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Breast Cancer Assistance Journey from the perspective of the Public Healthcare Service of Rio Grande do Sul

Jornada de Assistência ao Câncer de Mama na perspectiva do serviço de Saúde Pública do Rio Grande do Sul

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ABSTRACT

Objective: This study aims to characterize the breast cancer (BC) patient journey in Rio Grande do Sul (RS), Brazil, through the perspectives of the High Complexity Oncology Assistance Centers (CACONs) and High Complexity Oncology Assistance Units (UNACONs). **Methods:** Conducted between March and May 2023 across 17 RS Oncology public healthcare services, the cross-sectional study utilized a 54-question questionnaire administered to healthcare professionals. The survey covered various aspects, including diagnosis, treatment, funding, and multidisciplinary teamwork. We put special emphasis on the time of diagnosis and treatment, as Law No. 12,732/12 mandates that the first oncological treatment must begin within 60 days. **Results:** Descriptive analysis revealed that BC patients undergo screening tests upon treatment entry (88.2%), with immunohistochemistry commonly performed externally (64.7%) and PCR often requested (82.4%) for adjuvant therapy initiation, taking an average of 90 to 250 days for all procedures. Patients encounter challenges such as lengthy hospital stays, extensive travel to treatment centers, treatment side effects, and high transportation expenses, often leading to treatment discontinuation. The most time-consuming stage is treatment, with subcutaneous infusion proving more time-efficient than intravenous administration. Physical limitations, mobility issues, late diagnosis (90-day average), and limited access to care significantly impact patients' quality of life. Healthcare teams face difficulties with outdated guidelines, lack of intravenous treatment facilities, and extended administration durations. Institutions confront barriers like drug shortages, guideline disparities, and logistical challenges. **Conclusion:** The study concludes by emphasizing the identified hurdles in BC patients' public healthcare journey, underscoring the need to address delays in screening, resource constraints, and disparities in access to care based on geographical, socioeconomic, and racial/ethnic factors to enhance overall quality of care and equity within the system.

Keywords: breast cancer; treatment; journey; Brazil; disease burden.

RESUMO

Objetivo: Caracterizar a jornada do paciente com câncer de mama (CM) no Rio Grande do Sul (RS), Brasil, através das perspectivas dos Centros de Assistência Oncológica de Alta Complexidade (CACONs) e Unidades de Assistência Oncológica de Alta Complexidade (UNACONs). **Métodos:** Realizado entre março e maio de 2023 em 17 serviços públicos de Oncologia do RS, o estudo transversal utilizou um questionário de 54 perguntas aplicado a profissionais de saúde. A pesquisa cobriu vários aspectos, incluindo diagnóstico, tratamento, financiamento e trabalho em equipe multidisciplinar. Enfarizamos momento do diagnóstico e tratamento, pois a Lei nº 12.732/12 determina que o primeiro tratamento oncológico deve ser iniciado em até 60 dias.. **Resultados:** Pacientes com CM realizam testes de triagem ao iniciar o tratamento (88,2%), com imunohistoquímica comumente realizada externamente (64,7%) e a PCR frequentemente solicitada (82,4%), levando uma média de 90 a 250 dias para todos os procedimentos. Os pacientes enfrentam desafios, como longas permanências hospitalares, viagens extensas para centros de tratamento, efeitos colaterais do tratamento e altos custos de transporte, muitas vezes levando à interrupção do tratamento. O estágio mais demorado é o tratamento, sendo que a infusão subcutânea é mais eficiente em termos de tempo do que a administração intravenosa. Limitações físicas, problemas de mobilidade, diagnóstico tardio (média de 90 dias) e acesso limitado aos cuidados afetam significativamente a qualidade de vida dos pacientes. As equipes de saúde enfrentam dificuldades com diretrizes desatualizadas, falta de instalações para tratamento intravenoso e durações prolongadas das infusões. **Conclusão:** O estudo destaca a necessidade de abordar atrasos na triagem, restrições de recursos e disparidades no acesso aos cuidados, com a finalidade de aprimorar a qualidade do atendimento e a equidade no sistema, enfatizando obstáculos identificados na jornada dos pacientes com CM no sistema de saúde público.

Palavras-chave: câncer de mama; tratamento; jornada; Brasil; carga da doença.

Background

Cancer is a serious public health problem. Worldwide, it is estimated that 19.3 million new cases of cancer and nearly 10.0 million cancer-related deaths occurred in 2020. Female breast cancer surpassed lung cancer as the most diagnosed cancer, with an estimated 2.3 million new cases annually (1).

While breast cancer, in general, has a favorable oncological prognosis compared to other neoplasms, in developing countries such as Brazil, the five-year survival rate is 75.2%, whereas in developed countries, it reaches 90% (2). The observed disparity in mortality rates reflects a combination of factors, such as differences in access to early detection and more effective therapeutic interventions (2,3).

High Complexity Oncology Centers (CACON) and High Complexity Oncology Units (UNACON) play a crucial role in the Brazilian healthcare system, providing a wide range of services dedicated to the diagnosis, treatment, and follow-up of cancer patients. The specialized units in question are of utmost importance in ensuring that patients receive high-quality care and in managing the Unified Health System (SUS) in Brazil. CACONs, located in large hospitals and oncology reference centers, offer advanced services such as bone marrow transplants, targeted therapies, and complex surgeries, catering to patients with rare and complex cancers. UNACONs, present at various levels of hospital complexity, focus on less complex procedures, decentralizing treatment and expanding access to specialized care for a significantly larger number of patients (4,5). According to TabNet/DataSUS data, specifically in the Rio Grande do Sul region over the last 5 years (2018 to 2023), approximately 19,864 patients with breast cancer (ICD C50, D05) were diagnosed and treated in the public health system (6).

One of the significant challenges in cancer treatment is initiating treatment at the opportune time when it is most effective. This requires health services to undertake a complex and coordinated set of actions capable of enabling comprehensive, quality, and efficient care. Currently, breast cancer control is a priority on the country's health agenda and is part of the Strategic Action Plan to Address Non-Communicable Chronic Diseases (DCNT) in Brazil (7). Despite this, we still face intense fragmentation of health actions and services, leading to late diagnosis, treatment delays, a decline in care quality, and inequities (8–10). This impacts disease progression, patient quality of life, diagnosis at advanced stages, and increased costs in oncological treatment.

One strategy for organizing and integrating different types of care is the implementation of a breast cancer patient care pathway, a tool that proposes the reorganization of care flow and the implementation of best practices in attention to provide humanized and quality care throughout the patient journey. By identifying points in the care journey, it is possible to act in eliminating barriers to timely care, diagnosis, and treatment continuity. This strategy aims to promote greater adherence to the diagnostic and therapeutic plan, increased access to care promptly, higher attendance rates at appointments, and improved care quality (9,11).

In this study, our objective is to evaluate the breast cancer patient journey from the perspective of CACONs and UNACONs in the Rio Grande do Sul (RS), a Brazilian state.

Methods

A cross-sectional study involving public service institutions in Brazil was conducted from March to May 2023. A field survey was carried out using a specific questionnaire developed by the study team. This questionnaire comprised 54 questions related to diagnosis and screening, treatment, transportation, financing, and resource allocation, as well as the involvement of a multidisciplinary team (supplementary material). Each question in the questionnaire had response categories indicated in terms of periods in days, types of treatment or diagnostic tests, and possibilities of reasons for determining difficulties and barriers.

The participants in this project were the CACONs and UNACONs of the RS, represented by their healthcare professionals such as nurses, pharmacists, and doctors. Each health institution was contacted by email, and upon acceptance to participate in the research, the data collection tool was made available (supplementary material).

In this paper, emphasis was given to questions related to the time of diagnosis and treatment. We considered time as a fundamental variable in our analysis due to the enactment of two laws that directly impact oncological treatment in the Unified Health System (SUS) of Brazil. The first of these, Law No. 12,732/12, in effect since May 23, 2013, established a significant milestone by determining that the first oncological treatment in SUS must be initiated within a maximum period of 60 days from the signing of the pathological report or in a shorter period if there is a specific therapeutic need recorded in the patient's medical record (12). Furthermore, Law No. 13,896, dated October 30, 2019, which amended Law No. 12,732/12, stipulated that examinations related to the diagnosis of malignant neoplasms must be performed within 30 days under specific circumstances. Therefore, the analysis of time is crucial to assess compliance with these regulations and ensure timely and adequate access to oncological treatment in the Brazilian healthcare system (13).

The data obtained were evaluated through a public hearing on June 19, 2023, at the Legislative Assembly of RS, in a hybrid format, involving the multidisciplinary teams of CACONs/UNACONs. The results were analyzed descriptively, identifying the number and proportion of participants who responded to each category presented in each question, as well as the proportion of responses. This analysis was conducted using the Microsoft Excel platform (version 2305, 2023, 64 bits).

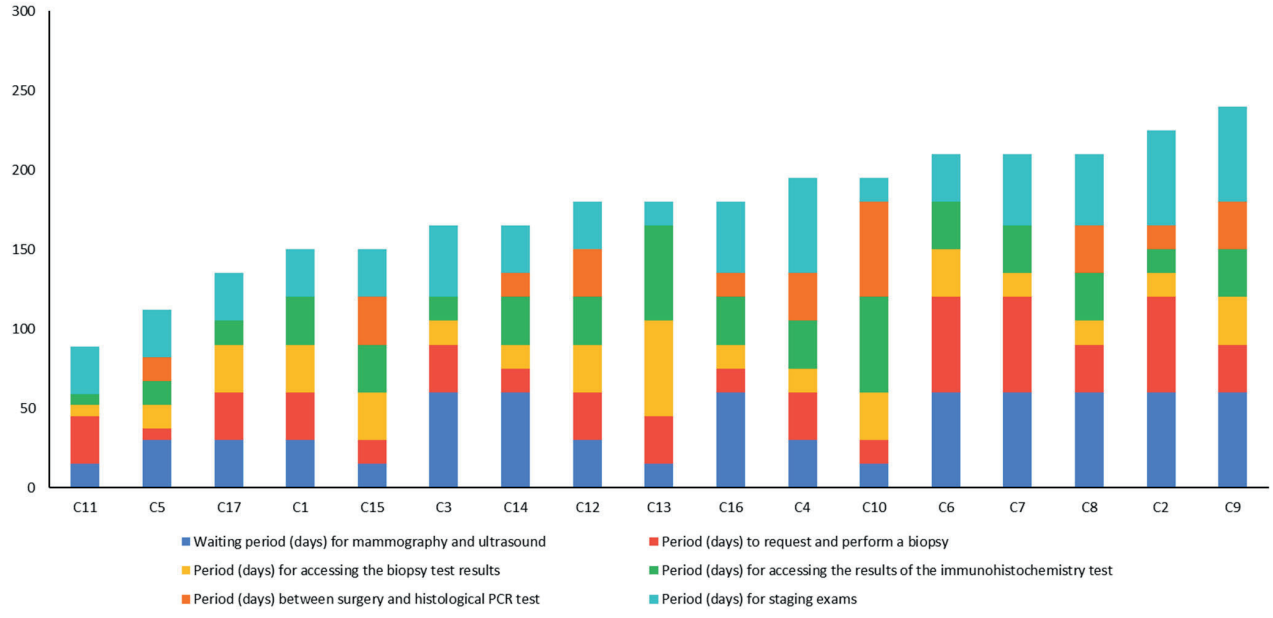
Results

Responses were obtained from 17 out of 31 CACONs and UNACONs in RS, indicating a 55% participation rate of the centers. The data were grouped into the following topics: 1) average time elapsed for the performance of exams; 2) time burden; 3) mobility; 4) quality of life and barriers experienced.

The average time elapsed until diagnosis exams were performed

Eight centers had an average time for performing mammography and breast ultrasound above 50 days. The average time for the completion of all procedures varied from 90 to 250 days. The breakdown of time between the completion of each procedure (waiting time for breast ultrasound, mammography, clinical breast examination, self-examination, mammography and MRI, biopsy, and immunohistochemistry) in each of the 17 centers is presented in Figure 1.

Figure 1. The average time elapsed for exams in the 17 evaluated CACON/UNACON.



Legend: The values refer to the maximum numbers for the completion of each procedure within each time range category. C: Center.

Time burden for the treatment administration

We identified that treatment is the stage of the care journey that consumes most of the time. When analyzing the time spent in the oncology center for treatment, the time consumed for the administration of subcutaneous (SC) medications (82.4% - administration time of 30 minutes to 1 hour) was considerably less compared to the intravenous (IV) administration route, where 6% reported taking 30 minutes to an hour, with the majority, 79.9%, stating it takes 2 to 4 hours (Figure 2).

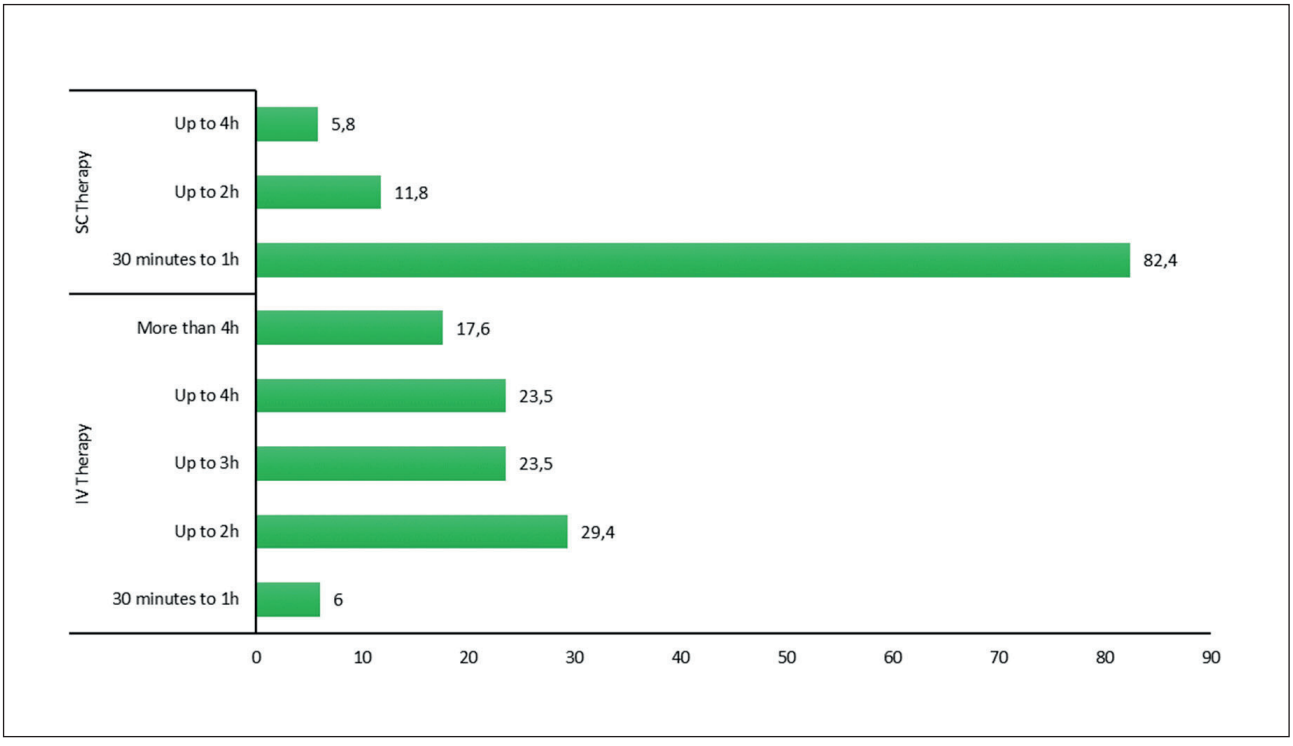
Mobility

The average distance from the patient's residence to the treatment center was reported by 14 Centers, ranging from 16 to 40 km in 6 centers, 40 to 70 km in 3 centers, and above 70 km in 5 centers. Most centers referred to municipal transportation provided by the local government as the way patients travel to the treatment center (Table 1). In the absence of access to radiotherapy at the service, patients are referred to reference locations that often are not close to the service where they are already receiving treatment. On average, these patients are referred to services with distances ranging from 45 km to 180 km from the current treatment center.

Main barriers identified

Regarding the difficulties and barriers faced by all stakeholders in breast cancer treatment (patient, healthcare team, and institution), most centers (16/17 centers) reported that patients face the following difficulties regarding the treatment: 1) long hospital stay (8/17); 2) frequency of visits to the hospital/clinic for treatment (11/17); 3) adverse effects to treatment (14/17); 4) distance/travel to the treatment location (12/17); and 5) transportation expenses to the treatment location (6/17). These difficulties were also reasons for patients to interrupt treatment, in addition to disease progression (11/17), self-withdrawal from treatment (10/17 centers), and lack of support network.

Figure 2. Length of stay at the cancer center to undergo IV and SC therapies.



Legend: The values represent the proportion of centers that reported the duration of stay. SC: subcutaneous; IV: intravenous.

Table 1. Distance Traveled for Treatment.

Mobility	n (%)
Means of transportation to the treatment center	
Bus	4 (23.5)
Municipal government transportation	12 (70.6)
Transportation by application, bus, or municipal transportation provided by the patient's municipality of origin	1 (5.9)
Average distance from the patient's residence to the treatment center	
Up to 5 km	1 (5.9)
6 to 15 km	2 (11.8)
16 to 40 km	6 (35.3)
40 to 70 km	3 (17.6)
Above 70 km	5 (29.4)

Legend: n – number of patients

Most centers reported that the barriers faced by patients are: 1) physical limitations/pain (13/17); 2) travel to the treatment location (11/17); 3) delay in diagnosis/treatment initiation (7/17); and 4) lack of access to adequate care (11/17). Regarding the healthcare team, most centers reported that difficulties related to chemotherapy treatment are: 1) the center's guidelines do not reflect the current Ministry of Health's Diagnosis and Treatment Guideline (DDT) (6/17 centers); 2) lack of chairs (beds) for intravenous treatment application (4/17 centers); and 3) long application time for the intravenous route (3/17 centers). Barriers to chemotherapy treatment related to the centers were: 1) shortages (3/17 centers); 2) the center's guidelines do not reflect the current DDT (6/17 centers); and 3) logistics (4/17 centers) (Table 2).

Table 2. Barriers reported by the patient for quality of life.

Barriers	n (%)
Physical limitations/pain	13 (76.5)
Limited social life	7 (41.2)
Unable to work	8 (47.1)
Prejudice	3 (17.6)
Time spent in the hospital	2 (11.8)
Commute to the treatment location	11 (64.7)
Lack of multidisciplinary support	3 (17.6)
Lack of information	4 (23.5)
Delay in diagnosis/initiation of treatment	7 (41.2)
Lack of access to appropriate care	12 (70.6)

Legend: n – number of patients

Discussion

This study offers an analysis of the CACONs and UNACON operations in the state of RS, Brazil. The results are revealing as they highlight the challenges and opportunities that surround the treatment of breast cancer in a national context and present the main barriers to be overcome for timely, equitable, quality, and adherent diagnosis and treatment.

Regarding the average time elapsed for the performance of exams, the findings indicate significant variations in the speed of procedures, reflecting a reality often experienced by Brazilian patients. The variation above 50 days in eight centers for the waiting time for diagnostic procedures, such as mammography and breast ultrasound, reveals the disparity in accessibility to essential exams. In a study conducted in Tunisia, about one-third of patients (34.9%) experienced delays of more than 60 days for diagnosis (14). Brand et al. (2019) identified time intervals and barriers to cancer diagnosis in 57 low- and middle-income countries. The average intervals for early diagnosis were similar in three stages: access (1.2 months), diagnosis (0.9 months), and treatment (0.8 months) (15). Furthermore, low-income countries had longer access-to-diagnosis intervals (6.5 months) (15). Some barriers associated with diagnosis time suggest low health literacy, lack of awareness, the cost of screening services, and distance to the screening center (15–18). The range of 90 to 250 days to complete all procedures emphasizes the need to prioritize strategies aimed at reducing these deadlines to improve early detection and, consequently, treatment effectiveness. Moreover, this aspect may have profound implications for early detection and treatment effectiveness, highlighting the need for approaches to reduce waiting times and optimize workflows in centers. The mammography rate in the country is substantially below the guidelines recommended by the World Health Organization (WHO). However, it is noteworthy that there is a significant discrepancy between this coverage rate and the number of confirmatory diagnostic exams conducted by the Unified Health System (SUS) (19,20).

The results of this study regarding the time for diagnosis are in agreement with the conclusions pre-

sented by Traldi et al. (21). In this previous study, an average of 5 months (142.6 ± 10.1 days, ranging from 12 to 451 days) was identified until the diagnostic process was performed. Additionally, it was found that 60% of diagnoses were confirmed between 4 and 6 months (120 and 180 days), while 8.9% of the sample had the opportunity to receive the diagnosis within 60 days. According to the Ministry of Health, access to diagnostic exams and treatment, when necessary, is intrinsically linked to established references and the structure of the care network, as evidenced by previous studies. Additionally, the availability of qualified human resources and equipment exerts a crucial influence on this process (22).

In the context of the time burden for treatment administration, the study presents a significant difference between SC and IV administration routes, confirming the expected, as the subcutaneous route is quickly administered, and the intravenous route is mostly administered slowly, even when performed as a push. Treatment, a critical milestone in the patient's journey, consumed considerably more time when administered by the IV route. This scenario is relevant in the Brazilian context, where healthcare infrastructure is often challenged to meet a significant demand of patients, thus reducing the possibility of access for new patients. The observation that the SC route takes less time compared to the IV route emphasizes the importance of making more efficient options widely available. This discrepancy suggests an area for improvement, where the search for more efficient and less time-consuming administration methods can positively impact patient quality of life by reducing time spent in the oncology center (23). This can not only improve the patient experience but also free up resources to improve other areas of cancer care (24–26).

Patient mobility to treatment centers has emerged as another area of concern. Findings on the average distance between the patient's residence and the treatment center directly impact accessibility and patient strain, especially relevant in a country of continental dimensions like Brazil. The reliance on municipal transportation, often the only option for many patients, highlights the accessibility challenges faced by those seeking treatment and underscores the importance of partnerships with local authorities to improve access. Ensuring transportation for appointments and tests conducted outside the patient's municipality emerges as a measure as crucial as the availability itself, even in scenarios where municipalities are part of metropolitan regions, where access could be more accessible. The depletion of supply in municipal services often highlights transportation availability as a barrier to accessibility. The difficulty of access to treatment is attributed to the municipality's inability to perform certain confirmatory exams, exacerbated by the need for transportation to distant locations (27). The need to refer patients to reference locations for certain types of treatment, with considerable distances from the current center, underscores the complexity of logistics in geographically extensive areas and highlights the need for greater coordination between institutions and health authorities to ensure accessibility to all aspects of cancer treatment. Research indicates that obstacles in accessing specialized services lead to seeking private care, generating conflicts between formal and informal care flows. This dynamic compromises the ability to effectively coordinate healthcare and highlights a significant barrier to treatment (28–31). According to a study conducted in Brazil, based on DataSUS records from 2019-2020, more than half of female breast cancer cases started oncological treatment more than 60 days after diagnosis. In addition to old age, having to travel more than 200 km from home for treatment was a factor that influenced this delay (32).

In terms of barriers during treatment, the research shows the main obstacles experienced by patients, healthcare teams and institutions. The mentioned difficulties, such as long hospital stays, adverse effects, frequent travel and lack of support, reflect real challenges affecting the patient's journey in Brazil (33). The need for frequent hospital visits for treatment, combined with side effects and physical limitations, contributes to a reduction in the quality of life of patients (30,34). Difficulties related to treatment compliance were evident, with patients interrupting treatment for various reasons (35). Lack of a support network and lack of access to adequate care also emerged as factors adversely impacting treatment continuity (36). The discrepancy between treatment guidelines and practice in cen-

ters highlights the need for better implementation of health policies and constant updates to ensure that patients receive treatment according to the best available practices (37,38).

This research enabled the identification of the main barriers to be overcome in the breast cancer care pathway to reduce diagnosis and treatment time, aiming to provide patient-centered care. The restructuring of the care pathway for women with breast cancer is necessary so that the care network can expedite and coordinate the care of breast cancer patients, transitioning care across the healthcare network, helping them overcome the various barriers encountered during their journey, and prioritizing the steps necessary to start treatment as soon as possible.

Therefore, it is suggested to create an optimized BC care pathway, bringing together all healthcare network stakeholders for a deliberative dialogue with the structuring of necessary processes, electing priorities based on the synthesis of scientific evidence and situational planning to reduce the time between diagnosis and treatment and improve the care provided to these women.

This study has some limitations that should be considered when interpreting its results. Firstly, the questionnaire used by the authors consisted of multiple-choice questions, which may not cover all possible reasons for the investigated phenomenon, limiting the complete understanding of underlying causes. Additionally, the subjectivity inherent in the responses of specific participants from treatment units may not reflect a consensus within these units, leading to a partial view of reality. Another limitation is the geographical location of the treatment units, which may represent an economically more favorable scenario compared to other regions of Brazil, affecting the generalization of results to the entire country. The representativeness of the data is also a concern, as the results may not be extrapolatable to other populations or contexts. Furthermore, as the study does not follow the same population over time, it is not possible to establish causal relationships between conditions and risk factors. Finally, the inability to establish causal relationships arises from a lack of evidence of a temporal sequence between exposure to a factor and the subsequent development of the disease, limiting the inference of cause-and-effect relationships based on the obtained results.

Conclusion

In conclusion, this study provides a comprehensive analysis of the situation of oncology centers in RS, focusing on aspects of adherence, efficiency, and treatment quality. Additionally, the study contributes substantially to understanding the situation of oncology centers in the Brazilian context, especially concerning breast cancer treatment. Despite the lack of sample representativeness, the data shown by this study are aligned with the literature in the research area. The results presented reinforce the urgency of addressing the challenges encountered, such as prolonged waiting times, efficiency in drug administration, patient mobility, and quality of life during treatment. The research serves as an important reminder that joint efforts between governments, healthcare professionals, and society are needed to address these challenges, ensuring a more effective, accessible, and humanized BC treatment for all Brazilian patients.

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