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Psychological Representation of Disease in Breast Cancer

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Abstract: Cancer represents the second major cause of mortality worldwide, after cardiovascular disease. The most common type of cancer that affects women is the breast cancer. This article presents a study about different representations of cancer on diagnosed patients, nurses working on oncology and healthy family members. Previous and actual experience influence the content and structure of representation for all of us, so different individuals will have different psychological representation of the disease. Evaluation of psychological representation of breast cancer was based on Illness Perceptions Questionnaire (IPQ) described by Weinman in 1996 for all five stages of disease: identity, causes, evolution, consequences and control. Results reveal that nurses and family member got high scores on evolution, understanding that cancer is more like a chronic disease under treatment, but patients got low scores on evolution and control of cancer, thinking these are dictated by faith and luck. All participants got high results about identity, the most negative consequence is the impact on women's image. This article presents unique interpretation and results about psychological differences in representation of cancer from perspective of patients, nurses and healthy persons and can contribute to improving both medical care and psychotherapy of suffering patients.

Keywords: psychotherapy; cancer therapy; psychotraumatology; human development

1. Introduction

Generic term of cancer covers more than 200 affections characterized by fast grow of abnormal cells beyond their usual boundaries that can spread to other organs and the latter process is known as metastasizing. Changes produced by cancer are the result the action of both genetic factors and 3 categories of external agents: physical carcinogens (ultraviolet and ionizing radiation), chemical carcinogens (asbestos from tobacco smoke, aflatoxin from contaminated food and arsenic from drinking contaminated water) and biological carcinogens (viruses, bacteria or parasites). All these factors are more likely to produce cancer cells as a person grows older, so age is another factor for this disease, because human cells' repair capacity is reduced by ageing.²

This article's goal is to present the results of a study about differences in psychological representations of this disease on distinct categories of populations: women patients diagnosed with breast cancer, nurses from Oncology hospital sections and healthy women. We also tried to describe the nature of the differences perceived for all the five dimensions followed: identity, evolution in time, causes, consequences and control.

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²Ferlay, J.; Soerjomataram, I.; Ervik, M.,; Dikshit, R.; Eser, S.; Mathers, C. et al. GLOBOCAN 2012 v1.0, Cancer Incidence and Mortality Worldwide: IARC Cancer Base No. 11-Lyon, France: International Agency for Research on Cancer; 2013.

Breast cancer is the most frequent type of cancer for women worldwide, this is why In 2017, the World Health Assembly passed the resolution *Cancer Prevention and Control through an Integrated Approach* (WHA70.12), urging governments and WHO to accelerate action to achieve the targets specified in the *Global Action Plan and 2030 UN Agenda for Sustainable Development* to reduce premature mortality from cancer.

When people receive cancer diagnosis they have different reactions about the disease, but also about treatment. These differences suggest that patients have different representations of their experiences, based on cognitive factors of psychological response to this extreme situation.¹ Patients' response to this situation is integrated in cognitive structures and mental representations previously created, in order to explain and give sense to the actual health state and the appearance of the disease. Mental representations are defined by five elements: identity (tags, signs, symbols), causes, evolution in time, consequences (results of disease and response to treatment and its effects on the patient) and control (the patient controls the treatment to be followed and its efficiency).

Past and present experience influence content and structure of mental representation of illness. Therefore, different individuals will have different mental representations of the disease, depending on the perspective: weather they are patients, nurses or healthy persons.

2. Related Work

Worldwide, every year 7 million people are diagnosed with cancer and without the proper treatment this disease usually leads to death. It is estimated that cancer will become the leading cause of mortality and morbidity within the next period in the high industrialized countries, since the incidence and prevalence of cancer is constantly growing.

In Romania the situation is similar to other countries and breast cancer is the most frequent type, the situation for every type of cancer is presented in the Table 1 below:

Table 1. Incidence, mortality and prevalence of cancer types in Romania²

Cancer type	Incidence	Mortality	5 years Prevalence	% Mortality/incidence
Breast	8981	3244	33388	36%
Colorectal	4496	2446	10516	54%
Cervix uteri	4343	1909	14834	44%
Lung	2327	2047	2319	88%
Ovary	1850	1020	4176	55%
Corpus Uteri	1539	359	5819	23%
Bladder	1390	1236	657	89%
Stomach	1364	1149	1593	84%
Brain& nervous system	800	732	906	92%
Leukaemia	741	501	1517	68%
Liver	729	595	1012	82%
Kidney	690	295	1866	43%
Thyroid	662	109	2602	16%
Skin	593	175	2034	30%

¹ (Buick, 1997) In Petrie, K.J. & Weinman, A.J.: Perceptions of health and illness: current research and applications, Hardwood Academic Publishers, Amsterdam.

² <http://globocan.iarc.fr>

Other types of cancer	1562	910	2744	58%
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And even more specific, in our city Galati, from the evidence of the Public Health Department (DSP) results that thousands of people suffer from a different type of cancer. Doctors from our county diagnose over 1.000 new patients with cancer every year, the most frequent types are breast cancer, prostate and colorectum.

For example, just for the first three months of last year, 2017, over 200 new cancer cases were discovered in our city. Total number of cancer patients was 17.362, and from the 100 new cases, 27 were breast cancer. 2402 women from our city suffer from this disease.

Despite the gravity of the disease, cancer diagnosis is not the equivalent of a death sentence, nowadays there are efficient treatments to ameliorate the pain and there are intense international programmes for prevention, early diagnosis, screening, treatment and palliative care.¹

3. Problem Statement

Howard Leventhal and his colleagues, in the early 1980s, departed from the initial researches in the field of mental threat representation and threat processing, focusing on studying how people perceive disease as a threat. They developed a theoretical model, the pattern of self-correction of disease responses, which comprises in an integrated system the emotional and cognitive mechanisms involved in the formation of mental illness representation.²

The self-regulation model proposed by Leventhal, Nerenz and Steele³ describes three recursive stages that regulate behavior.

These studies are:

- cognitive representation of the disease - whose characteristics are: identity, causes, consequences, evolution over time, controllability/curability;
- coping - which involves different ways adopted by the patient to cope with the disease;
- Evaluation - the individual uses various criteria to assess the effectiveness of coping actions; Depending on these results patient determines the changes at the level of previous stages.⁴

The model proposed by Leventhal presents two essential features:

- people are seen as active participants in the accumulation and processing of disease information;
- cognitive representations play an important role in selecting coping modalities that will serve the individual.

¹ <http://dsp-galati.ro/>.

² (Leventhal & Diefenbach, 1991). In J.A. Skelton & R.T.Croyle (ed.) *Mental Representations in Health and Illness*. New York: Springer Verlag Inc.

³ Leventhal, H.; Nerenz, D.R. & Steele, D.J. (1984). *Illness representations and coping with health threats*. In A. Baum, S. E. Taylor & J. E. Singer (eds.): *Handbook of psychology and health*. N.J.: Lawrence Erlbaum Associates, Hillsdale.

⁴ (Scharloo & Kaptein, 1997). In Petrie, K.J. & Weinman, J.A. (eds.): *Perceptions of Health and illness: Current Research and Applications*. Amsterdam: Harwood Academic Publishers.

4. Concept and Terms

4.1. Objectives of the Study

In this article we present a study starting from the theoretical hypothesis that the individual is an active problem solver and in his attempt to give meaning and sense to the current state of health or illness he represents this state based on his past and present experiences. Starting from this theoretical general hypothesis, the study aims to identify the differences in the mental representation of breast cancer in different groups of individuals: cancer diagnosed patients, Oncology nurses and healthy women.

4.2. Methodology

For the investigations proposed in the research objectives, three groups of subjects were used.

The first group of subjects consisted of 34 patients diagnosed with various forms of breast cancer (N = 34) that completed the survey directly in the Sf. Ap. Andrei County Hospital Galati or intermediated by Association of Cancer Patients Galati. The mean age of the patients was 56.8 years, with the range between 36 and 73 years. Of these, 23 were retired (82.8%) and the rest were professionally active (17.8%). A total of 11 patients (36.11%) came from the rural area and 23 (63.88%) from urban. Depending on the stage of the disease, there were 2 cases (5.5%) in the first stage, 14 cases (38.8%) in the second stage, 17 cases (47.2%) in the third stage and 1 case (7%) in Stage IV.

The second group of subjects consisted of 22 nurses (N = 22) from oncology specializing in breast cancer. The subjects work in the the Sf. Ap. Andrei County Hospital Galati.

The third group of subjects consists of 24 female subjects (N = 24) who have not been diagnosed with any chronic disease. The average age was 59-64 years with the range between 50 and 76 years. We selected female individuals aged 50 years because this characteristic, i.e. 50 years of age with menopause and menarche at 12 years or earlier, the first birth at > 30 years, is the main risk factor of breast cancer. (Ghilezan, 1992)

4.3. Instruments

Assessment of the clinical stage of the disease - for the subjects of the first batch was done according to staging system. The data were taken from the patient's medical records provided by patients themselves.

Stage I - characterizes small-tumor, less than 2 cm, stage II - characterizes the tumor between 2 and 5 cm, stage III - large tumor over 5 cm and stage IV - enlarged thoracic and/or skin tumor, with or without extension.

The evaluation of the mental representations of the disease was based on two questionnaires made for the three groups of subjects. The first questionnaire addresses the batch of patients diagnosed with breast cancer, while the second questionnaire is for the two groups - nurses and healthy people The elaborated questionnaire was based on the Illness Perceptions Questionnaire (IPQ) developed in 1996 by Weinman, Petrie, Moss-Morris and Horn. (Petrie & Weinman, 1997)

IPQ is a new method of assessing the mental representations of the driving disease in Leventhal's mental illness model. The questionnaire contains items for assessing the five components of the disease: identity-related, cause, evolution over time, consequences and control.

4.4. Study Procedures

The questionnaires were completed by patients in the salon where they were hospitalized in the Sf. Ap. Andrei County Hospital Galati or intermediated by Association of Cancer Patients Galati (ABC Galati). There was no time limit for the discussion accompanying the questionnaire completion. This was beneficial, in the sense of clarifying some issues that occurred while filling the survey. The individuals of the three groups included in the study agreed to participate in this research.

5. Analysis of Results

The raw data of the study were processed using the SPSS statistical program. In a first part the descriptive statistical values (averages, standard deviations) were calculated. For the examination of differences between variables we compared the averages obtained by each group (the T test for independent groups and P on the five dimensions of the mental representation of the disease.)

Table 2. Statistical values obtained by the group: cancer patients Vs. Oncology nurses

Dimensions of Cancer Mental representation	Breast cancer diagnosed patients		Oncology nurses		Calcul. T test	P (on 5 dimensions)
	average	standard deviation	average	standard deviation		
identity	1.67	0.35	2.50	0.51	7.82	<001
Evolution in time	2.34	0.65	3.85	0.83	8.49	<001
consequences	3.53	0.38	3.98	0.55	3.99	002
control	3.10	0.43	3.74	0.56	5.32	<0001

Table 3. Statistical values obtained by the group: cancer patients Vs. Healthy women

Dimensions of Cancer Mental representation	Breast cancer diagnosed patients		Healthy women		Calcul. T test	P (on 5 dimensions)
	average	standard deviation	average	standard deviation		
identitate	1.67	0.35	2.47	0.49	7.99	<001
Evolutie in timp	2.34	0.65	3.63	0.80	7.55	<001
consecinte	3.53	0.38	3.66	0.59	1.16	.246
control	3.10	0.43	3.30	0.56	1.72	.089

Examining average scores for each dimension of mental illnesses indicates the issues: people diagnosed with breast cancer have a lower identity of disease than nurses and healthy women. This implies that the cancer symptoms are little known and insufficiently identified by individuals, which explains the high percentage of people in the late stages of the disease. Studies indicate cancer as a rather asymptomatic than symptomatic disease, the treatment being generally more unpleasant than the disease itself - this distinguishes cancer from other chronic diseases. It is a “*silent killer*”.

The high scores obtained by the subjects included in the two groups (nurses and healthy people) are explained by the fact that both nurses in oncology and healthy people perceive breast cancer as a disease that involves a high degree of suffering from both the symptoms and treatment involved in the disease. The differences resulting from these scores indicate that there are some discrepancies in the mode of representation of breast cancer in different populations. The belief of sick people in a limited time span of their illness shows the presence of a poor education of the patient related to the consequences and duration of their illness. And not only poor education, but also a lack of adapted

psychotherapy. Control perceptions can be modified in the direction of increasing self-confidence and the ability to control disease progression through informative programs to learn how to manage the treatment of the disease and the side effects that occur.

Table 3. Causes of breast cancer: perceived by patient Vs. Real caus accordng to medical file

Perceived caused by patient	% of patients indicating the right cause
Stress	47,22%
Blows to the breast	25%
Hormonal disorders	11%
Other causes	11%
By chance	2,77%
Heredity	2,77%

Breast cancer is a chronic disease with serious economic, social and psychological consequences. The high scores obtained by the three study groups confirm the severity and effects of cancer.

In items referring to the consequences of the disease, most people rated them on the highest scale. An important consequence of diagnosing this disease is related to body image impairment. Indeed, for a large population, cancer treatment leads to impaired body image and trauma of the treatment itself (chemotherapy, radiotherapy, surgical).

6. Conclusions

Following the meetings with patients who participated on this study, we can conclude that women with an extinct breast, following mastectomy, wanted to receive information about the purchase of a prosthesis (cost, place of purchase, financial help etc.). These questions appear after a while, when we also see the need for group meetings, including specialized breast cancer psychotherapy programs. A first step in this direction could be to produce leaflets with the necessary information specific to the group to which they are addressed: people diagnosed with breast cancer or prone to this type of cancer.

Patients who have chosen lumpectomy instead of mastectomy have different “breast cancer” opinions compared to women who decide for mastectomy. Women who choose partial resection and radiotherapy consider that they will have difficulty adapting to the loss of a breast after mastectomy and are more concerned with their body image and more dependent on the presence of breasts for maintaining self-esteem. In contrast, women who choose mastectomy, perceive their cancer as something ‘strange’ that has to be cut away from their body and are more concerned about the secondary effects of radiation.¹

Interpretation of these data according to Leventhal's model suggests that patients have taken the treatment decision that was congruent with their mental representation of cancer.

The study's goal is to identify the differences of representation and their nature at the level of three distinct populations, based on the model of mental illness representation. The results of the study confirmed the existence of differences in the mental representation of breast cancer and outlined the characteristics of the five defining dimensions in the representation of cancer.

The processing and analysis of the data obtained on the basis of the two questionnaires revealed the following conclusions:

¹ Ashcroft, J.J.; Leinster, S.j. of Shade, P.S. (1985). Breast, cancer patient choice of treatment: Preliminary communication. *Journal of Royal Society of medicine*, 1978.

- People diagnosed with breast cancer have a lower identity of disease than nurses and healthy people. This implies that cancer symptoms are little known and insufficiently identified by individuals;
- Healthy people and nurses perceive the disease as having a chronic, long-lasting development, but being controllable due to their professional status, confidence in their profession and treatment efficiency;
- The belief of people diagnosed with breast cancer over a limited time period of their illness indicates the presence of their poor education in relation to the consequences and duration of their illness and insufficient psychotherapy for patients
- The perception of control is often related to “destiny” or “chance”, which can be changed in the direction of increasing self-confidence and the possibility of controlling disease progression by means of informative programs by which patients are taught various ways of management the treatment of the disease that follows and the side effects that occur and psychological support;
- All subjects estimate the same level of consequences of such a disease with a huge impact on body image
- The causal attributions of the disease vary according to the type of membership and specialized knowledge of the subjects in the present study.

7. Future Work

Further research should identify the nature of the relationships between the components of the mental representations of the disease and the coping mechanisms; also to look at how the mechanisms of coping mediate the relationships between the mental representations of the disease and the aspects of adaptation to the illness (physical, social, mental health and vitality).

Another starting point for future research is the development of disease assessment tools that can be used as clinical methods for detecting patients at high risk for poor disease adaptation.

Future intervention programs for patients diagnosed with breast cancer should provide information on the nature and consequences of treatment that will reduce the discrepancy between what patients think is happening and what is actually happening. We cannot say that there is an effective intervention strategy for all patients, but knowing a disease profile, a certain pattern in which they represent the disease experience, we can streamline the medical act and offer the psychological support that became very important in a breast cancer diagnosed patient.

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