

Cancer that takes the female body: dialogic representations

Câncer que toma o corpo feminino: representações dialogadas

Cáncer que toma el cuerpo femenino: representaciones dialógicas

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ABSTRACT

Objective: to describe the representational contents of women experiencing female cancer. **Method:** in this exploratory, qualitative, descriptive study of 20 women in an oncology center, data were collected through audio-recorded, semi-structured, fully transcribed interviews and analyzed using Bardin content analysis. Social Representations Theory was used as a theoretical framework. **Results:** from the analysis, four categories emerged that expressed the representational contents voiced by the women, which were permeated by inner suffering and anchored in representations of death and fear. Their words showed that depression is linked to these representations and reflects on decision-making. Social support and how women receive their diagnosis have decisive influence on the representations constructed and on treatment. **Conclusion:** within the social representations that each woman presented, were meanings that required thorough consideration in order to provide individualized care that contemplated the biopsychosocial processes experienced by women facing cancer.

Descriptors: Women's Health; Gynecology; Oncology Nursing; Neoplasms; Genital Neoplasms, Female.

RESUMO

Objetivo: descrever os conteúdos representacionais de mulheres vivenciando o câncer feminino. **Método:** estudo descritivo, exploratório e qualitativo, realizado com 20 mulheres em um centro de oncologia. Os dados foram coletados por entrevistas semiestruturadas áudio-gravadas, transcritas na íntegra, analisadas de acordo com a análise de conteúdo de Bardin. Utilizou-se como referencial teórico a Teoria das Representações Sociais. **Resultados:** da análise, emergiram quatro categorias que traduziram os conteúdos representacionais das mulheres, permeados pelo sofrimento interno e ancorados em representações de morte e medo. As falas apontaram que a depressão se une à essas representações, refletindo nas tomadas de decisões. O apoio social e forma como a mulher recebe o diagnóstico tem influência decisiva nas representações construídas e tratamento. **Conclusão:** dentro das representações sociais que cada mulher apresenta existem significados que requerem um olhar minucioso para se prestar uma assistência individualizada e que compreenda os processos biopsicossociais vivenciados pela mulher enfrentando o câncer.

Descritores: Saúde da Mulher; Ginecologia; Enfermagem Oncológica; Neoplasias; Neoplasias dos Genitais Femininos.

RESUMEN

Objetivo: describir los contenidos representativos de mujeres que padecen cáncer femenino. **Método:** estudio descriptivo, exploratorio y cualitativo, realizado junto a 20 mujeres en una unidad oncológica. Se recolectaron los datos fueron a través de entrevistas semiestructuradas grabadas en audio, transcritas en su totalidad, analizadas según el análisis de contenido de Bardin. Se utilizó la Teoría de las Representaciones Sociales como marco teórico. **Resultados:** del análisis surgieron cuatro categorías que tradujeron los contenidos representacionales de las mujeres, impregnados por el sufrimiento interno y anclados en representaciones de muerte y miedo. Las declaraciones mostraron que la depresión se une a estas representaciones, reflejándose en la toma de decisiones. El apoyo social y la forma cómo la mujer recibe el diagnóstico tiene influencia en las representaciones y el tratamiento. **Conclusión:** dentro de las representaciones que presenta cada mujer, existen significados que requieren una mirada profunda para brindar una atención individualizada que comprenda los procesos biopsicosociales que viven las mujeres frente al cáncer.

Descriptor: Salud de la Mujer; Ginecología; Enfermería Oncológica; Neoplasias; Neoplasias de los Genitales Femeninos.

INTRODUCTION

In the group of neoplasms, female cancers are responsible for more than half of cancer deaths among women in Brazil. These cancers refer to the origin of neoplastic diseases affecting the organs of the female reproductive system, and may originate in the breasts, cervix, uterine body, endometrium, ovary, vulva, vagina and fallopian tube. Its genesis occurs by extrinsic and intrinsic factors acting together or in sequence, causing a disorderly growth of abnormal cells with invasive potential to initiate or promote the disease. These cells tend to be very aggressive and uncontrollable, leading to the formation of tumors that can spread to other regions of the body^{1,2}.

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Cancer can affect women's physical and mental health, as well as marital and social relationships, lead to emotional problems such as depression, anxiety, insomnia and fear, impairing their quality of life^{3,4}. Individuals facing female cancer often suffer from body dysfunctions resulting from treatment, be it a removed breast or some pelvic floor dysfunction, which affects physical, emotional, professional and social wellbeing, leading to low self-esteem, loss of femininity and compromised sexuality^{3,5}.

From the moment a woman is faced with the diagnosis of cancer, her way of life and her interpersonal relationships become objects of reflection and questioning. Feelings when facing the disease can change during treatment, the body's reaction, the family's support, as well as the fears, doubts and anxieties suffered by each one throughout each therapeutic stage⁶.

Therefore, investigating the meaning attributed to this experience becomes fundamental to promote and optimize coping strategies in practice, contributing to increase women's quality of life in their biopsychosocial integrality. In view of what was discussed, emerges a question: How do women feel when facing female cancer? This study has the following objective: to describe the representational contents of women experiencing cancer.

METHOD

Qualitative, descriptive, exploratory study in which Serge Moscovici's Theory of Social Representations (TSR) was used.

Social representations are common sense knowledge that direct individual and group actions and have the purpose of turning something unfamiliar into something familiar. In this sense, the construction of representations involves two formative processes: anchoring and objectification. Through them, it is possible to identify and apprehend the knowledge disseminated in the various existing social relations⁷⁻⁹.

The study was developed in a High Complexity Center in Oncology, which serves exclusively users of the Brazilian Unified Health System (SUS). Using a non-probabilistic convenience sample, 20 women were selected according to their presence in the study site and availability to participate at the time of data collection, obeying the inclusion criteria.

Inclusion criteria were limited to women over 18 years of age undergoing treatment for female cancer at the High Complexity Center in Oncology during the data collection period. Exclusion criteria were women experiencing some emotional stress and/or weakness at the time of data collection that prevented them from participating in the study, as well as women with difficulties in interacting with the research instruments.

Data collection was performed between January and March 2021 by one of the researchers, and was held individually, ensuring the privacy of participants. Semi-structured interviews were conducted and recorded with use of a cell phone, and had an average duration of 40 minutes. They contained questions for the characterization of participants (sociodemographic data, information about cancer and the woman's health status), and open questions on the theme, with guiding questions for the investigation of social representations, such as: For you, what is cancer and what does it mean to have cancer? What was it like to receive the diagnosis? Did you feel you had support? From whom? What is quality of life for you? The collected data were transcribed in full.

The data analysis process was based on the content analysis technique, thematic modality as described by Bardin, which comprises a set of communication analysis techniques based on three stages: pre-analysis; exploration of the material; and treatment of results and interpretation of data, categorizing them into thematic units that use systematic procedures. The TSR was used as a theoretical framework^{10,11}.

The ethical aspects were followed in their entirety, respecting the Resolutions of the National Health Council (CNS) 466/2012 and 510/2016. The research protocol was assessed and approved by the Research Ethics Committee of the institution.

Participants signed the Informed Consent form and were made aware of all constituent elements of the study. Women's reports are identified by names of colors to guarantee the secrecy and anonymity of participants.

RESULTS

According to information obtained from the 20 participants, age ranged from 29 to 65 years; eight were married, five were single, four in a common-law marriage, two divorced and one was a widow. As for education, ten had incomplete primary education, five had complete primary education, three had incomplete secondary education, one incomplete higher education and one had complete higher education. Nine women declared

themselves as black, seven as mixed race, three white and one yellow. Regarding religion, twelve were Catholic, seven Evangelicals and one Spiritist.

As for women's clinical profile, fourteen were facing breast cancer, four had cervical cancer, one had uterine cancer and one had ovarian cancer. The time spent on treatment ranged from two to seven months, and 13 women reported having a family history of cancer.

The thematic categories that emerged after analyzing the content of participants' statements were: Social representations regarding the meaning of cancer; Social representations of women regarding diagnosis; Social representations of women regarding support for coping with cancer; and Social representations of women regarding the hope of a cure.

Social representations regarding the meaning of cancer

When asked about what cancer is, most participants reported not knowing anything about the disease, and only two of those who reported having knowledge had some information about the pathology:

It's a very serious disease, right? It messes with everything in the person's body, in all cells and in the head too. The bad cells start to multiply very fast, the person is in a lot of pain, very tired. (Lilac)

I think it's a very difficult disease, the cure... There are many types. It starts with a little lump, a little thing, and then it gets bigger, the cells get bigger, multiplying. And there is also the family issue, I forgot how to say it, that if there is a case in the family, you can have [cancer] too. (Yellow)

In view of everything heard regarding the cancer topic and the usually negative prognosis of the disease, the social representation constructed by women in this study are synonymous with punishment and pain, a threat that goes beyond health. When asked about what it means to have cancer, the socially constructed meaning overlapped with scientific knowledge, since in most reports, cancer appears as a synonym of the end of life and intense suffering:

It represents a lot of suffering, the exams, chemotherapy, everything. What we most see is people dying from this disease. (Green)

Punishment, at first, I didn't accept it. My boy thought I was going to die, and so did I. I felt a lot of pain, it got worse, until today [...] it was only later, when I went through the tests, that I calmed down. (Blue)

It's a lot of pain, my dear, a lot of suffering. (Red)

Social representations of women regarding diagnosis

Women revealed that the way they receive the diagnosis of female cancer brings important meanings to representations of the disease. At this moment, the hitherto unknown diagnosis becomes familiar, reflecting the prominence of the object in question and the meaning attributed through the processes of objectification and anchoring.

When asked about how it was for them to receive the diagnosis, they expressed:

Bad. I cried a lot I went into despair [...] I couldn't believe what was happening to me. (Pink)

It was horrible [...] because the whole time I was believing it wasn't malignant. (Lilac)

All women reported that upon receiving the diagnosis, the first feelings were negative. When faced with the diagnosis of cancer, interviewees expressed feelings of despair and disbelief given the possibility of facing the disease, reporting the perpetuation of a pessimistic image in which the word cancer is strongly anchored in social representations such as fear, suffering, death, disabling illness, dread and despair. The results also showed that the feeling of partial denial of their situation is common when faced with the diagnosis of female cancer.

Another feelings revealed by interviewees after the diagnosis were: deep sadness, anxiety and depression:

I was devastated, I spent many days just locked in the room, crying. (White)

I felt devastated, torn apart inside, not wanting to eat, take a shower [...] or live. I never imagined going through this. (Yellow)

When I left the doctor, I was... bewildered, I didn't know what to do, it was like it wasn't with me. I felt very scared, tight, I just cried. (Orange)

The study showed that depression ends up joining these representations, reflecting too much on the quality of life and prognosis of the disease, as well as on decision-making regarding adherence and continuity of treatment.

Study participants reported that depression symptoms prevent them from solving a series of problems, because, as they believe less in their potential, they tend not to act. Only after experiencing the process of psychological adaptation and acceptance of the disease, and expressing feelings of anguish, sadness and depression, women reported finally understanding the diagnosis and the new reality added to it, and then, continue in the process of coping with the disease.

Social representations of women regarding support for coping with cancer

When asked about the support they had in the face of diagnosis, all women mentioned having received some kind of support:

I had, from my husband, my daughter, my sisters, everyone. It was hard for everyone, but thanks to them, I always had it in my head that I was going to get out of this. They were the ones who gave me strength. (Gray)

I felt [there was support] from my family, friends, from the girls here [of the health team]. Otherwise, I don't know what it would have been like. I was very bad, thinking nonsense, in taking my own life [...] but I put it in God's hands. (Burgundy)

The representations of support and care expressed in women's speeches are based on the premise of finding the strength to continue life in people around them, when feeling discouragement and sadness.

Social representations of women regarding the hope of a cure

Anchored in social relationships, beliefs, culture and spirituality, and objectified in the so far negative stigma of the disease, the speeches showed that spirituality brings strength and confidence to these women, to face difficult situations throughout the process of searching for the cure, evidencing the use of faith as necessary in this trajectory:

All that has been happening is a miracle [...] it's a great lesson for us to value life, family, the simplest things [...] I'm going to heal myself with faith in God, and my will to live. (Orange)

The treatment went very well, thank God and the doctor, even himself was surprised at how good it was. I believe in my health back, in my cure. (Beige)

The study revealed that spirituality represents a fundamental strategy in the process of coping with cancer, allowing understanding the disease as a moment of re-signification of life, giving them inner strength and courage to deal with the situation, also for the effective adherence to treatment.

DISCUSSION

When analyzing the speeches and sociodemographic profile of participants, the lack or little knowledge of the pathology in women of this study is related to their low educational level. Their reports are similar to the findings of a study conducted with 220 cancer patients, predominantly women, who, despite having the disease, had little or no knowledge about the pathology¹².

According to another study, people with less time of schooling are less likely to seek information, and adults with limited literacy are less likely to ask questions to clinicians and have difficulties in understanding the information presented¹³.

The analysis of speeches showed that the meanings attributed to female cancer by women reflect the negative images arising in the social imagination, as well as the objective and subjective conditions experienced by each woman and the pre-knowledge of the disease.

Participants' information about cancer has consequences for the representativeness in lives of these women and the group in which they are inserted, since facing female cancer requires discipline and knowledge for the occurrence of a series of healthy behaviors such as taking medication, following diets, exercising, and going to follow-up appointments¹⁴.

These behaviors are necessary to control or prevent the progression of the disease, and decrease the side effects and interference in daily life, allowing the patient to have a life similar to that before the diagnosis¹⁵.

Through speeches, gestures and behaviors, people express the meanings attributed to the knowledge constructed daily by sharing thoughts, ideas and creating new knowledge. Social representation joins science at the same time that it is constituted by it, becoming part of the collective, of common sense^{8,16}.

The representational contents of female cancer are related to internal suffering and strongly anchored in representations of death, fear and despair. The lack of definition regarding the disease prognosis, side effects of chemotherapy and even the uncertainty of what will happen after treatment are always present questions¹⁷.

There are five phases of psychological adaptation to a chronic disease: denial, anger, bargaining, depression, and acceptance. When experiencing a stressful event, the person tends to go through these phases of internal conflict, ranging from denial to acceptance of the diagnosis¹⁸.

Denial, the first phase of psychological adaptation, was very present in the speeches as a reflection of a psychic defense, where some interviewees reported refusing to believe they were facing cancer, in order to somehow try to distance themselves of reality. It is a phase of intense suffering and difficulty in accepting the new health condition and all confrontations that cancer requires.

These phases are observed in deeply stressful situations, such as the detection of cancer, loss of a loved one, traumatic surgery, among other situations that can cause great distress and suffering¹⁹.

In oncology, it is common for clinical follow-up to reveal symptoms of anxiety and depression. Psychic suffering and its cumulative effect favor the development of various psychosomatic diseases. The findings of another study conducted with 99 cancer patients corroborates this fact, as depression also appeared as a social representation, as well as the feeling of loneliness²⁰.

Understanding the social representations of these women in the face of depression caused or accentuated by the diagnosis of female cancer means distinguishing the processes of classification and naming, which allow understanding psychic suffering and anchoring it in a network of meaning. The greater the woman's perception and emotional stability the greater her chance of performing self-care²¹.

The diagnosis of cancer rarely affects exclusively the patient: it also affects the entire family and social network in a way that they experience long periods of hospitalization, frequent hospitalizations, therapy with various side effects, changes in routine, financial maladjustment, anguish, pain, suffering and the constant fear of the possibility of death²².

The family is indispensable in the process of treating cancer, essential in encouragement, psychological support, the performance of day-to-day activities, monitoring medical appointments, helping with bureaucratic issues or even seeking information about the disease and the patient's rights²².

A present and supportive social network reflects in better living conditions for people, the network contributes to better self-esteem and increase in their quality of life. On the other hand, the lack of this support results in a difficult experience throughout the treatment process.

Faced with cancer and its biopsychosocial repercussions, spirituality expresses its role and importance, as it is where many women find strength to face all the stress and turmoil of feelings resulting from cancer. Spiritual needs are the variables that encourage the search for the meaning of life and help the person to transcend amid difficulties²³.

CONCLUSION

Through the results obtained, it was observed that the representational contents of female cancer are related to internal suffering and strongly anchored in representations of death, fear and despair. Despite scientific advances in the area of oncology, cancer continues to be surrounded by a painful meaning for women who have it.

In view of this, it is necessary to demystify the negative image associated with this disease in order that women achieve good treatment adherence and reduce the negative impacts related to it.

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