ameaçadora (M=3,15). **Conclusões:** A percepção do CM, a percepção de risco e o autocuidado são variáveis inter-relacionadas em mulheres saudáveis.

Palavras-chave: Neoplasias; Autorregulação; Câncer de mama; Autocuidado.

Prevención del cancer de mama: qué piensan las mujeres sobre la enfermedad, sus riesgos y el autocuidado

Resumen

Introducción: La detección precoz del câncer de mama (CM) es importante para reducir los índices de mortalidad. Para prevenirlo, la mujer debe adoptar conductas de autocuidado en salud. El objetivo es examinar la percepción de riesgo, la percepción de la enfermedad y el autocuidado de mujeres sanas con relación al CM. **Método:** Participaron 211 mujeres (M=59,11 años; DP=8,54), sin histórico de CM seleccionadas por conveniencia. Los instrumentos fueron cuestionario de datos sociodeográficos, clínicos y de conductas em salud, cuestionários de percepción de la enfermedad y percepción de riesgo. Estadística no paramétrica (Spearman) ha sido utilizada para examinar la relación entre percepción de la enfermedad, de riesgo y variables sociodemográficas. Las preguntas abiertas sobre las causas de la enfermedad fueron clasificadas a través de análisis de contenido. **Resultados:** Se observó que existe relación entre percepción de riesgo y de la enfermedady el autocuidado em mujeres sanas. Se identifico que las mujeres tienen razonable percepción de comprehensión de la enfermedad (M=3,18), la consideran más crónica que aguda (M=3,22), razonablemente cíclioca (M=3,36), con consecuencias graves a la salud (M=4,22) y relativamente amenazadora (M=3,15). **Conclusiones:** la percepción del CM, la percepción de riesgo y el autocuidado son variables inter-relacionadas em mujeres sanas.

Palabras clave: Neoplasias; Autorregulación; Câncer de mama; Autocuidado.

Background

Breast cancer (BC) is an illness that accounts for 25% of all cases of cancer and the second leading cause of death by malignant tumors in the world, being the most common cause of death among women (American Cancer Society, 2015). On the other hand, male breast cancer is rare, accounting for less than 1% of cases (Ferzoco & Ruddy, 2016). However, early BC detection has excellent prognosis and significantly reduces mortality rates among women. Its incidence increases after 40 years of age (DeSantis et al., 2015), when screening involving clinical breast examination, mammography, and ultrasound, respecting the patient's characteristics, is recommended (Dey, 2014). For the prevention of breast cancer, an annual mammography for women aged 45 to 54 years of age, starting from the age of 40, is recommended.(American Cancer Society, 2015) For women over 54 years of age the exam is recommended every two years(DeSantis et al., 2015).

Risk factors for BC are: sex (female), obesity (increase in anthropometric measurements) and frequent use of alcohol (Del Valle et al., 2014). Other studies suggest that breast cancer may be associated with age, family history, genetic susceptibility, and overexposure to hormones(Catania et al., 2016; Snape et al., 2012). There are no primary practical breast cancer prevention measures applicable to the entire population as the illness is discovered only when there is a palpable or visible lump in imaging, which makes preventive practices of secondary nature or early detection. The only possible primary prevention measures are in genetic testing cases for patients with a family history(Snape et al., 2012).

For breast cancer to be detected early, it is essential that women have health self-care behaviors through early illness detection methods. One of the most effective ways for the initial diagnosis is mammography(Dey, 2014).

Adherence to preventive screening is related to risk perception of having the illness (Fehniger et al., 2014), defined by an individual notion of vulnerability in face of it. It is known that this perception can motivate the adoption of prophylactic self-care behaviors (e.g. getting mammographys or not) (Gibbons & Groarke, 2016; Jones et al., 2011). Although risk perception is subjective and not necessarily reflect the real risks of the disease, it is known that educational level is an important variable that affect risk perception (Lizama et al., 2016). Women with a family history of breast cancer, smokers, and with low educational and socioeconomic status have lower adherence rates to the exam (Caleffi et al., 2010). Younger age, good knowledge about preventive screening and family history of breast cancer were associated with recent mammography (Anagnostopoulos et al., 2012). Women with heightened risk perception, due to BC family history, when compared to women who do not have the family history or have another type of cancer, have higher mammography repetition rates (Fehniger et al., 2014; Haber, Ahmed, & Pekovic, 2012).

In addition to risk perception, breast cancer perception can also have implications for self-care (Fehniger et al., 2014; Gibbons & Groarke, 2016). According to the Common Sense Model (Leventhal, H., Nerenz, D., Steele, 1984), individuals organize their thoughts in face of an illness (diagnosed or hypothetical/possible, in case of healthy individuals), by means of mental schemes, called illness perception. Faced with a diagnosis, the individual will use these schemes to identify the possibilities of cure and/or restoration of health in the adoption of behaviors. Currently, the CSM is structured from seven dimensions: 1) identity (symptoms); 2) timeline (acute or chronic or cyclic); 3) causes; 4) consequences; 5) control (personal and treatment); 6) illness coherence; 7) emotional representation(Moss-Morris et al., 2002).

Regarding breast cancer perception among healthy women, the idea that it is a threatening and out of control illness may influence non-adherence to self-care behaviors, especially for mammography (Anagnostopoulos et al., 2012; Gibbons & Groarke, 2016; Seabra, Peuker, & Castro, 2015). In addition, it is possible that mental disorders like anxiety and depression, very common in breast cancer patients (Maass, Roorda, Berendsen, Verhaak, & de Bock, 2015; McCorry et al., 2013; Van Esch, Roukema, Ernst, Nieuwenhuijzen, & De Vries, 2012) affect illness perceptions, specially emotional representation. On the other hand, adjusted beliefs about the illness may allow the perception of the real risk and favor autonomy in caring for their own health (Fehniger et al., 2014; Kaptein et al., 2015). Thus, the objective of this study was to examine risk perception, illness perception, and self-care among healthy women regarding breast cancer.

Method

Sample

The sample consisted of women over 40 years of age treated at a primary care service of a large city in the south of Brazil. Of the 318 women invited to participate, 84 (26.4%) refused, 16 (5.1%) samples initiated were discontinued for lack of time available to complete the questionnaires, four (1.3%) were discontinued due to difficulties in understanding the

questionnaire, and three (0.9%) were discontinued due to consultations and examinations, resulting in a final sample of 211 participants (66.3% of women invited). This sample corresponds to 47% of women treated at the service during the data collection period (three months). Participants were recruited for convenience (non probabilist sample).

Instruments

1. Sociodemographic, clinical and health behavior questionnaire: included variables such as age, marital status, education, labor activity, psychological and psychiatric care, self-care examinations, consultations with the gynecologist/mastologist, among others.

2. Revised Illness Perception Questionnaire for Healthy People (IPQ-RH) (Maria João Figueiras, 2014): based on the IPQ-R (Weinman, Petrie, Moss-Morris, & Horne, 1996) for healthy people, the instrument is divided in three sections: the first one corresponds to the identity dimension, which presents 17 symptoms that participants relate or not to BC. The second includes the timeline acute/chronic or cyclical, consequences, personal control and treatment, coherence and emotional representation dimensions. The third section is related to the possible causes of the illness. It also asks the participant to enumerate freely three main causes they considered to be related to the development of the illness. The second and third subscales include a Likert scale (strongly disagree to strongly agree). Cronbach's alpha (internal consistency) of the dimensions were 0.85 (emotional representation), 0.73 (consistency), 0.61 (timeline acute/chronic), 0.60 (consequences), 0.58 (timeline cyclic). The personal control and treatment control had low alphas ($\geq$0.55) and all items contributed for it. Then, the two subscales were excluded.

3. Risk perception questionnaire: analog measure that varies in intensity and includes four questions concerning the individual risk to develop and contribute to the risk reduction of BC (Figueiras, 2014). The mean of the scores for each item and the total mean were used for the evaluation of the answers.

Ethical and research procedures

Women were invited to participate as they waited for medical consultations in the waiting rooms of the basic health unit. The average response time to the questionnaires was 30 minutes. The study was approved by the Ethics Committee and all participants signed the Informed Consent Form.

Data Analysis

Data were analyzed using SPSS (Statistical Package for Social Sciences) version 22.0. Descriptive statistics were performed (frequencies, mean, and standard deviation). The Shapiro-Wilk test was used to check if the sample distribution was normal. Spearman's nonparametric correlation test was employed to analyze the strength and direction of the relationship between illness perception, risk perception and sociodemographic variables. The open answers to the causes of the illness were classified according to the content, based on the criteria used in the literature(Peuker, Armiliato, Souza, & Castro, 2016). Two independent judges and experts in the subject assessed and categorized all the answers, and, in case of disagreement, a third judge set the appropriate category. The Kappa coefficient of agreement between them was 0.97, which is considered a good reliability index. For all the analyses, a value of p$\leq$0.05 (95% confidence interval) was used.

Results

Participants had a mean age of 59.11 years (SD=8.54) and had an average of two children (SD=1.29). Among them, 53.1% (n=112) had a steady partner and 37% (n=78) worked. Regarding schooling, 50.2% (n=106) had even finished high school, 31.3% (n=66) completed primary education, 16.6% (n=35) higher education and 1.9% (n=4) were illiterate. Of the total, 26.1% (n=55) had a family history of breast cancer and the average age of the first mammography was 39.91 years (SD=8.84).

Health Status

According to the subjective assessment of their own health status, women rated their current health status as "excellent" (n=22, 10.4%), "good" (n=106; 50.2%), "fair" (n=69; 32.7%), "bad" (n=8, 3.8%) and "very bad" (n=6, 2.8%). Furthermore, 51.1% (n=96) reported the diagnosis of a chronic illness (hypertension, diabetes, hypothyroidism).

Illness perception

Considering the data regarding the symptoms attributed to breast cancer (identity), women attributed a mean of 7.43 symptoms (SD=4.68), out of the 17 listed. The symptoms most often attributed to BC were fatigue (74.9%), weight loss (69.2%) and infections (62.1%). The data are reported in **Table 1**.

As to the other dimensions of illness perception, women considered the illness a little more timeline acute (M=3.22), fairly cyclical (M=3.56) and of severe consequences to one's health (M=4.22). In relation to the coherence dimension (M=3.18), women considered they understood the illness partially. As for

the emotional representation (fear, anxiety and sadness) of BC, women perceived the illness as relatively threatening (M=3.15) (**Table 2**).

In the third section of the illness perception instrument, concerning its causes, it was observed that women attributed the etiology of the illness to more general risks than psychological issues. The

causes spontaneously attributed to breast cancer by participants are described in **Table 3**.

Risk perception

When asked about their control to reduce their own risk, women found that they could reduce their risk significantly (M=8.00, SD=2.78). However, they considered that they had a low personal risk (M=4.17, SD=3.27) even when compared to other women of the same age (M=4.87, SD=3.09). On the severity of BC, women signaled that it is very serious (M=9.25, SD=1.69). Regarding the overall risk perception, a mean score (M=5.07, SD=1.67) was found, which suggests that women perceived themselves with a moderate vulnerability of having the illness (maximum score of 10 points).

Self-care

In relation to self-care practices, 29.0% (N=63) of women say they do not carry out the self-examination and 20.4% (N=43) report they rarely perform it. As for gynecological consultations, most said they had consultations within the period of one year (85.7%, N=174). Additionally, most women also claim to perform mammography (76.9%, N=159) and ultrasound (47.8%, N=100) within the period of one year. Clinical data on the frequency of preventive behaviors is described in **Table 4**.

TABLE 1
Symptoms attributed to BC (N=211)

	(n)	*(%)*
Fatigue	158	74.9
Weight loss	146	69.2
Infections	131	62.1
Loss of strength	130	61.6
Appearance of moles on the skin	113	53.6
Pain	110	52.1
Dizziness	108	51.2
Difficulty sleeping	104	49.3
Headache	89	42.2
Nausea	85	40.3
Upset stomach	84	39.8
Difficulty breathing	83	39.3
Breathlessness	54	25.6
Diarrhea	54	25.6
Cough	45	21.3
Sore throat	43	20.4
Inflamed eyes	27	12.8

TABLE 2
Mean, standard deviation, minimum, maximum and variation of IPQ-RH dimensions

	Mean	*SD*	*Min.*	*Max.*	*Variation*
Timeline Acute/Chronic	3.22	0.66	1.2	5	1-5
Timeline Cyclic	3.56	0.68	1.3	5	1-5
Consequences	4.22	0.52	2.7	5	1-5
Coherence	3.18	0.98	1	5	1-5
Emotional Representation	3.15	1.06	1	5	1-5
Psychological Attribution Causes	3.17	0.81	1	5	1-5
General Risk Causes	3.24	0.49	1	5	1-5

TABLE 3
Frequency and rate of spontaneous causes

Category	*Cause 1*		*Cause 2*		*Cause 3*	
	n	*%*	*n*	*%*	*n*	*%*
Biological Risk Factors	94	44.55	41	19.43	40	18.96
Behavioral Risk Factors	45	21.33	53	25.12	48	22.75
Psychological Attribution	39	18.48	47	22.27	42	19.91
Physical Lesion	13	6.16	18	8.53	8	3.79
Does not know	11	5.21	27	12.80	49	23.22
Lack of access to resources	8	3.79	15	7.11	19	9.00
Bad luck/Fate	1	0.47	6	2.84	2	0.95
Chemical Agents	0	0	4	1.90	2	0.95

TABLE 4
Frequency and rate of clinical data (N=211)

	(n)	(%)
Self-examination		
Does not perform realiza	63	29.9
Rarely	43	20.4
Occasionally	31	14.7
Weekly	37	17.5
Monthly	37	17.5
Consultations with a gynecologist*		
Does not have	7	3.3
Within the period eríodo de um ano	174	85.7
Beyond the period eríodo de um ano	23	11
Mammography**		
Does not perform	9	4.3
Within the period período de um ano	159	76.9
Beyond the period	39	18.8
Breast ultrasound*		
Does not perform	70	33.5
Within the period eríodo de um ano	100	47.8
Beyond the period	39	18.6

* Two participants did not answer the question.
** Four participants did answer the question.

As the data distribution was not normal, a nonparametric bivariate analysis was used. Spearman's correlation analysis revealed that some dimensions of illness perception were associated with sociodemographic variables and risk perception. The cyclical dimension correlated positively with coherence ($\rho=0.366$; $p<0.01$), with the emotional representation ($\rho=0.310$; $p<0.01$), with the identity ($\rho=0.227$; $p<0, 01$) and negatively with education ($\rho=-0.251$; $p<0.01$). The consequences correlated positively with consistency ($\rho=0.201$; $p<0.01$) and emotional representation ($\rho=0.160$; $p<0.05$). The coherence dimension correlated positively with the emotional representation ($\rho=0.528$; $p<0.01$) and negatively with education ($\rho=-0.282$; $p<0.01$). The emotional representation was positively correlated with identity ($\rho=0.165$; $p<0.05$), with risk perception ($\rho=0.139$; $p<0.05$), with the age of the first mammography ($\rho=0.184$; $p<0.01$) and negatively with education ($\rho=-0.295$; $p<0.01$). Identity was correlated positively with risk perception ($\rho=0.138$; $p<0.05$) and negatively with age ($\rho=-0.139$; $p<0.05$). In addition, the variable age at first mammography was negatively correlated with education ($\rho=-0.214$; $p<0.01$).

Discussion

The results showed that there is a relationship between risk perception, illness perception, and self-care in healthy women regarding breast cancer. Some dimensions of illness perception (identity and emotional representation) are related to risk perception, besides the correlations between the dimensions of the concept of illness perception itself. Moreover, the importance of education for self-care (age at completion of the first mammography) and in relation to the perception of how much women understand about breast cancer (coherence dimension) was highlighted.

Regarding the identity dimension, it was found that women had some confusion about the symptoms that characterize breast cancer. Most of the symptoms attributed by them are found in patients undergoing chemotherapy (e.g. fatigue and weight loss), and are not necessarily related to the illness symptoms. This result may indicate that healthy women can confuse the symptoms of cancer with the side effects of the treatment.

The perception of symptoms is correlated with the emotional representation of the illness. There is evidence that women with BC tend to notice many symptoms related to the illness, resulting in greater emotional distress (McCorry et al., 2013). Thus, preventive interventions, such as psychoeducational interventions with healthy women on the symptoms, major changes in breast health and diagnostic possibilities for early detection can be effective for the acquisition of knowledge about the symptoms and adherence to screening at posttest, increasing women's knowledge and clarifying erroneous beliefs about the actual symptoms of BC (Thomson et al., 2014).

The negative emotional representation was associated with the perception of chronicity, and breast cancer has been identified as a threatening and traumatic illness. The suffering caused by cancer may be responsible for the development of mental disorders such as depression and anxiety (Maass et al., 2015; Van Esch et al., 2012). This indicates that cancer can cause emotional distress that is so intense as to entail serious psychiatric disorders, especially in people with a history of mental disorders, requiring specialized care not to worsen their condition(Van Esch et al., 2012). These data suggest that, when considering cancer as a serious and great suffering illness, healthy women may feel negatively impacted by the adoption of behaviors to prevent it (Anagnostopoulos et al., 2012). Therefore, women should seek consistent information, and health services should be concerned with the format for presenting the information, allowing it to be adjusted rather than impacting.

Women identified the illness as having serious consequences to their health and their life, which was also associated with a negative emotional

representation. This data had been found among ill women as an association between perceived negative consequences and emotional injury (Anagnostopoulos & Spanea, 2005). The consequences dimension also correlated with illness coherence. The negative consequences are perceived as extremely impactful (negative emotional representation), affecting women's level of understanding about the illness(McCorry et al., 2013).

According to the results of this research, healthy women attributed few psychological causes to BC. Literature has shown that women who fall ill with breast cancer tend to blame and assign the etiology of the illness to emotional issues (e.g. family problems, sorrows, worries) (Kaptein et al., 2015; Peuker et al., 2016; Thomson et al., 2014). From an important event such as having cancer, perceptions about the illness, particularly causal attributions may be changed spontaneously so that the person can make sense of their illness (Peuker et al., 2016). In this sense, the illness experience can directly affect the way women attribute causes to their illness. Furthermore, it was found that healthy women considered that the cause of breast cancer was associated with biological and behavioral risk factors rather than to causes of emotional origin. From the preventive point of view, this data can be positive. If healthy women are aware that their lifestyle may be related to the illness, they may adopt preventive measures (e.g. not smoking, performing physical activities). Aspects such as motivation can be worked with cognitive-behavioral interventions, such as motivational interview, for example.

Women with higher education reported having had a mammography earlier. However, Anagnostopoulos et al. (2012) found that just younger age, good knowledge about mammography screening and family history of breast cancer were associate with recent mammography. It is possible that the educational level might promote knowledge of the risk factors for breast cancer, which is consistent with the literature (Lizama et al., 2016). On the other hand, it is known that in Brazil there are vast differences between public and private health system. Regarding to mammography, a Brazilian national study about the topic (Silva, Souza-Júnior, Damacena, & Szwarcwald, 2017) showed that white women with higher education and with a private health insurance have more chance to do the exam. In this sense, breast cancer prevention programs should be targeted to the most vulnerable populations, such as, for example, women with less education. Nevertheless, the relationship between education and health behavior might not be causal and its understanding may involve interaction with more complex variables.

This study showed that the perception of breast cancer, risk perception, self-care and education are interrelated variables in women without the illness. Young women with more education have more adjusted illness perceptions and risk perceptions and, therefore, seem to have better self-care. It is possible that risk perception mediate illness perceptions and self-care, as like Gibbons and Groarke (2016) study found that risk perceptions mediated negative illness perceptions and cancer worry. However, studies with larger samples are need to confirm this hypothesis.

Illness and risk perceptions are an important constructs to be assessed, but it is not enough to explain the complexity of factors involved in self-care and prevention of breast cancer. Nevertheless, the results presented here are relevant to understand the representations of healthy women and assist in the design of specific preventive actions for this population.

It was observed in this study that women reported to prevent the illness through current recommendations for early detection of breast cancer with satisfactory levels of consultations with gynecologists/mastologists and mammography. Because it is a non-clinical sample composed of public health service users, this result can be restricted to a part of reality, leaving out women who do not make use of health services. It is important that future studies should focus on those who do not often use health services, and do not understand the value of their health behaviors for preventing breast cancer.

The study has several limitations. Participants were women who used health services, and the data may have an important bias for this reason. Maybe, if the data collection was done in another place (like work, for example), the data would be different. In addition, there is no agreement in the literature about how to measure risk perception. Because risk perception varies across different illnesses and risks, there is no measure about risk perception validated for this population.

Further studies may include other relevant variables, such as those related to emotional disorders (depression and anxiety, for example) to integrate these factors in order to understand the beliefs shared in the community about breast cancer. In addition, new studies may encompass questions about personal lifestyle (smoking, alcohol consumption, physical activity), which are closely linked to risk factors. Longitudinal studies may also be developed in order to identify self-care predictors based on the beliefs held by women in the community, which may influence self-care practices.

In terms of practical and clinical implications, this study revealed that healthy women perceive cancer as

relatively threatening, with serious health consequences and negative emotional representation. Therefore, interventions for breast cancer prevention should consider the CSM dimensions in the development of guidance materials to expand the knowledge of women in this regard. It is important that public policies are also aimed at older women with less education as they might adhere less to breast cancer screening.

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