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ILLNESS PERCEPTIONS IN BRAZILIAN WOMEN WITH CERVICAL CANCER, WOMEN WITH PRECURSORY LESIONS AND HEALTHY WOMEN

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Abstract

Purpose: to compare the perceptions about cervical cancer in: 1) women with cervical cancer, 2) women with precursory lesions; and 3) healthy women. Participants were 150 adult women from southern Brazil.

Measures: Sociodemographic and Clinical Data sheet, Illness Perception Questionnaire – Revised and Illness Perception Questionnaire for healthy people.

Results showed significant differences between groups in the dimensions of timeline cyclic and identity, indicating that healthy women perceived more symptoms, but as more cyclical (acute/chronic) compared to the other two groups. With regard to the causes of illness, women with cancer more often attributed it to their emotional state/stress/ concerns than healthy women or those with precursory lesions.

Key words: Illness perception, illness representations, cancer, cervical cancer, human papilloma virus.

Resumen

Objetivo: comparar las percepciones sobre el cáncer de cuello uterino en: 1) las mujeres con cáncer de cuello uterino, 2) las mujeres con lesiones precursoras, y 3) las mujeres sanas. Los participantes fueron 150 mujeres adultas procedentes del sur de Brasil.

Medidas: Formulario de datos sociodemográficos y clínicos, *Illness Perception Questionnaire – Revised and Illness Perception Questionnaire for healthy people*

Los resultados mostraron diferencias significativas entre los grupos en las dimensiones curso cíclico e identidad, lo que indica que las mujeres sanas perciben más síntomas, pero dependen más del curso cíclico (agudo/crónico) en comparación con los otros dos grupos. Con respecto a las causas de enfermedad, las mujeres con cáncer lo atribuyen con más frecuencia a su estado emocional/estrés/preocupaciones que las mujeres sanas o con lesiones precursoras.

Palabras clave: Percepción de la enfermedad; representaciones de la enfermedad, el cáncer, el cáncer cervical, el virus del papiloma humano.

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INTRODUCTION

The cervical cancer is the second highest cause of incidents of cancer among Brazilian women[1]. This type of cancer has no symptoms in its precursory stages, which makes it very difficult to diagnose. It impacts, more often, women aged between 35 and 55 years old[2]. Around 90% of cases of the disease are related to being infected by the Human Papilloma Virus (HPV), and 44% are caused due to precursory lesions caused by viruses. In addition, poor hygiene, precursory onset of sexual activity, multiple partners, smoking, prolonged use of oral contraceptives and low intake of vitamins are considered risk factors for cervical cancer[1].

When cervical cancer is diagnosed at a precursory stage, the healing potential is high[1,3]. Despite being a type of cancer with a good prognosis, mortality rates are still high in Brazil[2] and may be related to poor treatment in the public health services. Although there is an increase in precursory diagnosis in the country[1], there still is not a noted the drop in the number of deaths.

According to the Common-Sense Model, illness perceptions are related to the thoughts and emotions derived from the experience of being sick and relate to individual beliefs about health / illness[4]. In this sense, the representational content can be linked to the risks that the disease can bring to an individual's health. The self-regulation is linked, in part, to the assessment of symptoms and knowledge, beliefs and risk perceptions, as being factors that can affect an individual's behavior[5]. Although some people might go through similar experiences, the way that illness perceptions are established is different because each individual lives in a unique way and have their own perceptions about such an illness[6].

A systematic review of the literature on illness perception and cancer[7] showed that none of them focused on perceptions about cervical cancer. In regard of the illness perceptions in healthy people, Figueiras and Alves[8] emphasize that they can serve as guides for behavior in relation to prevention. Soon, they imply that thoughts precede the preventive measures for the individual so that he or she does not get sick, promoting health. Whereas illness perceptions appear to be precursors of behavior and coping with the disease, it may be useful to assess not only the perceptions of sick people, but also those of healthy people about a particular disease, to guide disease prevention behaviors. The objective of this study is to evaluate and compare the illness perceptions in women with cervical cancer, women with precursory lesions and healthy women.

MATERIAL AND METHODS

Design: Cross-sectional study.

Sample: 150 adult women who were divided into three groups:

- Group 1: 50 women diagnosed with cervical cancer and treated in accordance with medical advice;
- Group 2: 50 women with uterine cancer precursory lesions;
- Group 3: 50 women without cancer, without precursory lesions and without known HPV infection.

The selection of participants in group 1 occurred consecutively among those who were in outpatient treatment for cancer in a hospital in the city of Porto Alegre, Brazil, between April - September 2011. The other participants in groups 2 and 3 were also recruited in a consecutive manner in the gynecology outpatient clinic of the same hospital, with the intention being to pair them with participants in group 1 with the variable age groups and education levels. The response rate to participate in the study

was 100%. All participants were treated by the Brazilian Public Health Systems, which means that the treatment was free for them.

Measures

1) Biodemographical Data about the disease and treatment: patient age, age at diagnosis, marital status, children, education, employment, type of treatment, stage of disease, among others. The data were obtained from the medical records of patients.

2) Revised Illness Perception Questionnaire (IPQ-R)[9], assesses the illness perceptions according to the Common-sense model. The instrument has a version and adaptation to Portuguese[10]. Instrument consists of five dimensions which were subdivided into four scales: 1) Identity of the disease, through the presentation of 14 symptoms of chronic disease, where the patient must assess whether there is presence or absence; 2) Timeline, consequences, personal control and treatment control, illness coherence and emotional representation through 38 questions on a five-point Likert scale; 3) Causes of the disease, with 18 questions on a five-point Likert scale to which the patient responds from strongly disagree to agree fully; 4) after the objective questions, the patient is asked a question about what are the main causes that contributed to the onset of the illness. Higher scores signify a more negative perception of the disease.

3) Revised Illness Perception Questionnaire for Healthy People (IPQ-RH): Instrument adapted the IPQ-R to assess the perception of illness in healthy individuals[8]. Instrument assesses what healthy people think about health and certain disease, and how their ways of thinking are related to behaviors associated with health. The dimensions are the same as in the IPQ-R. All IPQ-RH items were included in the original version and grouped according to the dimensions IPQ-R. Higher scores signify a more negative perception of the disease.

Ethical Procedures

The research project was approved by the Research Ethics of [name]. All patients signed a Consent Form to participate in the study, following all necessary ethical recommendations inherent in a scientific project.

Procedures for data collection

Patients were invited to participate after analysis of their medical records and verification of the inclusion and exclusion criteria. The application of instruments occurred in hospital, outpatient room, on the days of the target-patients consultation, before the medical appointments, of the three groups. Due to the low level of education and the difficulty of reading many participants, the questions were read out loud to all participants and the filling out of the form was done by the researchers. The applications were all individualized, while maintaining the privacy of the patients

Results

The mean age of patients with cervical cancer was 45.27 years (SD = 10.89), while the group with precursory lesions was 40.16 (SD = 10.65) and the group of healthy women was 39.10 years (SD = 11.55). In table 1 are presented the main sociodemographic data of the sample.

In women with cancer, 8 (16%) were diagnosed with stage IV, 15 women (30%) in stage III, 11 (22%) with stage II, and 6 (12%) were stage I. These patients were treated by radiotherapy (19 or 38%), chemotherapy and brachytherapy (13 or 26%) and conization and hormone therapy (2 or 4%). Among the group of patients with precursory lesions, the sample was

Table 1. **Demographic Data of the patients according to the three groups**

	Patients Cancer (n = 50) N (%)	Patients with precursory lesions (n= 50)N (%)	Healthy patients (n = 50) N (%)
Marital status			
Single	17 (34%)	18 (36%)	11 (22%)
Married / Live together	25 (50%)	23 (46%)	33 (66%)
Divorced	5 (10%)	5 (10%)	4 (8%)
Widow	3 (6%)	4 (8%)	2.4.
Education			
Illiterate	-	1 (2%)	-
Elementary school not completed	24 (48%)	17 (34%)	14 (28%)
Elementary school completed	3 (6%)	5 (10%)	5 (10%)
Incomplete high school education	5 (10%)	5 (10%)	7 (14%)
High school graduate	9 (18%)	14 (28%)	19 (38%)
Incomplete higher education	2 (4%)	5 (10%)	1 (2%)
College degree	4 (8%)	2 (4%)	4 (8%)
Labor activity			
Works	22 (44%)	29 (58%)	27 (54%)
Does not work	28 (56%)	21 (42%)	23 (46%)
Stopped working due to disease	12 (24%)	5 (10%)	-
Children			
Yes	45 (90%)	40 (80%)	34 (68%)
No	5 (10%)	10 (20%)	16 (32%)

divided into: 22 patients with cervical intraepithelial neoplasia (CIN) III (44%), 16 with CIN I (32%), and nine with CIN II (18%). Thirteen (26%) of the women in this group were diagnosed with HPV. Of these patients, 35 (70%) underwent conization, with a mean of 10.73 months (25.07).

The results showed the existence of significant differences between groups in the identity ($F = 11.654$, $p < 0.001$), cyclic timeline ($F = 4.416$, $p < 0.05$) and causes of illness ($F = 15.941$, $p < 0.001$). The *post hoc* test of Tukey indicated that women without cancer or lesions scored higher than the other groups in the identity (symptoms) dimension. With respect to the cyclic timeline, *post hoc* test showed that women without cancer or lesions perceive the disease as more stable than women in the other groups. With regard to the possible causes of the disease, results show that women with cancer attributed less psychological causes to the disease significantly when compared to healthy women with precursory lesions ($X^2 = 34.031$, $p < 0.001$).

As for the open-ended question about the three leading causes of cervical cancer, categories were created adapted from the study of Figueiras and Alves[8]. The group with cancer named as the main cause of the disease "emotional state / stress and worries" while the group with precursory lesions and the group of women without cancer or lesions attributed it to "personal attitude / behavior" ($X^2 = 34.031$, $p < 0.001$).

DISCUSSION AND CONCLUSIONS

This study showed significant results with regard to what women think about cervical cancer. The differences found between the three groups show essentially that women with precursory lesions or illness have different perceptions about cervical cancer when compared to healthy women in the dimensions of identity and timeline cyclic, which can have consequences for the way they deal with the disease and prevent it. Moreover, women with cancer have more intense perceptions of variety of causes related to cervical cancer than that of women in the other groups. Although there are no similar studies in the literature using a sample of patients with cervical cancer, a study[11] had already identified differences between groups in relation to the identity dimension in patients with risk of developing lung cancer and patients with the disease. The patient groups at risk do not see how real the possibility of developing the disease is and do not attribute the symptoms to the possibility of cancer, even exposing themselves daily and directly to risks such as tobacco. This shows that patients at risk of developing the disease do not consider the risk a real possibility and probably do not take the necessary precautions to prevent the disease, which increases the chances of them having it.

The results for the group of healthy women indicated that they believe that women with cervical cancer have more symptoms of the disease (identity) than women with cancer and with precursory lesions. This result maybe demonstrates that in, a certain way, the disease is seen as more threatening to the group of healthy women. Thus the threat of disease may be related to measures of preventive care, since the belief that the disease is severe ensures that these women use effective self-care.

The fact that no significant differences were found in the dimensions of timeline (acute / chronic), consequences, personal control, treatment control, coherence and emotional representations of illness among the three groups, shows that most illness perceptions are independent of the experience of illness or the perception of the likewise risk. However the dimensions of identity and cyclic timeline were distinctly different between groups. If on one hand, the healthy women see that women with cancer suffer from many symptoms related to the disease, on the other hand they perceive the disease as more stable and they do not seem to worry much about the risk of relapse. In contrast to increased awareness of the cyclic nature of the disease by way of groups of women at risk with cancer and demonstrates that the perception about the chronicity is not related to the disease experience itself.

With respect to differences in the responses on the possible causes of the disease, women with cancer believed that the disease was more related to the emotional state than in the other groups. This data can be linked to the feeling of guilt that impacts cancer patients[12]. The experience of having the disease as well as treatment effects, to the contrary of the other groups, makes it so that women with cancer suffer an important psychological impact. It is possible that these cancer patients to feel pain and symptoms related to the disease, do a retrospective of their lives in an attempt to understand possible emotional states, behaviors and events that may have contributed to the outbreak of the disease. This data can also highlight a possible active role in the onset of the disease and therefore feelings of guilt.

This study has some limitations that prevent the data from being generalized. Despite the pairing made between the three groups, the group of women with cancer was quite heterogeneous with regard to the

time of diagnosis. Moreover, some women in the sample were also diagnosed with HIV. The low education level of the study participants is also a factor to be considered, since it can interfere with the understanding of the disease itself and also in their perception about the disease[13,14] .

It is hoped that this study contributes to the understanding of the attitudes of self-care and coping with the disease of women, and the development of psychological interventions that besides informing about the disease can work on the perceptions and mistaken beliefs of these women through increased knowledge about their own body, self-care behaviors and sex, in order to prevent cervical cancer. For this it is necessary to sensitize the relevant bodies about the need for greater investment in the prevention of the disease and thus create educational systems which provide incentive for performing Pap smears, colposcopy and hybrid capture, leveraging the easy access to these examinations and while addressing the difficulties related to self-care and disease prevention.

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