PERCEPTION AND FEELINGS OF PATIENTS AND THEIR CAREGIVERS IN THE COURSE OF ONCOLOGICAL TREATMENT: A LITERATURE REVIEW

Percepção e sentimentos de pacientes e seus cuidadores no enfrentamento ao tratamento oncológico: uma revisão de literatura

Valdinei Ferreira de Jesus¹
Fernanda Cardoso Rocha²
Jéssica Tayane Ferreira Lima Xavier¹
Álvaro Parrela Piris³

Abstract: Cancer is a worldwide health problem that grew in incidence of 20% in the last decade, it can be considered a chronic disease, which requires continuous treatment. This research is a study of integrative literature review that aimed to understand the perceptions and feelings of patients and their caregivers in coping with cancer treatment. To select the articles two databases were used, BDENF and LILACS, and the sample of this review consisted of seven articles. After analyzing the articles included in the review, the results of the studies showed that in addition to physical treatment, patients need caregivers’ support not only mentally but also spiritually. The family needs an apparatus of professionals, complemented by a psychological support service and also to create spaces facilitating the interfamilial communication is required. Concerning the health team, it was evidenced the need for educational complementations, concerning assistance in oncology, raising awareness and empowering from students to professionals and professors.

Keywords: Oncology; Feeling; Perception.

Corresponding author: Valdinei Ferreira de Jesus.
E-mail: valdineipmc@gmail.com

¹ Faculdades Unidas do Norte de Minas.
² Faculdade de Saúde Ibituruna.
³ Universidade Estadual de Montes Claros.
**Resumo:** O câncer é um problema de saúde mundial que teve um crescimento na sua incidência de 20% na última década, pode ser considerada uma doença crônica, pois exige tratamento contínuo. A presente investigação é um estudo de revisão integrativa da literatura que teve como objetivo compreender as percepções e sentimentos de pacientes e de seus cuidadores no enfrentamento ao tratamento do câncer. Para a seleção dos artigos foram utilizadas duas bases de dados, BDENF e LILACS, e a amostra desta revisão constituiu-se de sete artigos. Após análise dos artigos incluídos na revisão, os resultados dos estudos apontaram que o além do tratamento físico, os pacientes necessitam de apoio dos cuidadores, tanto mental quanto espiritual. A família precisa de um aparato dos profissionais, complementado por um serviço de apoio psicológico e, também, é necessária a criação de espaços facilitadores da comunicação interfamiliar. Referente à equipe de saúde, evidenciou-se a necessidade de complementações educacionais, referentes à assistência em oncologia, sensibilizando e capacitando desde estudantes a profissionais e docentes.

**Palavras-chave:** Oncologia; Sentimentos; Percepção.
INTRODUCTION

According to data from the National Institute of Cancer (INCA), cancer is a global health issue which had a growth in the incidence of 20% in the last decade. For the year 2030 it is estimated that there will be approximately 21.4 million new cases of cancer and 13.2 million cancer deaths in the world. In Brazil, the estimate for the year 2014, which will be validated for the year 2015, indicates the occurrence of approximately 576 thousand new cases of cancer, strengthening the magnitude of the problem of cancer in the country.¹

According to Nettina (2014) ²

[...] cancer can be considered a chronic disease requiring continuous treatment. It consists of over 100 different conditions, characterised by the uncontrolled growth of abnormal cells and their dissemination. The mechanisms of normal growth and proliferation are affected, resulting in distinct morphological changes of the cell and histological patterns aberrations. The malignant cell has the ability to invade the surrounding tissue and regional lymph nodes. The metastasis refers to secondary growth of primary cancer, has a natural history and predictable dissemination pattern...]

The method of treatment depends on the type of malignant neoplasia, the specific histological cell type the stage, the presence of metastases and the condition of the patient.² There are three main ways of treating cancer: chemotherapy, radiation therapy and surgery. They can be used in conjunction, varying only on the susceptibility of tumors to each of the therapeutic modalities and the best sequence of their administration. Few are the malignant neoplasms treated with only a therapeutic modality.¹

Being one of the types of treatment, chemotherapy is a modality that refers to the use of antineoplastic agents to promote the destruction of tumor cells to interfere in the function and reproduction of cells.² However, because it is a form of systemic treatment, it reaches indiscriminately all cells of the body, especially cells of rapid proliferation, producing with this those unwanted or toxic side effects; depending on the state of the individual, disease staging and also of drugs used.³

The chemotherapeutic treatment can be neoadjuvant, adjuvant, curative or palliative. In the neoadjuvant chemotherapy the purpose is to make the tumors resectable or improve the patient’s prognosis. The adjuvant, also called prophylactic is initiated after the surgical treatment when the patient presents no evidence of malignant neoplasia detectable by physical examination and laboratory tests. Whereas the curative is intended to cure patients with malignant neoplasms for which represents the main treatment (which may be associated or not with surgery and/or radiotherapy). Also, there is the palliative treatment, which is indicated for the alleviation of signs and symptoms that compromise the patient’s functional capacity, but they are not passed, compulsorily, on his or her survival. This is used to reduce the tumor, relieving symptoms and improving the patient’s quality of life.¹

The radiotherapy exerts its effects at the application site and operates in the DNA of the affected cells, preventing the multiplication of these and/or inducing their apoptosis death. This therapy is less aggressive to normal cells than chemotherapy, because cells have greater capacity to repair DNA than the malignant ones and, also, the radiation is not a systemic treatment, reaches only the cells that are located in the region for which radiation is directed.⁴
Just as in the chemotherapy treatment, the radiation therapy can be divided for various purposes, namely curative, aiming to cure the patient; the pre-operative, made prior to the surgery, helping in the reduction of the tumor and thereby facilitating the surgical procedure; the prophylactic to sterilize possible microscopic tumor foci, usually performed after surgery or after chemotherapy; and finally, the palliative care, which aims to treat the site of the primary tumor or metastasis, without affecting the rate of overall survival of patients and is used primarily in the analgesic and anti-hemorrhagic circumstances, reducing pain and controlling bleeding, respectively.¹

The surgical treatment of cancer is one of the options in the oncologic treatment and can be considered as: curative, palliative, prophylactic and collection of material. The treatment is considered curative when indicated in early cases of solid tumors, in these cases the tumor is removed with a margin of safety. Whereas the palliative, the aim is to reduce the population of tumor cells or control symptoms that put at risk the patient’s life or undermine his or her quality of life. In addition to being used as treatment, this technique is prophylactic, because for individuals who have a genetic predisposition to a certain type of cancer, may be recommending the surgery in order to prevent the development of this neoplasm in tissue or organ which may be affected. It is also made in the identification of tumors (biopsies).⁵

“Being with cancer brings a number of physical, emotional, spiritual, cultural implications and close contact with the own limitation and finitude”.⁶

“Taking into consideration its magnitude, upon experiencing it, the individual goes through a moment of reflection on life, because after the onset of the disease it requires changes in life habits and greater attention to the care with his or her health, after all, cancer is subject to relapses.”⁷

The consequences caused by cancer treatment also influence the feelings of clients and their families.⁸ These are forced to adapt to a new routine, the disease, with its disturbances and stigmas, becomes part of the everyday family and social life⁹

It is essential to the emotional preparation of the professional in order to provide the best possible assistance, considering the therapeutic value of a quiet and safe environment for the nursing staff, patients and family members. In this context, a word of comfort, the support of a company sufficiently discreet and homey atmosphere in the presence with the other may qualify the interpersonal relationship among the nurses, patients and family members who experience the process of neoplastic disease.¹⁰

The experience of difficult situations in a unit of oncology can awake a multitude of sentiments to the caregiver, with emotional and physical repercussions.¹⁰

Aiming at contributing, adding and extending knowledge about the subject, the objective of this study was to understand the perceptions and feelings of patients and their caregivers in coping with cancer treatment, using the integrative review of literature as a tool.

**LITERATURE REVIEW**

For the preparation of this review the following steps were performed: establishment of hypothesis and objectives of the review; criteria for inclusion of articles (sample selection); definition of the information to be extracted from the articles selected; analysis, discussion and presentation of results and the last step consists in the presentation of the review.

To guide the integrative review, the
following question was formulated: what are the perceptions and feelings from the oncological treatment in the patient’s life and his or her caregivers?

Through the portal of online surveys of the Virtual Health Library - BVS a search of scientific articles was made using the keywords “Oncology Treatment Feelings”, in an attempt to answer the question, reaching 62 articles.

The inclusion criteria of the articles were: articles published in Portuguese; with full texts, which portrayed the theme for the research and articles published and indexed in this database in the last 5 years, period within 2011-2015; selection of two databases: Latin American and Caribbean Center on Health Sciences Informatio (LILACS) and Brazilian Nursing Database (BDENF), and finally, articles of relevance according to the application of classification of vehicles for the dissemination of scientific production, i.e., WebQualis, classified in B2 or greater relevance. The only criterion for exclusion of articles was quantitative articles, because they do not fit the research. After setting the criteria the search was performed and the final sample of this integrative review that consisted of 7 articles.

For the analysis and synthesis of the articles that met the inclusion criteria a synoptic table was used specially built for this purpose, which included the following aspects, considered relevant: origin, the title of the article; authors; journal (volume, number, page and year) and goal.

For the data collection a validated instrument will be used, Ursi (2005)\textsuperscript{11}, that through this will

be ensured that all the relevant data be withdrawn minimizing the risk of errors in transcription, ensuring accuracy in tracking of information and serving as a record.

The presentation of results and discussion of data obtained was done in a descriptive manner, allowing the reader to assess the applicability of the integrative review developed in order to achieve the objective of this method, positively impacting the attempt to bring information to individuals, in general, and by providing subsidies that help the patients and their caregivers in coping with the treatment.

After analysis of seven articles that met the inclusion criteria established in advance, an overview of the articles evaluated was presented.

Among the articles included in this review, six were performed by nurses from various specialties and one by a multidisciplinary team composed by nurses, physiotherapists and doctors. Of the articles evaluated, seven were developed in hospital institutions. It was also observed that four surveys were conducted in single institutions, and three could not define the headquarter institution.

In relation to the type of journal in which the articles included in the review were published, five were published in journals of general nursing, one in collective health journal and another review of another area of health.

An analysis was made of the articles, through a comprehensive reading and trying to achieve the objectives proposed in the present study. Next, table 1 presents the summary extracted from selected articles.

<table>
<thead>
<tr>
<th>Origin</th>
<th>Article title</th>
<th>Authors</th>
<th>Journal (vol., number, page.,year)</th>
<th>Goal</th>
</tr>
</thead>
</table>
After examining the contents, three categories emerged: Feelings and perceptions experienced by cancer patients undergoing treatment; the family as caregiver for a family member in oncologic treatment; the experience of the healthcare team in patient care in oncological treatment.

### Feelings and perceptions experienced by cancer patients in treatment phase

Different feelings were observed that are caused when the patient is in the process of oncologic treatment, due to the adverse effects that it causes. It is well evident in all patients the feeling of fear that death causes and often causes an ambivalence between acceptance and denial of the disease.

The fact of accepting and/or denying represents only one form of the individual to protect himself or herself of what brings him or her pain, suffering and fear. And that the denial of the disease within the psychological stages of coping with same represents the stage at which the person does not believe in the information given to him or her,

<table>
<thead>
<tr>
<th>Origin</th>
<th>Article title</th>
<th>Authors</th>
<th>Journal (vol., number, page., year)</th>
<th>Goal</th>
</tr>
</thead>
<tbody>
<tr>
<td>LILACS</td>
<td>The trajectory of cancer is told by nurse: moments of revelation, adaptation and experience of healing.</td>
<td>Justino, E T; Mantovani, M de F; Kalinke, L P; Ulbrich, E M; Moreira, R C; Abini, L.</td>
<td>Escola Anna Nery. 18(1): 41-46, Jan-Mar/2014.</td>
<td>Describe the trajectory of people with colorectal cancer from diagnosis to the end of the chemotherapy.</td>
</tr>
<tr>
<td>LILACS</td>
<td>The nurses’ coexistence regarding the oncologic patient cares.</td>
<td>Salimena, A M de O; Teixeira, S de R; Amorim, T V; Paiva, A do C P C; Melo, M C S C de.</td>
<td>Cogitare Enfermagem. 18(1): 142-147, jan.-mar. 2013.</td>
<td>Knowing the perceptions and feelings of nurses in a hospital of oncology reference in the diagnosis and treatment of patients with cancer in Zona da Mata Mineira.</td>
</tr>
<tr>
<td>LILACS</td>
<td>Musical meeting: nursing care strategy in chemotherapy to discuss sickness/death.</td>
<td>Bergold, L B; Lima, R de; Alvim, N A T.</td>
<td>Revista de Enfermagem UERJ. 20(2.n. esp): 758-763, dez. 2012.</td>
<td>To analyze the conceptions of clients undergoing chemotherapy and rooms for musical meetings about death and the resources used for solving them.</td>
</tr>
</tbody>
</table>
being a temporary stage that is soon replaced with a partial acceptance. And already in the acceptance, the facts begin to settle, causing to realize its possibilities and limitations; and, generally, such acceptance is geared to the religiosity.\textsuperscript{12}

The oncologic treatment is, in most cases, time-consuming, exhausting and painful, and results in changes in life style. At first, the side effects trigger feelings of sadness and helplessness. Each individual presents divergent reactions to the antineoplastic treatment, taking into consideration that an individual suffering from cancer is more sensitive, the denial is present at this stage and should be worked for the success of the treatment with fewer difficulties. However, when the optimism prevails, it can be considered a strong ally for himself or herself and for the caregivers\textsuperscript{13}

The difficulties of women in tackling the oncologic treatment is evident and may be surgery, chemotherapy, radiotherapy or in conjunction. A number of difficulties were detected among women regarding the involvement of the self-image, being highlighted some adverse effects, such as alopecia, prejudice, social rejection and physical limitations. The issue of mutilation of the body, due to mastectomies, be it partial or total, caused feelings of sadness, hopelessness and despair, but these women sought the religiosity as a refuge.\textsuperscript{15}

The bearers of cancer in treatment often do not expose their feelings, as worries and fears, silences with the aim of protecting their family against possible reactions regarding the disease, because in their vision, many times, their families show more fear and this produces negative effects on family relationships. When involving the family and the other people of his or her socialising in this new phase of his or her life, the subject can trigger feelings of concern for their beloved people.\textsuperscript{13}

The routine of parents of children with cancer the feelings of fear, depression and guilt are presented as evidences. Such feelings are associated with concern about the future of the child referring mainly to the treatment, interpersonal relations and to professional aspects. The feeling of fear was expressed with greater frequency among parents, characterizing also the panic, fear, worry, insecurity, anxiety, nervousness, distress, unrest, anguish, despair, fright, fear among others. Many parents have symptoms of depression with a predominance of hopelessness, helplessness and despair. Each one has a way of expressing their feelings, some isolate themselves, cry and do not talk. Others show their sadness visually, because it is in appearance that many times there are signs of depression. With regard to care for the family, the caregiver must identify that this unit of care also needs assistance to cope with moments of sadness. The faith, for families, has an important role in emotional balance and the acceptance of the disease, giving strength to continue fighting.\textsuperscript{16}

**The experience of the healthcare team in patient care in oncology treatment**

From reports of professionals interviewed, it is identified the difficulty in not being intimidated psychologically and emotionally before care, showing emotion before the situations experienced by them in their routine, even though caring for someone with a severe pathology is considered a difficult task, the assistance provided in this area is full of positive feelings, such as the reward, because the little that the team can offer to patients and family members is seen as a great support and the professionals are recognized before the work they have done. This team lives with various feelings, since the suffering until the professional satisfaction, some facts disrupt them emotionally and others make them fulfilled and happy\textsuperscript{10}
The support to oncologic clients is still exercised primarily through guidance and clarification about the disease and treatment. The health team can also present difficulties to deal with the situation of death due to the bond formed with the clients in treatment and their families, which leads to suffering in the act. However, understanding the complexity of illness by cancer may promote sensitive approaches, developing the care not only in the physical dimension, but also psychological, social and spiritual.\(^{13}\)

**FINAL CONSIDERATIONS**

In conclusion, the present bibliographical research, in search of the best evidence available in relation to the feelings and perceptions of oncologic patients in treatment and their caregivers, it is understood that in view of the vulnerability that the disease brings, and in some cases death, we may conclude that this treatment should not only be focused on physical, but also, mental and spiritual healing. It is essential to the dissemination of therapeutic strategies that include psychosocial support, aiming to reduce the anxiety related to death during the cancer treatment.

A second part of this oncologic process is the form in which the family face the treatment of the disease caused by its undesirable side effects until the fear of loss, in this process the need is eminent for a better preparation of professionals responsible for assisting daily, complemented by a service of psychological support, in order to include effectively this family in treatment, knowing that his or her mental balance will influence directly on the patient. It is also necessary to create spaces that facilitate the interfamiliar communication.

There was a need for a theoretical/practical approach more efficiently directed to the oncology in all its dimensions so that the professional clinicians are more prepared to deal with the demand that they will face in their career. Raising awareness and empowering from students to professionals and Professors until the update of those whom are already working in the market.

**REFERENCES**


5. RODRIGUES, K. de S. Análise do uso de interferona em pacientes com neoplasia não-hematológicas no hospital universitário de
Brasília. Monografia (Graduação) – Faculdade de Ceilândia, Universidade de Brasília, Brasília, DF, 2014.


