

SELF IMAGE AND RESILIENCE OF ONCOLOGICAL PATIENTS

Autoimagem e resiliência de pacientes oncológicos

Autoimagen y resiliencia de pacientes oncológicos

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SUMMARY

Objective: Resilience of patients diagnosed with cancer in the face of changing body self-image. **Method:** exploratory research with quantitative and qualitative approach, the research scenario was a large hospital with adult participants. The instrument for data collection included a sociodemographic questionnaire, the BIS scale and the Wagnild Resilience Scale. **Results:** The interviewed patients presented according to the BIS scale a greater number of symptoms and discomfort with their self-image, and regarding resilience, the interviewees concentrated on the moderately low to high score. **Conclusion:** the patients exposed their needs, demonstrated their weaknesses, as well as the difficulties in facing a treatment full of stigmas, sometimes from their family or even health professionals, and showed that the greater the change in body image felt by the patient, the higher the level of resilience they may have or develop during treatment.

Descriptors: Nursing; Oncology Nursing; Neoplasms; Self Concept; Resilience.

RESUMO

Objetivo: resiliência dos pacientes com diagnóstico de câncer diante da mudança da autoimagem corporal. **Método:** pesquisa exploratória com abordagem quanti-qualitativa, o cenário de pesquisa foi um Hospital de Grande porte, com participantes em idade adulta. O instrumento de coleta de dados conteve um questionário sociodemográfico, a escala BIS e Escala de Resiliência de Wagnild. **Resultados:** Os pacientes entrevistados apresentaram segundo a escala BIS um maior número de sintomas e perturbação acerca da sua autoimagem, e no que diz respeito a resiliência, os entrevistados se concentraram no score de moderadamente baixo a alto. **Conclusão:** os pacientes expuseram suas necessidades, demonstraram suas fragilidades, bem como as dificuldades de enfrentar um tratamento cheio de estigmas, por vezes de sua família ou até dos profissionais de saúde e mostraram que quanto maior a mudança na imagem corporal sentida pelo paciente o mesmo poderá apresentar ou desenvolver um alto nível de resiliência durante o tratamento.

Descritores: Enfermagem; Enfermagem Oncológica; Neoplasias; Autoimagem; Resiliência.

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RESUMÉN

Objetivo: resistencia de los pacientes diagnosticados con cáncer frente a la autoimagen corporal cambiante. **Método:** investigación exploratoria con un enfoque cuantitativo y cualitativo, el escenario de investigación fue un Hospital grande, con participantes en la edad adulta. El instrumento de recolección de datos contenía un cuestionario sociodemográfico, la escala BIS y la Escala de Resiliencia de Wagnild.

Resultados: los pacientes entrevistados presentaron, según la escala BIS, un mayor número de síntomas y trastornos con respecto a su propia imagen, y con respecto a la capacidad de recuperación, los entrevistados se concentraron en el puntaje de moderadamente bajo a alto.

Conclusión: los pacientes expusieron sus necesidades, demostraron sus debilidades, así como las dificultades de enfrentar un tratamiento lleno de estigmas, a veces de su familia o incluso de profesionales de la salud, y mostraron que cuanto mayor era el cambio en la imagen corporal que sentía el paciente, lo mismo puede tener o desarrollar un alto nivel de resistencia durante el tratamiento.

Descriptor: Enfermería; Enfermería oncológica; Neoplasias; Autoimagen; Resiliencia

INTRODUCTION

The purpose of this study is based on the experience in a large hospital located in the city of Rio de Janeiro, where I came across a significant number of cancer patients who were treated for malignant neoplasms and often did not conform with the body image imposed by the society.

Cancer has great epidemiological importance and social magnitude, representing one of the main causes of mortality in Brazil and worldwide. Distribution of malignant neoplasms varies from region to region of the country and requires varied actions and health care services.¹

The incidence of cancer has been increasing in Brazil, as well as worldwide, following the changing age profile of the population. Currently, cancer is the second leading cause of death in Brazil.² This growth has led to the increase in the number of outpatient treatments, hospitalization rates and public resources required to pay for the treatments.³

According to a survey conducted by INCA, it is estimated that in 2016 there were 600,000 new cases of cancer throughout the Brazilian territory. Currently, according to data from the Ministry of Health, cancer is the second leading cause of death in Brazil, behind only heart and circulatory system diseases.⁴

Lifestyle, poor habits and aging population have increased the number of cancer cases in Brazil. Adults are the most affected, especially young adults. Due to the social pressure of entering the job market, seeking a better future, they end up suffering from factors such as stress and poor diet, among others that can trigger cancer.⁵

Cancer treatment is one of the most debilitating treatments and causes a drastic change not only in physical terms, but in the appearance of those who undergo it as

well by affecting skin, nails and hair. Scarring, asthenia, ostomy and limb amputation can also affect individuals with malignant neoplasms, causing permanent bodily changes, with severe impairment of body self-image.⁶

Nowadays people are increasingly influenced by social media which sells a stereotypical image of beauty that many do not have and oftentimes is virtually unattainable, especially for people on extremely debilitating treatment for malignant neoplasms.

Although it is a complex concept, body self-image is understood as mental representation of one's own body. The term image, in this case, is not restricted to the specific sense of vision, but encompasses the affective, social and physiological experiences that influence the way the subject perceives himself or herself. Body image is particular to each person, and is linked to the subject and his or her history.⁷

In modern life adults are exposed to dozens of stressors. They are challenged in forming a family, parenting, by work and career demands, personal projects, social relationships, including power relations, policies, duties and obligations required by the society.

This reality of today's society forces people to develop psychological and cultural defenses, which are currently being defined as resilience in social sciences, referring to the ability to resist and persevere in the face of difficulties. A personality attribute that, activated and developed, would enable human beings to overcome themselves and the pressures of their world, developing a realistic self-concept, self-confidence and a sense of self-protection that does not disregard the openness to innovation, to change, to others and to underlying reality.^{7,8}

Resilience, in the etymological sense, is a concept used since 1620, derived from the Latin *resilientia*, derived from the verb *resilio* (re + salio) with the meanings of jumping back, recovering, returning to normal. It is a concept derived from physics, which means the ability of a material to absorb energy without undergoing plastic or permanent deformation, i.e., it is the "property by which the energy stored in a deformed body is returned when the tension causing elastic deformation ceases".⁹

For George Brabosa, resilience "is an intrinsic force to all living beings and things. It is a conjunction of biological resources, psychic resources and social resources that structure the overcoming of adversity that threatens our existence". It is the ability of a person to transcend the obstacles, clashes, adversities and conflicts that life presents - to deal with the unexpected.

To be resilient is to respond positively to a situation of conflict or distress, breaking patterns that are expected by education, culture, religion, etc. without presenting periods of depression or sadness for a long time, on the contrary, extracting positive from the situation and overcome it gaining maturity.

In a research conducted via the Virtual Health Library (VHL), searching for the description of self-image, resilience and nursing, in the last five years, eighteen (18) articles were found, among which one (1) was able fully accessible, free of charge, in English and available for use in this study. This underscores the insipience of published works, mainly Brazilian, on the subject in question.

This research aims to contribute to the development of oncological care, associating the diagnosis with the way of coping with the disease, thus allowing to find out what helps cancer patients in dealing with the treatment in the best manner and helping medical care professionals in assisting their patients throughout the process of coping with the disease and building resilience. Not only medical professionals, but family members, friends as well as the patient himself or herself can use the identified empowerment factors to contribute to the improvement of treatment.

Given the above, the object of the study was defined as follows: resilience of patients diagnosed with cancer in the face of changing body self-image. The objectives of the study were: to identify responses of adult patients diagnosed with cancer and facing changes in their body, to map the resilience of patients diagnosed with cancer, and to verify correlation between resilience level and the change in body image among patients diagnosed with cancer.

METHOD

This was an exploratory research with quantitative and qualitative approach.^{10,11}

The research was conducted in a large hospital in the city of Rio de Janeiro, in the Internal Medicine, Gynecology, Urology, Proctology, General Surgery and Oncology (Chemotherapy and Ambulatory) sectors.

The study participants were patients of the above-mentioned adult hospital, aged 18 to 60 years (the cut was made according to the Child and Adolescent and Elderly Statute); lucid, oriented and literate; who were not on medication that could alter the quality of responses at the time of the interview. In addition, all had received diagnosis of malignant neoplasia.^{12,13}

Patients under 18 years old and over 60 years old, those without malignant neoplasia and illiterate were excluded.

Patients who agreed to participate in the study signed the Informed Consent Form (ICF) according to Resolution 466/2012.¹⁴

Data collection instrument contained a sociodemographic questionnaire, the Body Investment Scale (BIS) and the Wagnild Resilience Scale.^{15,16} Data was processed using Excel® spreadsheet, scales and charts.

RESULTS

During the data collection period, 60 patients were interviewed at the large Hospital in the city of Rio de

Janeiro, of which 63.3% were female, 36.7% male; with a maximum age of 60 years, a minimum of 25 years and average age of 49.25 years.

Of all patients interviewed, 52% are married, 28% are single, 15% are divorced, 3% are widowed, 2% others.

When asked about schooling, none answered to be illiterate, 30% said they had completed or enrolled in elementary school, 11% completed elementary school, 7% incomplete high school, 30% complete high school, 15% incomplete higher education and 7% complete higher education. One of the likely causes for this percentage was the inclusion criteria being literate and over 18 years old and under 60 years old.

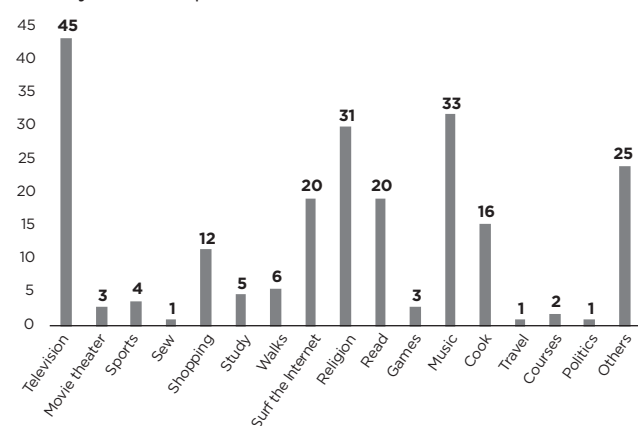
In terms of religion, 5% answered that they have no religion and 95% answered that they did. Of the latter group did 44% described being Christian-Evangelical, 42% Catholic, 7% Spiritist, 2% Umbanda and 5% other religions.

In terms of profession, 25% were employed and 75% did not work. Within the latter group 49% are retired, 31% are unemployed and 20% said they had another type of activity.

When asked about physical activities, 80% answered that they did not engage in sports and 20% answered affirmative. Among those who did engage in sports, 3.33% did so once a week, 5% twice a week, 5% 3 times a week, 6.66% 4 or more times a week.

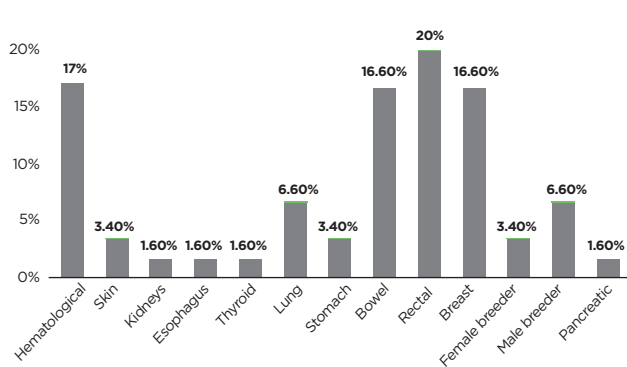
Regarding hobbies, television was cited 45 times in the interviews, music was the second most cited activity (33 times), 31 said religion, internet and reading were cited by 20 interviewees each, 16 take the time to cook, 12 people take the time to shop, and 25 people indicate other activities such as work, crafts, sleeping, cleaning the house, taking care of pets, etc.

Graph 1 - Absolute numbers of patients according to the activity that occupies most of their time



Regarding the types of primary cancer they had, the answers were as follows: 17% Hematological, 3.4% Skin, 1.6 Renal, 1.6 Esophagus, 1.6% Thyroid, 6.6% Lung, 3.4% Gastric, 16.6% Intestine, 20% Colon, 16.6% Breast, 3.4% Female Reproductive organs, 6.6% Male Reproductive organs and 1.6% Pancreas.

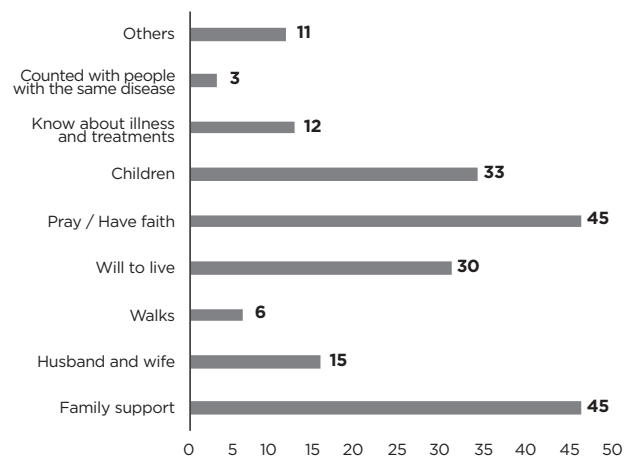
Graph 2 - Percentage of patients according to primary cancer type



In reference to the timing of diagnosis of primary cancer, 27% indicated that found out about the diagnosis six months prior to the interview, 17% from six months to one year before the interview, 28% between one and two years, 28% over two years.

When asked what helps to cope and overcome the difficulties of treatment and illness, 45 respondents answered that family support helps to cope and overcome, 45 relied on praying and faith, 33 on the children, 30 referred to willingness to live, 15 to companion support, 12 indicated knowledge on the disease and treatments, 6 were helped by walking, 13 by contact with other cancer patients, and 11 had other suggestions such as invisible operation, psychological help, help from friends and neighbors and realistic outlook on life.

Graph 3 - Percentage of patients according to what helps to cope with and overcome treatment and disease difficulties



According to the responses on the Body Investment Scale (BIS), 18.3% of patients had no symptoms or disturbances, 80% of patients had more symptoms or disorders and 1.7% of patients scored 30, which we consider to be significant disturbance.

Table 1 - Percentage of patients according to what helps to cope and overcome treatment and disease difficulties

Self image score (BIS)	N	%
0 No symptoms / No disturbance	11	18,3%
> 0 More Symptoms / Disturbance	48	80%
30 A lot of disturbance	1	1,7%

According to the responses on the Wagnild Resilience Scale, the resilience of the interviewed patients was mapped and 3.5% of them had a very low score, 0% low, 20% moderately low, 25% moderately high, 36.5% high and 15% very high.

Table 2 - Table with absolute numbers and percentage on Wagnild Scale Score of interviewed patients.

Wagnild Score	N	%
25-100 Very low	2	3,5%
101-115 Low	0	0%
116-130 Moderately Low	12	20%
131-145 Moderately High	15	25%
146-160 High	22	36,5%
161-175 Very high	9	15%

DISCUSSION

Cancer is a disease that affects people of all genders, ages, cultures and economic backgrounds and has biopsychosocial implications that affect patients, families and their caregivers. Its emergence brings emotional, social, cultural, financial and professional difficulties. This gives rise to the need to provide not only medical treatment but also prevention and early care, as well as different treatment options and care to prevent complications, rehabilitation and palliative measures.¹⁷

Cancer patient goes through major changes in the way of life due to discomfort, pain, disfigurement, dependence, loss of self-esteem, prejudice, stigma, fear, ideas of incurability and death, which unfortunately are justified by the countless cases that receive diagnosis and treatment at an advanced stage.

Weight loss, asthenia, hair loss, presence of scars, mutilating surgeries cause permanent or temporary body changes, with severe impairment of body self-image. The treatment itself (chemotherapy, radiotherapy, surgery) and its side effects can be traumatic, affecting the quality of life and body perception.¹⁸

Physical changes caused by cancer treatment, trigger a significant change in the patient's self-image due to the impairment of physical integrity and emotional fragility.¹⁹

Cancer treatments that affect women affect body image, self-image and self-esteem. The most common changes include hair loss, weight gain or loss, skin dryness, chronic fatigue, nausea, partial or total breast loss, and perception of incompleteness and loss of femininity. For men it is not that much different, but the most discussed impacts are urinary incontinence, fatigue, sexual dysfunction, loss of male identity, with role reversal, as the woman will take care of finances and family, and implications related to the continuity of professional life. For both, after diagnosis and treatment, many cancer survivors positively respond to the rehabilitation process so that the sequelae and complications are overcome. However, some patients do not share this reality and may have problems of mobility, cognition, self-care, loss of libido, suffer due to mutilations that are aggravated by belonging to a society that overestimates physical beauty, making it difficult to maintain the cult of beauty.¹⁷

Doro conducted a survey of health professionals working in an oncology clinic focusing on their perception of cancer. For the medical doctors, cancer was seen as a self-destructive, horrible disease, full of tabus and associated with death. Psychologists emphasized the sense of giving up on life, the passport to death. The nurses' response emphasized predominant feelings of morbidity that contaminate the perception of the situation as a whole, capturing only the losses. They said that cancer is an "animal", it has no cure, it is a disease that always comes back, a cruel and merciless killer. Clearly, the study shows that the view of health professionals is stigmatized, and the same is true to the common sense.²⁰

Another study by Bittencourt in the field of nursing states that nursing care presupposes a care paradigm that goes beyond drug therapy, highlighting the importance of establishing a therapeutic relationship between the patient and the nurse²¹ Unlike Doro, Bittencourt suggests a closer relationship between the professional nurse and the cancer patient, which in most cases helps the patient to cope with the disease, both physically and psychosocially.

In addition to the physical and emotional aspects, the person who has cancer suffers a series of psychosocial repercussions resulting from his illness process. Thus, social support is a factor that contributes positively to the patient's quality of life, as these social ties contribute to the maintenance of health and well-being. The innumerable physical, psychological and social changes imposed by cancer expose the individual to a complex network of conditions requiring adaptive responses under stress. To facilitate coping with these changes, Silva²² suggests

that the family make use of its own resources to adapt to the new context.

Several studies show that resilience is activated much more negative than positive aspects. No one is immune to crises, losses, and adversity, and these people recover faster, facing ever greater challenges. It is a competence that can be developed in any of us.⁵

Grotberg²³ says that "Resilience is the human capacity to cope, to overcome and to be strengthened or transformed by experiences of adversity." Measuring resilience is not simple. If it is really an ability or adaptation process, it would be necessary to assess real and not preconceived responses in a large set of adverse situations. For example, on a consultation day the patient discovers that his cancer has remitted and if he were to answer a resilience questionnaire that day, this situation would affect his responses. However, an imperfect measure is preferable to the absence of measures. Emotions and moods have a powerful influence on judgments, opinions and decision making.

While the patients answered the questionnaire, they explained their needs, demonstrated their weaknesses as well as the difficulties of facing treatment filled with stigma, which sometimes originated from their families or even health professionals. Protective factors used by patients include personal issues, beliefs and values, courage, faith, positive thinking, willingness to heal, and support from family and friends. The participants of this study were found to be resilient people, that is, capable of facing their problems, in this case cancer, and learning from it, adopting a new way of facing life.

Even though we have found some negative numbers for Wagnild's Resilience scale, we must remember Sabbag's words: "No one is resilient all the time."

FINAL CONSIDERATIONS

The interviewed patients had a higher number of symptoms and disturbance in reference to their self-image according to the BIS scale, and regarding resilience, the interviewees concentrated on the moderately low to high score. We can relate that the high level of disruption of self-image reflects the level of resilience the patients need to cope with the disease. We also note that most seek family help and rely on faith in order to cope with the disease, which demonstrates the need for support from a physical or spiritual person who can bring comfort at such a difficult time that a disease as debilitating as cancer brings.

Another interesting fact was that most respondents spend time with television and music, activities that do not necessarily depend on the company of someone else. Faith is the third most cited item as a way to occupy time, showing once again the importance of religion for building the resilience of these people.

We understand that evaluating resilience is not simple, especially since knowing that resilience is not a condition that can be considered stable and constant over time. There is only resilience if there is stress. Resilience is maintaining balance in the face of stress. The individual learns in adversity and reframes his beliefs in order to strengthen himself for a new struggle. It is at the time of facing the problems that we discover if, despite everything, people find ways out, are satisfied and realize that life is worthwhile. For this reason resilience research is difficult because resilience is a changing and shifting situation that can be difficult to analyze and compare. Moreover, the results of such research are based on respondents' answers that can be influenced by their current psychological situation.

According to the data of this research, 80% of the interviewed people have higher number of disturbances in relation to their self-image, and among these, 61.5% had a moderately high or high resilience score. Considering these results we can conclude that the greater the change in body image felt by the patient, the higher the potential to present or develop a higher level of resilience during treatment. With regard to helping the disease process, professionals should understand that religion, no matter which, and family participation are the pillars of building a coping force necessary to treat the disease.

It is also important to highlight the significance of Public Oncology Policies, such as the National Oncology Care Policy (PNAO), which shows that prevention and early detection can help cancer patients to have less aggressive and mutilating treatments.

Finally, the information obtained through this research shows us how important is a multidisciplinary team capable of receiving these patients. Nurses have a particularly important role in this process as they engage in continuous monitoring of the patient. Setting up discussion groups, creating newsletters, folders, and even conducting bedside conversations with patients and family members, addressing issues related to self-image and resilience, are alternatives that nurses can use to help patients cope with the disease and treatment.

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