Search for oncological care: perception...



# SEARCH FOR ONCOLOGICAL CARE: PERCEPTION OF PATIENTS AND FAMILY **MEMBERS**

BUSCA POR CUIDADO ONCOLÓGICO: PERCEPÇÃO DE PACIENTES E FAMILIARES BÚSOUEDA POR CUIDADO ONCOLÓGICO: PERCEPCIÓN DE PACIENTES Y FAMILIARES

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#### **ABSTRACT**

Objective: to understand the search for cancer care from the perception of patients and family / caregivers. Method: qualitative, exploratory-descriptive study and case study method. Patients who go through or went through cancer treatment and accompanying family / caregivers participated in the search for cancer care, in the application of questionnaires and an open interview. The interview data was transcribed and analyzed by the Content Analysis technique, in the Thematic Analysis modality, emerging categories. Results: they are presented in two categories - 1) The search path for cancer care, subdivided in "The trajectory between symptomatology", "Receipt of diagnosis" and "The trajectory of diagnosis to treatment"; 2) Coping with the disease, subdivided in "Routine changes", "Financial expenses", "Emotional changes", "Stigma and spirituality" and "Support of health professionals". Conclusion: patients and family members face several difficulties to perform the search for cancer care from the initial stage, to obtain the diagnosis of cancer, until the end of treatment. The study provides scientifically based information and aims to contribute to scientific advancement in the areas of Oncology and Nursing. In addition, it aims to transmit knowledge and raise a reflexive process for possible solutions on the issues addressed. Descriptors: Neoplasia; Patient; Family; Perception; Therapy; Clinical trajectory.

Objetivo: compreender a busca por cuidado do câncer a partir da percepção de pacientes e familiares/cuidadores. Método: estudo qualitativo, exploratório-descritivo e por método de estudo de caso. Participaram pacientes que realizam ou realizaram tratamento de câncer e familiares/cuidadores que os acompanham, na busca por cuidado do câncer, a partir da aplicação de questionários e entrevista aberta. Os dados da entrevista foram transcritos e analisados pela técnica de Análise de Conteúdo, na modalidade Análise Temática, emergindo categorias. *Resultados*: apresentam-se em duas categorias - 1) A trajetória de busca por cuidado do câncer, subdividida em "A trajetória entre sintomatologia", "Recebimento do diagnóstico" e "A trajetória do diagnóstico ao tratamento"; 2) Enfrentamento da doença, subdivida em "Alterações na rotina", "Gastos financeiros", "Alterações emocionais", "Estigma e espiritualidade" e "Apoio dos profissionais da saúde". Conclusão: pacientes e familiares enfrentam diversas dificuldades para realizar a busca por cuidado do câncer desde a etapa inicial, para a obtenção do diagnóstico de câncer, até o final do tratamento. O estudo provê informações embasadas cientificamente e visa a contribuir para o avanço científico nas áreas da Oncologia e Enfermagem. Além de tudo, possui o intuito de transmitir conhecimento e levantar processo reflexivo para possíveis soluções sobre a problemática abordada. Descritores: Neoplasia; Paciente; Família; Percepção; Terapêutica; Trajetória Clinica.

Objetivo: comprender la búsqueda por cuidado del cáncer a partir de la percepción depacientes y familiares / cuidadores. *Método*: estudio cualitativo, exploratorio-descriptivo y por método de estudio de caso. Participaron pacientes que realizan o realizaron tratamiento de cáncer, y familiares / cuidadores que los acompañan, en la búsqueda por cuidado del cáncer, a partir de la aplicación de cuestionarios y entrevista abierta. Los datos de la entrevista fueron transcritos y analizados por la técnica de Análisis de Contenido, en la modalidad Análisis Temática, emergiendo las categorías. Resultados: se presentan en dos categorías - 1) La trayectoria de búsqueda por cuidado del cáncer, siendo esta subdividida en "La trayectoria entre sintomatología", "Recepción del diagnóstico", "La trayectoria del diagnóstico al tratamiento"; 2) Enfrentamiento de la enfermedad, subdivida en "Alteraciones en la rutina", "Gastos financieros", "Cambios emocionales", "Estigma y espiritualidad" y "Apoyo de los profesionales de la salud". *Conclusión*: pacientes y familiares enfrentan diversas dificultades para realizar la búsqueda por cuidado del cáncer, desde la etapa inicial, para la obtención del diagnóstico de cáncer, hasta el final del tratamiento. El estudio provee informaciones fundamentadas científicamente y pretende contribuir para el avance científico en las áreas de la Oncología y Enfermería. Además de todo, tiene el propósito de transmitir conocimiento y levantar un proceso reflexivo para posibles soluciones sobre la problemática abordada. Descriptores: Neoplasia; Paciente; Familia; La percepción; Terapia; Trayectoria Clínica.

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#### INTRODUCTION

Cancer is a set of more than 100 diseases that have in common the growth and disordered multiplication of cells. It is not a disease of the present time because, historically, it has already been detected from studies in Egyptian mummies. This is a serious health problem, due to epidemiological, social and economic amplitude, being the second cause of death in the country, with 190 thousand deaths per annum.1

According to data from the National Cancer Institute (NCI), estimates of the disease are approximately 600,000 new cases of cancer per year in Brazil, where 60% are already diagnosed. Among the various types of cancer, the most prevalent among adults is non-melanoma skin cancer, with about 180,000 cases. With regard to sex, the most prevalent types among men are, in descending order of incidence: prostate, lung, intestine, stomach and oral cavity. For the female, the cancers are: breast, intestine, cervix, lung and stomach.<sup>1</sup>

The causes of cancer are divided into external factors such as exposure to chemicals, habits in tobacco and alcoholism, high-fat diet, sodium, sugar and industrialized products, sedentary lifestyle and obesity, infections caused by pathogenic microorganisms such as viruses, bacteria and parasites. Internal factors include genetic inheritance, which corresponds to 10% of the cancer-causing factors.<sup>1</sup>

Because it is a disease of multifactorial causes, its clinical course is through a set of nonspecific signs and symptoms that, in most cases, are not valued by patients and even by health professionals. For this reason, studies point to the need for professionals with a keen eye to detect possible changes that constitute signs of cancer.<sup>2</sup>

The process of care for people with cancer can be initiated in the primary health care network when the diagnosis is made and later on in the secondary and tertiary care network for treatment. Treatment should begin within the Unified Health System (UHS) within a maximum of 60 days after the diagnosis of the disease.<sup>3</sup>

The most used therapeutic modalities for the treatment of cancer are the following: surgical treatment, with removal of the tumor or tissue affected by surgery; chemotherapy, where regularly or continuously administered medications are used and in accordance with therapeutic regimens and radiotherapy, a method that directly affects the site or region Search for oncological care: perception...

of the cancer and uses equipment and techniques to irradiate the affected area. <sup>1</sup>

Patients may be submitted to a single type of treatment or to associations: the choice will depend on the clinical picture of the patient and the staging of the disease. The efficacy of the therapy used depends on the early diagnosis and, consequently, that the initiation of the treatment happens as soon as possible.<sup>4</sup>

Receiving confirmation of the diagnosis of cancer is a fact that changes people's lives. Cancer, because it is a disease with complex treatment, causes several difficulties, mishaps and confrontation during the process of search for care providing negative consequences in the life of the patient, the patient and / or their relatives / caregivers. Among these are: the difficulties to move from the residence to the specialized health service; distancing oneself from residences and staying for a long period away from home; financial difficulties generated by the treatment; fear of the unknown and insecurity; lack of information on the clinical picture by the professionals; changes in life habits as a result of  $treatment.^{\text{4-5}}$ 

Generally, the caregiver or caregiver of a cancer patient is some close relative such as the parents, spouse, children or siblings, and these also face changes in their routine, such as the withdrawal from employment or even the abdication of professional life , the distancing of daily activities and the maternal functions to dedicate themselves to the patient.<sup>4</sup>

Another difficulty pointed to the search for care are the side effects of treatment such as chemotherapy, the most common symptoms are: pain, nausea, hair loss, weight change, anxiety and fatigue. In addition, other signs, such as anorexia, depression, dysphagia, changes in physical appearance and mood, directly affect family and social relationships leading, in most cases, to withdrawal from treatment.<sup>5</sup>

Social isolation, negative transformations in relationships, alterations, impairment of physical and emotional aspects, failure to perform leisure moments, changes in eating habits for the patient who, sometimes, should re-adjust their diet as a result of the disease are factors that affect both patient and family / caregiver in the search process for cancer care. Given the aspects addressed, this study is totally relevant, since it surveys information regarding the search for cancer care based on the perceptions of patients and family / caregivers.

#### **OBJECTIVE**

• Understanding the search for cancer care from the perception of patients and family / caregivers.

#### **METHOD**

Qualitative study, exploratory-descriptive and by case study method. The population of this study consists of patients who perform or have been treated for cancer and their relatives / caregivers who accompany them in the search for cancer care. The qualitative approach has the purpose of deepening and understanding a certain fact, because it does worrv about the numerical representativeness. It has, as characteristics, the objectification of the phenomenon and the hierarchization of actions following the order to describe, understand and explain a certain fact. 7

The case study method is considered a strategy of mapping, describing and analyzing contexts, relationships and perceptions of a given phenomenon or episode. The purpose of this type of study is to understand the meaning of the search for care from the perspective of people who experience cancer and family / caregivers. The purpose of this type of study is to contextualize the facts covered and to increase the understanding of a phenomenon than to delimit it. <sup>8</sup>

study was carried out in the municipality of Tangará da Serra, Mato Grosso, Brazil. According to the Brazilian Institute of Geography and Statics (IBGE), the Municipality of Tangará da Serra is located in the northern region of the state of Mato Grosso - MT, approximately 240 kilometers from the capital, Cuiabá. It has an estimated population of 98,828 inhabitants in 2017.9 It has a network of health services with twentysix Family Health Units (FHUs), a municipal public hospital, a 24-hour Emergency Care Unit (ECU), a unit center of specialties and outpatient clinic, a clinic of nephrology specialties agreed to UHS, three private hospitals and other private clinics.

Fourteen interviewees participated in the study, being eight cancer patients and six family / caregivers who followed them during the treatment phase. The search for the subjects occurred through registers made at the Regulation Center and Municipal Health Secretariat of Tangará da Serra - MT. The municipality has no service for the treatment of cancer, and it is necessary to refer these patients to specialized centers, such as the cancer hospital in the capital of Cuiabá - MT.

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Participating subjects were chosen based on the inclusion criteria: patients who are or have been in the cancer treatment phase and relatives / caregivers who participated and / or participate in this trajectory. Patients and family / caregivers older than eighteen years of age, regardless of gender or gender. The choice of location for the interview was at the discretion of the interviewee provided that the environment provided privacy.

Persons who were unable to support the Free and Informed Consent Term and people who received the medical diagnosis of cancer in less than three months because they may still be confused with the new condition of life could not be delineated or explained. perceptions regarding the accomplishment of the search for cancer care or, still, did not have time to reflect on the course of the treatment.

Data production was performed using the method of applying questionnaires with sociodemographic questions and by means of an open interview, from February to May 2017. After the production of data through the interviews, these were transcribed in full for the analyze. The number of subjects was established by the criterion of saturation of qualitative data.

The data were analyzed using the Content Analysis technique, in the Thematic Analysis modality. The technique is divided into chronological stages: the pre-analysis; the exploitation of the material; the treatment of the results and the interpretation of the data. 8 After the analysis of the data, these were listed in categories from the information presented by patients and family / caregivers.

The study project was submitted to the Research and Ethics Committee (REC) of the State University of Mato Grosso (UNEMAT) in compliance with Resolution 466 of December 12, 2012, of the National Council of Health Research and then approved by the Research Ethics Committee of the University of the State of Mato Grosso (CEP-UNEMAT) under the opinion of number: 1.899.601 / 2017. The participants of this study received the Free and Informed Consent Form containing explanations about the research, as well as the risks and benefits.

The document was in two tracks: one remained with the researcher and another, with the participant. Research participants were identified by the letter P (referring to the patient) and the letter F / C (referring to the family / caregiver) listed sequentially. This measure is to preserve and guarantee the anonymity of those involved.

**RESULTS AND DISCUSSION** 

Fourteen interviewees participated, of which eight were diagnosed with cancer, who were or were still in the treatment phase of the disease, and six accompanying relatives / caregivers. With regard to the sociodemographic characterization of people with cancer, three men and five women participated. The age ranged from 22 to 72 years, concentrating on the age group between 50-60 years.

Regarding the treatment of cancer in these patients, the therapeutic modalities use<sup>d</sup> were surgery, chemotherapy and radiotherapy. In some cases, the modalities chosen were exclusive and others associated. According to NCI, cancer treatment is usually done through surgery, radiotherapy, chemotherapy and, if necessary, there are combinations of therapeutic modalities. <sup>10</sup>

Concerning the sociodemographic characterization of family members / caregivers, six subjects participated in the study, all of them women. With regard to the age group, it ranged from 20 to more than 50 years, with predominance over 50 years. The family members interviewed reside with the patient, present themselves as the informal caregivers and accompany them from the initial phase of the disease.

Given this, it is noted in this study that family support is essential for coping with the disease and it is characterized as the basis of support for the patient. In this sense, the family member provides care to the patient so Search for oncological care: perception...

that they feel better in the physical and emotional aspects of the situation they are experiencing. One of the concerns of family members is regarding the patient's clinical status. On the other hand, they remain firm and feel obliged to face this process in a positive way so that the patient faces the disease and carries out the treatment. <sup>4</sup>

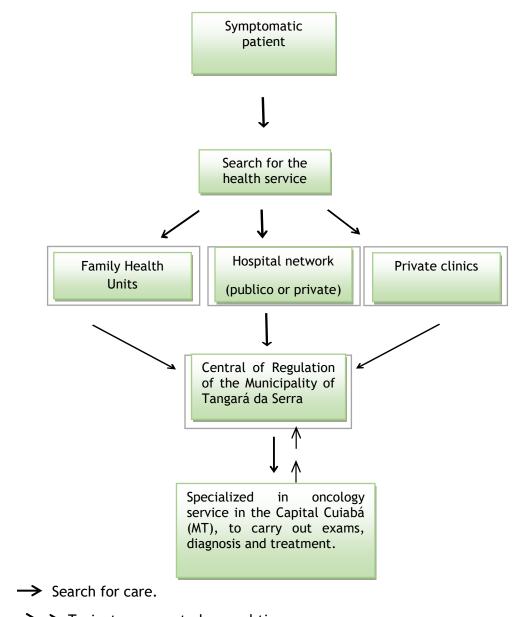
The thematic analysis of the contexts resulted in the construction of two thematic axes in order of relevance. The first was the search path for cancer care, which resulted in two subcategories: The trajectory between the symptomatology and the diagnosis and The trajectory of the diagnosis to the treatment.

The second thematic axis - Facing the disease - was divided in four subcategories: 1 - Changes in the routine; 2 - Financial expenses; 3 - Emotional changes, stigma and spirituality and 4 - Support of health professionals. The results were abstracted, treated and grouped according to the conformities presented between patient and family discourses according to relevance.

## • The search path for cancer care

This category emerged due to the relevance in the speeches of patients and family members who cite the trajectory as difficulties faced for the search for cancer treatment.

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→ Trajectory executed several times.

Figure 1. The trajectory performed by the patients for the search for cancer care. Source: Tangará da Serra (MT), 2017, Brazil.

The flow chart (Figure 1) represents the trajectory performed by the patients and can be understood as follows: when a symptom emerges, the patient begins the search for care through health services, which may be the family health unit (FHU), the hospital network or the private clinic. Upon passing the first service and consultation, the health professional directs the patient to the regulation center of the municipality of Tangará da Serra, for later referral to the capital, Cuiabá, to perform confirmatory tests for cancer diagnosis and the beginning of treatment.

# ♦ The trajectory between symptomatology and diagnosis

The trajectory can be demarcated by numerous comings and goings between the health services. The difficulties begin from the execution of the exams such as, for example, imaging, biopsy, among others, to confirm the diagnosis of câncer, until the treatment itself.

I went through the doctor at the health center, but to make another appointment ... he (the unit's doctor) asked me to find a dermatology specialist who understands this because he had some reddish spots [...] he went to the control center and then to Cuiabá. (P2)

Here, in the post, always has the preventive effort, then I used to not do because I was ashamed ... I went there and I did, in a fortnight, my health agent came here and told me that the nurse of the unit asked to go there (BHU). I was about three months coming and going until this surgery happened. (P7)

The path taken by the patient in search of treatment is marked by multiple barriers that start even before diagnosis is established and extend after treatment.2 The study also points to the difficulty of delaying the results diagnosis confirming the οf cancer, consequently delaying the onset of cancer treatment, as well as the bureaucracy patients face in order to have access to the specialized service, and also due to their need to be referred to the capital of the State of Mato Grosso for the conducting examinations and treatment.

Now, I am doing the treatment in Cuiabá, and waiting for another surgery, since

January, I have to do another surgery to remove this stain here, I got a return to June, still. (P1)

Thus, it is observed that the slowness to obtain the diagnosis leads to delays in the initiation of therapy and, consequently, the progression of the disease and the difficulty to cure.5 In this perspective, it shows how bureaucratic and difficult access to services. Brazilian 196 Article of the Federal Constitution states that health is a right of the entire population and it is the State's duty to guarantee it through social and economic policies aimed at reducing the risk of disease and other diseases. 11

Although health is the right of everyone and the duty of the State, access can be difficult and bureaucratic, which implies delays in the conduct of examinations, late diagnosis of cancer and delayed treatment, thus hurting the rights of the cancer patient.

# ♦ The path from diagnosis to treatment

Upon receipt of the diagnosis of cancer, the oncologic patient is referred through the regulation center of the municipality of Tangará da Serra to the capital of the State of Mato Grosso. At that moment, a new journey begins, surrounded by difficulties, due to the need to transfer between the municipality of origin to the service specialized in oncology.

The difficulty always has, because it is very tiring, you leave here, two hundred and a few kilometers to Cuiabá, [...] you leave at two-thirty in the morning, you have to get those bumpy roads, there you have the whole day there, doctor. (F / C1)

So the worst part is the displacement because we have to leave here from Tangará, walk about 250 kilometers that you have to walk out at dawn, come back at dusk. We left three, four o'clock in the morning, and arrived at about twenty-two. (P8)

Accessibility to health services is one of the difficulties faced by patients from cities in the interior, because of the deficiency and availability of services, in addition to the great distances traveled that disfavor the use of the health service by the patients.<sup>4</sup>

Patients and families talk about the difficulties they face in order to perform the treatment due to the displacement they need to perform from the resident municipality to the state capital to search for specialized service, resulting in physical and mental fatigue suffered; the time of leaving the bus, because it is at dawn; the time of return to the residence; the waiting time to go through the medical care and poor conditions of the pavement. They also point out that if the municipality offered the specialized service for the treatment of cancer, these difficulties would be minimized. Therefore, it is verified

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that the need for locomotion causes physical and psychological wear to patients who are debilitated due to the disease. The process of locomotion implies dependence on the help of family members to accompany them in face of the physical and psychic weaknesses resulting from the disease and the treatment itself.<sup>5</sup>

# ♦ Confronting the disease

The coping of the disease is the individual's ability to adapt, control, reduce or eliminate emotional responses to the stressor event, that is, they are behavioral and cognitive abilities to face the process of illness. <sup>12</sup>

We have to face it, so we always try to keep surrounded by good people to help people because it's not easy. We have God and always try to believe in him, he who gives strength every day, family and friends. (P8)

The difficulties imposed by the cancer to the affected and familiar individual cause them to seek support of various natures for coping with the disease.13 Each patient and family member is unique and each of them has a way of coping with the disease. Nursing professionals are responsible for ensuring that individuals and the community understand and understand the disease process and the development of coping strategies.<sup>14</sup>

## ♦ Routine changes

The modification in the routine of the patients and, consequently, of the relatives was one of the difficulties presented in this the Among them, changes study. professional and social life stand out. There is evidence of withdrawal from social life as a result of treatment, changes in the routine of daily activities such as the functions of domestic and professional life, change of address, adaptation in another municipality and change of employment to be able to follow the patient during the care process. Therefore, it is verified that changes in routine are present in the patient's life and also in the family member who accompanies him on this journey.

The change in my routine, because the doctor said that I could not be in many crowds of people, in fact I told him that I really like to leave. [...] (P3)

I can no longer clean my house, wash my clothes, because of the soap, today, it is my daughter who does it for me. She has her house, she is married, she works, but she comes to take care of me and my house. What I thought was bad about this disease was that. (P1)

Because cancer is a chronic disease, it exposes not only the cancer patient, but also their family members through routine transformation.4 This experience is very

painful because routine changes, triggered by the process of illness, can to generate depressive crises, insecurity, fear of death, abandonment or change of employment, which can lead to financial expenses and generate other emotional worries and dysfunctions. <sup>13</sup>

# ♦ Financial expenses

The financial costs are also due to the changes in the routine that lead to an increase in financial expenses due to the process of seeking cancer care. Therefore, it is stated, in the following speech, that the financial costs become a factor of difficulty to face the disease.

We're in a lot of spending, go there, come here. I'm going to chemotherapy, the immunity is low, I have to go back, you know, and it's all gone. I think if I had the hospital here in Tangará for us it would be better. (P3)

As seen in the above, the financial expenses arise mainly due to the need of the displacement and with the comings and goings between the municipality of origin and the capital of the State for the accomplishment of the treatment. Other factors that generate expenses are associated with the food and public transportation of the support house to the cancer hospital.

The need to recognize the importance of the establishment of a specialized cancer care service in the city of Tangará da Serra, Mato Grosso, Brazil, is analyzed, as it would thus minimize part of the financial expenses, since these are generated mainly by the need for the displacement.

The financial expenses generated by the treatment, which is a great difficulty factor for coping with the disease, which has negative repercussions and concerns for the patient and family interfering with the care process, with possible emotional sequelae that persist even after treatment. <sup>4</sup>

# Emotional changes, stigma and spirituality

Another aspect raised during the content analysis was in relation to the emotional changes that affect the patients and their relatives in the process of becoming ill. Emotional difficulties arise mainly during the discovery of cancer and, depending on the coping capacity of each patient, last until the end of the care of the illness. Many seek spirituality as a form of support to minimize suffering.

The main difficulty I experienced was that it was emotional for me to know that I was sick and pregnant, [...] I was more worried because I was afraid that something would

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happen to me because you get news like you do not know how to deal because cancer is a very strong word, we already receive in a way, that is very upset the emotional of people. (P7)

The day I heard about my mother-in-law's illness, I only cried, I cried, and prayed asking God, asking God ... because God? [...] on the day of surgery, God did a work in her bosom, he understood, nor did he look like he had surgery. (F / C3)

The emotional aspect of patients and family / caregivers may be affected, probably due to the stigma that the cancer carries. It is a disease that can be associated with suffering, anguish, revolt and fear in the face of future uncertainties generating suffering, feeling of despair and impotence in the face of illness.4 Patients and families seek faith and religion as strategies, and this is a positive factor for to face the disease. Spirituality is the way that patients and families adopt to deal with the stress and problems arising from the process of seeking care for cancer disease. <sup>15</sup>

# ♦ Support from health professionals

The support of health professionals are considered as fundamental positives, since they can minimize the mishaps and strengthen the coping of the disease. In the following speeches, it is observed that, despite all the difficulty faced in the quest for cancer care, patients are grateful for access to treatment, family support and more humanized care from health professionals who are and empathize with their patients. Therefore, it is noted that patients and relatives leave satisfied and recognize the work performed by health professionals, minimizing the difficulties faced, being this positive factor for coping with the disease.

They treat us there with so much love, with so much affection, the nurses came all the time and told me that everything was fine with my mother-in-law. (F / C3)

I arranged a partnership of very good people in there, who takes care of us very well, the doctors attend well, the girls who do the radio too. So, we are encouraged. (P2)

In this way, it is vital that health professionals obtain holistic vision for their patients and their families. It is essential that they provide assistance with quality, empathy and in a more humanized way. The work developed by the team enhances the conditions so that they can respond, in a positive way, to the adversities arising from the process of illness and treatment.<sup>16</sup>

#### CONCLUSION

The results of this study made it possible to understand how cancer care is pursued through the perception of patients and process relatives / caregivers. This accompanied by difficulties from the trajectory between the symptomatology and the diagnosis and from the diagnosis to the accomplishment of the treatment. The search for cancer care is demarcated by numerous comings and goings between health services due to the need to transfer between the city of origin to the specialized service in oncology in the capital Cuiabá - MT.

Patients and family / caregivers have strategies for coping with the disease, such as family support and health, faith and spirituality support, but also the appearance of difficulties such as: changes in routine, financial costs and emotional changes. The support of health professionals is a positive point considered fundamental, since it can minimize the mishaps and strengthen the coping of the disease in the search for cancer care.

The findings of the research correspond to the objective, as they provide clarification and understanding of the process of searching cancer care. The study provides scientifically based information contributes to scientific advancement in the areas of Oncology and Nursing. In addition, it aims to transmit knowledge and raise a reflexive process to the managers of the municipality of the study, nurses and health professionals, in general, for possible solutions on the issue addressed.

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