



RESEARCH ARTICLE

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## LIFE OF CANCER PATIENTS: DIFFICULTIES FACED IN ACCESS AND THERAPEUTIC ITINERARY TO THE ONCOLOGICAL CARE NETWORK

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### ABSTRACT

**Objetivo:** identificar los estudios sobre las dificultades con respecto al itinerario terapéutico de los pacientes con cáncer a la red de atención oncológica. **Método:** revisión integradora, datos recopilados en bases de datos electrónicas Lilacs, Medline / Pubmed, Scielo, donde se identificaron 3.400 artículos, y de los criterios de inclusión y exclusión, quedaron 3 estudios. Las publicaciones analizadas datan de 2008 a 2018 y se llevan a cabo en países desarrollados y en desarrollo. **Resultados:** a la vista de los hallazgos, se identificó el itinerario de pacientes oncológicos en el sistema de salud, desde la primera consulta en Atención Primaria de Salud hasta el diagnóstico. Las dificultades de este sistema para efectuar esta línea de atención en el servicio de salud han demostrado que la espera prolongada puede tener serias consecuencias. **Conclusión:** se verificó que las publicaciones sobre el tema aún son escasas en comparación con la investigación sobre el cuidado de enfermería y / o el tratamiento del cáncer en el control del dolor y se verificó la importancia de realizar más estudios sobre el acceso terapéutico de pacientes con cáncer.

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## INTRODUCTION

Cancer is a chronic-degenerative condition characterized by disordered growth of rapidly multiplying cells, determining the formation of tumors that can invade other adjacent tissues and organs by direct dissemination and/or lymphatic and blood ways causing metastasis. If the tumor is detected before the cells become malignant and before they promote carcinogenesis, there is a more favorable condition for treatment and, consequently, for the cure (INCA, 2014). In recent decades, cancer has stood out among chronic non-communicable diseases. Reaching alarming levels, it has been considered a contemporary problem of global public health. According to the World Health Organization (WHO) estimate

that in 2030, cancer will reach approximately 27 million incident cases worldwide, 17 million deaths and 75 million people diagnosed annually. The biggest effect will be noticeable in low- and middle-income countries. In Brazil, statistical data directed to an occurrence equivalent to the appearance of about 580,000 new cases of cancer, thus revealing the magnitude of the problem in the country (MS, 2017). However, a very important aspect needs to be taken into account, with the increasing incidence of cancer, proportionally to population growth, population aging and socioeconomic development, great will be the challenge that will represent for the oncology care network, in order to guarantee full access of the population to the diagnosis and treatment of this disease (OLIVEIRA, 2011), because if nothing is done, the expectation is that cancer can take the

**Table 1. Search strategies for querying in databases**

Crossing in English	Crossing in Spanish	Crossing in Portuguese
Cancer (Decs) and Therapeutic Trajectory (Mesh Terms)	Cáncer (Decs) and Viaje Terapéutico (Mesh Terms)	Câncer(Decs) and Percurso Terapêutico (Mesh Terms).
Cancer (Decs) and Health Services Accessibility (Mesh Terms).	Cáncer (Decs) and Accesibilidad a los Servicios de Salud (Mesh Terms).	Câncer (Decs) and Acesso aos Serviços de Saúde (Mesh Terms).
Cancer (Decs) and Therapeutic Itinerary (Mesh Terms).	Cáncer (Decs) and Itinerario Terapéutico (Mesh Terms).	Câncer (Decs) and Itinerário Terapêutico (Mesh Terms).
Cancer (Decs) and Health Care (Mesh Terms).	Cáncer (Decs) and Atención a la Salud (mesh terms).	Câncer (Decs) and Atenção à Saúde (Mesh Terms).

Source: Table Constructed by the Project authors, using as source the database Lilacs, Medline databases via Virtual Health Library (Bireme).

lives of 9.6 million people in 2019, representing one in eight deaths among men and one in 11 deaths among women (WHO, 2017). In Brazil, the most incidental cancers are those of skin, prostate (28.6%), breast (28.1%), lung (8.1%) and cervix (7.9%). Estimates indicate that cancer rates generally tend to increase if there is no effective change in lifestyle (INCA, 2015) and the implementation of strategies recommended by the National Policy for Cancer Prevention. Until the creation of the Unified Health System (SUS) in 1990, several campaigns and programs were developed in favor of combating cancer and there was a significant increase in the number of establishments intended for its treatment. Early detection covers two strategies: early diagnosis and screening (BRASIL, 2016). With regard to care, screening actions for early diagnosis are part of the attributions of primary health care services (PHC), while research for the effectiveness of diagnosis and treatment are part of the set of actions of the specialized services of secondary care and terciaria, respectively. (NICOLAOU, 2013). However, some barriers to this access to the oncological care network originate from the characteristics of health systems and services, from the availability of services and their geographical distribution, availability and quality of resources human and technological, financing mechanisms, the care model and information about the system are characteristics of supply that directly affect access (PINHO, 2012).

Another factor that contributes to the obstacles regarding the therapeutic access of the cancer patient to the care network, are the weaknesses with regard to the flow and communication between health services and the user, in addition to the time spent between the diagnosis to the treatment, according to Travassos (2006), considering previous examinations, length of hospitalization (surgery) and specific treatment is approximately 60 to 90 days. Because it is a rapidly evolving pathology, reaching the limit of this period may not be strategic to act on the advancement of the disease. According to Federal Law 12,732 of November 22, 2012, patients with malignant neoplasia are entitled to undergo the first treatment in the Unified Health System (SUS), within 60 (sixty) days counted from the day on which the diagnosis is signed in 1 pathological or shorter-term, according to the therapeutic need of the case recorded in a single medical record (MS, 2012). Cancer prevention in the world is one of the most urgent challenges faced by researchers and public health managers, among others, where knowledge about the path made by the individual can contribute substantially to the reduction of time between the diagnosis and effective treatment, reducing the number of deaths caused by long waiting and late diagnosis periods. Understanding how the therapeutic itinerary of cancer

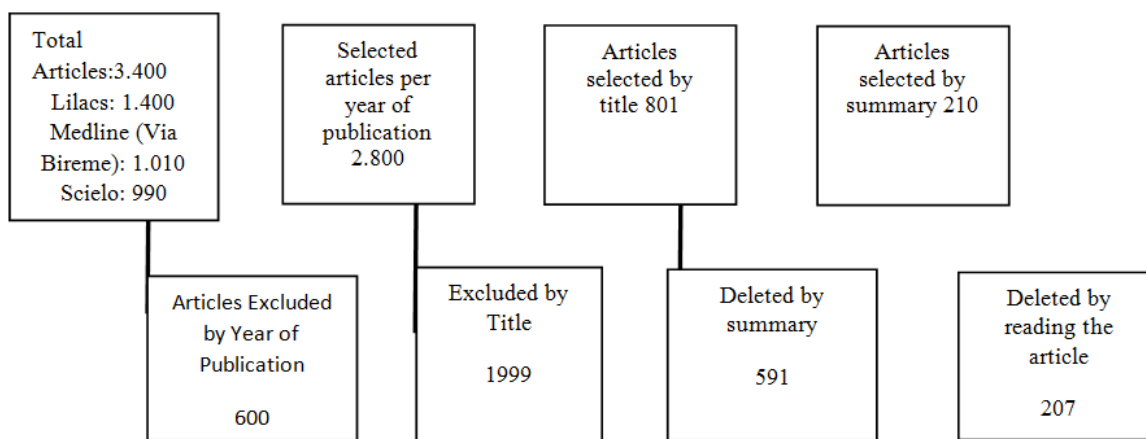
patients and their difficulties works, enables the general population and, mainly, health professionals a more detailed view of the urgent need to include this patient in the oncologic attention. The present research aimed to know the difficulties faced by patients regarding the therapeutic itinerary and accessibility in the network of cancer services.

## METHODOLOGY

This is an integrative review of the literature, defined as the one in which research results on a given subject or questioning are analyzed and synthesized, with the purpose of deepening knowledge on a particular topic (MENDES, 2008). A survey of scientific articles was conducted in the Medline databases via PubMed, Medline via Virtual Health Library (Bireme), Scientific Electronic Library Online (Scielo) and Latin American and Caribbean Literature in Health Sciences (Lilacs), the search for data occurred in July/2017. For the research, descriptors (Mesh/Decs) and free terms (Mesh Terms) were used, crossed through the boolean operator "AND", Table 1. Articles that addressed the theme of oncological pain and the perception of nursing professionals, without language restriction, publishing country and period. When the titles did not contain all the information required or generated any doubt about the object of study, the abstracts were read, and when not satisfied, the complete reading of the articles to decide on their inclusion. Articles that addressed literature reviews, technical manuals, monographs, dissertations and theses were excluded. Articles whose abstracts were unavailable and those that did not address the proposed theme were also excluded. After pre-selection of the articles, through the floating reading of the abstracts a second analysis was performed, through the detailed reading of the pre-selected publications to decide the inclusion and exclusion of these productions, according to criteria pre-established. At this stage, the work was carried out by 02 independent reviewers, who used the consensus technique to select the articles to be used for research.

## RESULTS

Figure 1 presents the flowchart of the strategy of selecting the articles, according to the pre-established eligibility criteria. It was observed in the database the absence of some descriptors that have a direct relationship with the theme researched, and it is necessary to use synonyms so that the proposed goal could be achieved (free terms). Table 2 shows the characterization of the analysis of articles referring to the year and place of publication of the articles, methodological design of the studies, representativeness of the sample, perception of nursing



Source: Flowchart Constructed by the Project authors, using as source the database Lilacs, Medline databases via Virtual Health Library (Bireme).

Figure 1. Flowchart with search strategy in electronic databases

Table 2. Analysis of related articles experience of cancer patients: difficulties faced in accessing and therapeutic itinerary to the oncology care network

Author and Year	Study Design	Sample	Therapeutic Access	Results
Paul C et al., 2012.	Self-report section; Cross section; Quantitative. Research conducted in Australia.	Approximately 52% reported concern during one phase of treatment and 8.9% reported concern in other phases. 31% reported concern about waiting time between deciding radiotherapy and starting radiotherapy	Access to health services is an indicator of quality of care; Relationship of waiting time between access to diagnosis / treatment and disease evolution; especially among the most vulnerable groups.	95% reported concern about waiting times in all spheres of treatment. 43% report concern at some stages of cancer treatment 48% report concern at any stage of treatment.
Brustolin A; Ferretti F, 2017.	Exploratory study of a qualitative nature.	04 people with cancer, by interview.	Difficulties in accessing medium complexity regarding specialized consultations and examinations are one of the major challenges of SUS.	The path taken by the elderly goes from the discovery of signs and symptoms; the walk for diagnosis in the Health System; the confirmation of cancer; surgery and chemotherapy and the inclusion of alternative and complementary practices.
Debus PS; Girardon-Perlini NMO; Rosa BVC et al., 2018.	Qualitative descriptive study.	18 people aged 49 to 77 years on chemotherapy and radiotherapy treatment.	The therapeutic itinerary of people with cancer began with the recognition of the problem, based on previous perceptions and experiences. It shows the long way between the first signs and symptoms and the search for a solution that still remains restricted.	The itinerary followed by the patients took place in the public and private health services, being marked by the delay for diagnosis and treatment.

Source: Table Constructed by the Project authors, using as source the database Lilacs, Medline databases via Virtual Health Library (Bireme).

measuring the quality of health of individuals as a method of evaluating the care provided to their population, but have low feasibility of resources and services to patients seeking some particular therapy, which contrasts that of developed countries. Because this is a very recent theme, it is verified that publications on therapeutic itinerary are still reduced, especially those that refer to the individual with cancer and the average time spent for cancer care (AQUINO, 2014), agreeing with the research developed by Cabral (2011), in which he states that an organized health care network, with well-defined flows and well-articulated actions, can contribute to the correct direction of the individual to the service he really needs, in addition to reducing the waiting time at all stages of its therapeutic path, leading to a good prognosis of the disease. A study conducted in Sydney, Australia, found that patients are more distressed by the long waiting period between diagnosis and treatment than with the complications of therapy performed. One of the barriers to access to comprehensive care to the population is the delay in scheduling specialized consultations, which ends up delaying early diagnosis, as well

as the most effective treatment for the disease, in addition, the lack of criteria defined for the choice of the reference service in which users will be referred is another aspect that hinders access (PAUL, 2012; SOUZA, 2016). According to Simino (2010), care for people with cancer should contemplate the different points of care of the Health Network in order to ensure access and comprehensive care. And to this end, care is organized considering the establishment of reference flow and counter-reference between primary care, which constitutes the user's gateway to the health system, and the services of medium and high complexity. Another somewhat advanced characteristic study that simino's explains the existence of two types of health networks: the tree nets that are characterized by the limitation of connections between its various branches, while networks organized in mesh in which each node is connects to several others, allow to go through varied paths between points, so that the various branches of the network are interconnected, thus stands out the need to structure a regionalized and hierarchical service network that ensures attention access to consultations and tests for the early

diagnosis of cancer (OLIVEIRA, 2012). Regarding the difficulties for access to health services, financial resources, such as transportation and food costs, have been identified as the main obstacle to the use of these services. In the oncology care services, among some factors, the distance that the user travels until entering the oncology care network and the costs involved for this displacement are highlighted. The distance covered by the patient should be considered, as it will require repeated visits to health services for specific care and treatment. In this sense, the location and decentralization of services, the time and costs involved with displacement are fundamental for the evaluation of the accessibility standard of these individuals (ENGEL, 2013). Access to and quality of health care of people affected by this disease, several aspects should be considered, from diagnosis to definition of the treatment modality. Therefore, these aspects involve the path trodden at different points of attention, experiences and movements triggered, referring to a succession of events and decision-making that will influence the treatment of the disease (CABRAL, 2011). Another study addressed the interference of the degree of satisfaction of the individual in the face of the lack of information necessary for the understanding of the disease and its relationship with the search for specialized services (LY, 2007). The wrong understanding about his pathological condition or the lack of effective communication with the professionals involved in the trajectory that the patient performs, can lead him to seek unconventional therapies and thus, not satisfy the individual, prolonging the time spent for healing, or even causing undesirable outcomes such as death (AQUINO, 2014).

Therefore, the time spent between diagnosis and death reinforce the importance of strengthening the oncology care network, considering that difficulties of this order can lead the individual to the diagnosis of the disease in advanced phases and considerably reduce the chances of healing. These findings, found in Ly's studies corroborate another research conducted in Colombia, which points out that patients, in addition to lack of information, face problems related to the health system, economic, political, geographical issues, social support network and the family which makes patients even more weakened and vulnerable (SÁNCHEZ-VANEGAS, 2013). This vulnerability can lead to denial of the disease, compromising adherence to treatment. It should be considered that the difficulties faced by patients are the result of a series of structural barriers that require deep reforms in the health system.

## CONCLUSION

The study portrays on low scientific production regarding the itinerary of cancer patients and their inclusion in the network of cancer services. This picture hinders the more in-depth evaluation on the theme and its implications regarding the late diagnosis of the disease. Although some factors condition the late search for patients to care for cancer and treatment of the disease, among them those related to accessibility, which include problems related to the availability and integration of actions and services. The results of the study suggest the importance of thinking and evaluating the Organization of health services and practices with a view to comprehensive and quality care, based on relationship that enable the search, access, inclusion and continuity of care.

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