

# Integrality Care for Women with Breast Cancer: Challenges in Implementing the Line of Care in a Brazilian Northeast State

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*Integralidade do Cuidado à Mulher com Câncer de Mama: Desafios na Implementação da Linha de Cuidado em um Estado do Nordeste do Brasil*

*Atención Integral a Mujeres con Cáncer de Mama: Desafíos en la Implementación de la Línea de Atención en un Estado del Nordeste del Brasil*

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## ABSTRACT

**Introduction:** Breast cancer is a significant public health problem due to its high incidence and mortality among women. **Objective:** To analyze the integral care provided to women with breast cancer in the Health Care Network in a Brazilian Northeast State based on the perceptions of users with breast cancer, health professionals and managers. **Method:** Qualitative research with semi-structured interviews with users with breast cancer, professionals from oncology referral services and primary care, and managers at the municipal, state and federal levels. **Results:** The Breast Cancer Line of Care has not been implemented, exposing the weakness of the coordination of care and organization of the Health Care Network, affecting the continuum of care at different levels. The spontaneous demand for treatment and the access flows created by users and health professionals have resulted in significant inequities in access to health services, deepening the existing inequalities. Comprehensive care has been compromised due to the absence of well-established protocols and care flows, incipient queue management in the regulatory system, and referral and counter-referral. **Conclusion:** The lack of a line of care has impacted the accessibility and equity of access to health services. The findings of this study provide crucial guidance for planning the health care network and the need to implement the Breast Cancer Line of Care to improve comprehensive care for women diagnosed with breast cancer.

**Key words:** Breast Neoplasms; Integrality in Health; Continuity of Patient Care; Equity.

## RESUMO

**Introdução:** O câncer de mama é um problema de saúde pública significativo em razão da alta incidência e mortalidade entre as mulheres. **Objetivo:** Analisar a integralidade do cuidado à mulher com câncer de mama na Rede de Atenção à Saúde em um Estado do Nordeste brasileiro, a partir das percepções de usuárias com câncer de mama, profissionais de saúde e gestores. **Método:** Pesquisa de abordagem qualitativa com entrevistas semiestruturadas com usuárias com câncer de mama, profissionais dos serviços de referência oncológica e da atenção primária, e gestores das esferas municipal, estadual e federal. **Resultados:** A Linha de Cuidado do Câncer de Mama não está implementada, destacando fragilidades na coordenação do cuidado e na organização da Rede de Atenção à Saúde, afetando o *continuum* do cuidado nos diferentes níveis assistenciais. A demanda espontânea para o tratamento e os fluxos de acesso criados por usuárias e profissionais de saúde resultaram em significativas iniquidades no acesso aos serviços de saúde, ampliando as desigualdades existentes. A integralidade tem sido comprometida por causa da ausência de protocolos e fluxos assistenciais bem estabelecidos, incipiência na gestão de filas do sistema de regulação e referência e contrarreferência. **Conclusão:** A falta de uma linha de cuidado tem impactado na acessibilidade e na equidade de acesso aos serviços de saúde. Os achados deste estudo fornecem orientações cruciais para o planejamento da Rede de Atenção à Saúde e a necessidade da implementação da Linha de Cuidado do Câncer de Mama para melhorar a integralidade da atenção às mulheres diagnosticadas com câncer de mama. **Palavras-chave:** Neoplasias da Mama; Integralidade em Saúde; Continuidade da Assistência ao Paciente; Equidade.

## RESUMEN

**Introducción:** El cáncer de mama es un importante problema de salud pública debido a su alta incidencia y mortalidad entre las mujeres. **Objetivo:** Analizar la integralidad de la atención a mujeres con cáncer de mama en la Red de Atención a la Salud en un estado del nordeste brasileño, a partir de las percepciones de usuarias con cáncer de mama, profesionales de la salud y gestores. **Método:** Investigación con enfoque cualitativo, con entrevistas semiestructuradas a usuarias con cáncer de mama, profesionales de servicios de referencia en oncología y atención primaria, y directivos de los ámbitos municipal, estatal y federal. **Resultados:** La Línea de Atención al Cáncer de Mama no está implementada, destacando debilidades en la coordinación de la atención y en la organización de la Red de Atención en Salud, afectando la continuidad de la atención en los diferentes niveles de atención. La demanda espontánea de tratamiento y los flujos de acceso creados por usuarios y profesionales de la salud dieron como resultado importantes desigualdades en el acceso a los servicios de salud, ampliando las desigualdades existentes. La atención integral se ha visto comprometida por la ausencia de protocolos y flujos de atención bien establecidos, mala gestión de colas en el sistema de regulación y derivación y contrarreferencia. **Conclusión:** La falta de una línea de atención ha impactado la accesibilidad y equidad de acceso a los servicios de salud. Los hallazgos de este estudio brindan una guía crucial para la planificación de la red de atención de salud y la necesidad de implementar la Línea de Atención al Cáncer de Mama para mejorar la integralidad de la atención a las mujeres diagnosticadas con cáncer de mama. **Palabras clave:** Neoplasias de la Mama; Integralidad en Salud; Continuidad de la Atención al Paciente; Equidad.

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## INTRODUCTION

Breast cancer is a global public health issue, especially challenging for developing countries like Brazil. Excluding non-melanoma skin cancer, breast cancer was the most incident malign neoplasm in Brazil and worldwide in 2020, surpassing lung cancer<sup>1,2</sup>. For the 2023-2025 period, 73,610 breast cancer cases are estimated, with 15,690 of those in the Northeast Region and 2,880 in Pernambuco alone<sup>1,2</sup>. It is worth highlighting that delays in early detection and late diagnoses make the treatment more costly and complex, decreasing survival and increasing mortality<sup>3,4</sup>.

Coping with breast cancer requires an integral approach, considering the woman as a whole, catering to all her needs. The achievement of such an integral approach is a challenge for the National Health System (SUS) that is compromised when the Health Care Network (HCN) has no adequate health services structure timely available for women<sup>2,3,5,6</sup>.

To broaden access, accessibility and quality of care at the HCN, the Ministry of Health has implanted Lines of Care (LC) that approach health surveillance, diagnosis, treatment, palliative care and user follow-up, in addition to pointing out flows, referral criteria, and effective communication with references and counter references among the diverse healthcare sites in the HCN<sup>7</sup>. LC has Primary Healthcare Consultation (PHC) as manager of assistance flows, responsible for coordinating care and organization of HCN<sup>7-10</sup>.

The Breast Cancer Line of Care (BCLC) is among the primary LC to organize the provision of health actions and services, establishing competences according to the complexity level of the service<sup>7</sup>. The navigation of the person with cancer is a model centered on the person and their care journey in the different HCN sites and has been one of the essential strategies to ensure continuity<sup>11-15</sup>. Trained health professionals integrated into the team play the role of navigators, guiding the users in each step of the LC.

The legal framework ensures universal, integral and equal access to women with breast cancer<sup>16</sup>. Obstacles must be revealed so they can be removed. LC with navigating strategies strengthens the integrity of care, ensuring coordinated, efficient service that is sensitive to the individual needs of women<sup>11-15</sup>. Therefore, with the LC it's possible to assess the guarantee of integrity and its effective implementation at HCN. Inefficiency in care coordination at any point of the LC may impact integral care and expand health inequities<sup>9,10</sup>.

This study assumes the BCLC is not implemented in the State of Pernambuco, which compromises the integrity

of care in all its nuances. In this context, this study has the objective of analyzing the integrity of care for women with breast cancer in the HCN of a State in the Brazilian Northeast Region, from the perceptions of breast cancer patients, health professionals and managers.

## METHOD

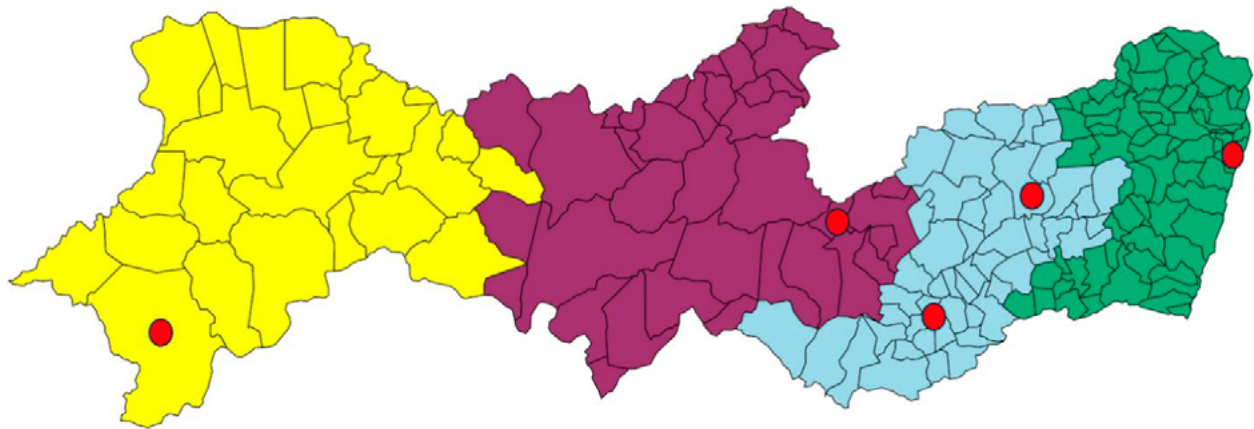
Qualitative research was conducted using sequential data collection method<sup>17</sup>. Based on the principle of integrity and the BCLC<sup>7</sup>, this study is based on the theoretical-methodological framework of empirical phenomenology<sup>18</sup>, from the perceptions and experiences of users, health professionals and managers.

The studied site was the State of Pernambuco, which owns ten oncology reference services that treat breast cancer, spread over four Health Macro-regions (Figure 1).

The sequential collection began with the users and enabled a progressive building of knowledge, promoting an integral and broad view of the process of care, considering the perspectives of those who receive care, and the professionals who manage the care services and are responsible for planning actions. The answers at this stage were key to elaborate the following scripts, initially directed to health professionals, and later, to health managers. Twenty semi-structured interviews were conducted to achieve the study objective and contemplate the normative and theoretical framework for the effectiveness of the integrity of care to women with breast cancer. The study, based on the sequential data collection method<sup>17</sup>, followed six steps (Figure 2).

Of the interviewed users with breast cancer, nine were from the four Health Macro-regions, five were in treatment at the High-Complexity Oncology Unit (Unacon) of the *Hospital de Câncer de Pernambuco* (HCP) and four were in treatment at the High-Complexity Oncology Center (Cacon) at the *Instituto de Medicina Professor Fernando Figueira* (IMIP) (Chart 1). The Unacon and Cacon were selected for servicing patients from every city in the State of Pernambuco. Also took part in the study three professionals from the Unacon/Cacon involved in breast cancer treatment, five professionals from the PHC, one from the municipal management, one from the State management, and one from the federal management, with the aim of exploring the essential building blocks of BCLC in every healthcare level (Chart 1).

The sample was intentional, including women in breast cancer treatment at the HCP Unacon and the IMIP Cacon. The first author of the study had access to the oncology references' care schedules and,



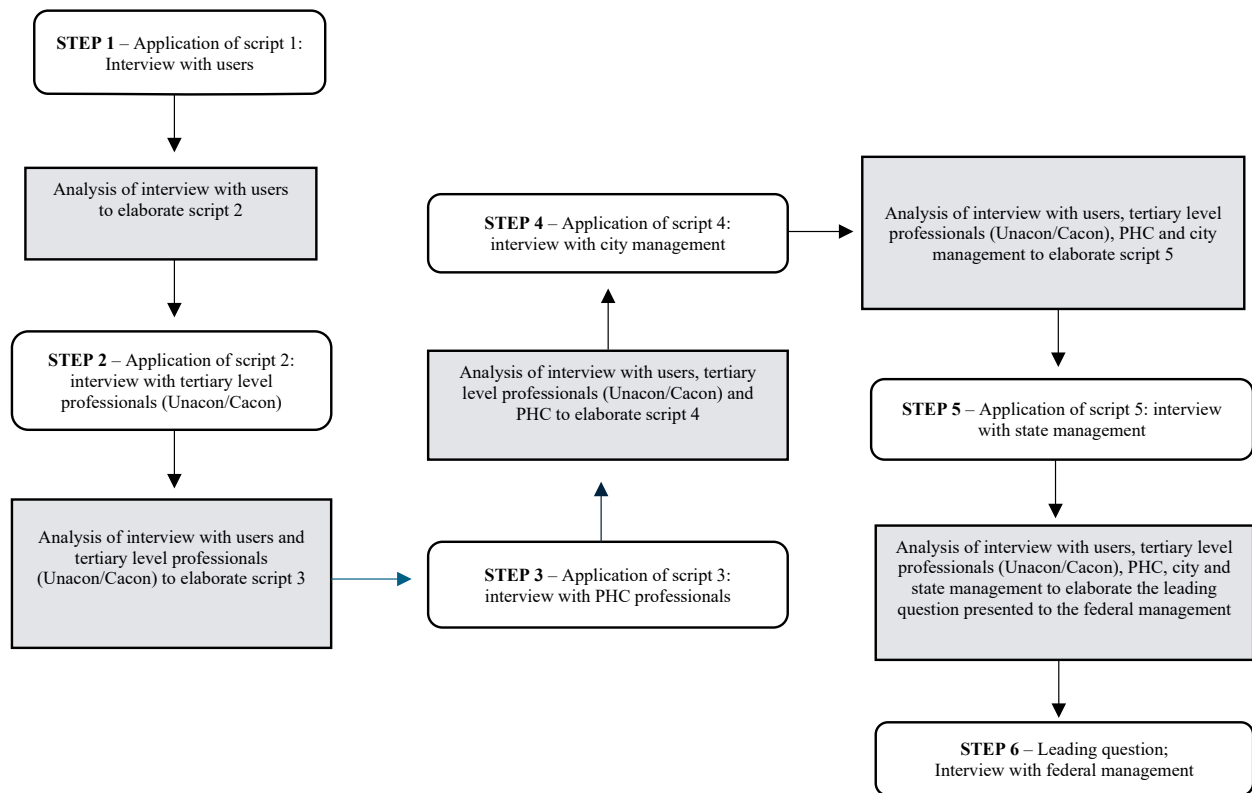
- Macro-region I – Metropolitan area (Health regions I, II, III and XII) – Four Unacon and one Cacon, all in Region I (city of Recife).
- Macro-region II – *Agreste* (Health regions IV and V) – Three Unacon, two in Region IV (city of Caruaru) and one in Region V (city of Garanhuns).
- Macro-region III – *Sertão* (Health regions VI, X and XI) – One Unacon in Region VI (city of Arcoverde).
- Macro-region IV – *Vale do São Francisco* and *Sertão do Araripe* (Health regions VII, VIII and IX) – One Unacon in Region VIII (city of Petrolina).
- Cities with high complexity oncology reference services (Unacon/Cacon).

**Figure 1.** Health macro-regions in the State of Pernambuco and Unacon and Cacon distribution. Pernambuco, Brazil, 2023

**Source:** Elaborated by the authors, based on Order SAES/MS n.º 688, August 28, 2023<sup>19</sup> and the Pernambuco Region Division Master Plan<sup>20</sup>.

**Captions:** Cacon = High-Complexity Oncology Center; Unacon = High-Complexity Oncology Unit

**Note:** The Hemope Unacon is not included in the quantitative of the table due to it being part of the exclusion criteria, since it does not offer breast cancer treatment.



**Figure 2.** Sequential data collection method. Pernambuco, Brazil, 2023

**Captions:** Cacon = High-Complexity Oncology Center; Unacon = High-Complexity Oncology Unit.

from that, invited users to participate in the research, ensuring representation of the State’s Macro-regions. To facilitate access, the PHC professionals invited to participate worked in the same units as the users living

in Recife (Macro-region I) The municipal, state and federal managers were indicated by their respective superiors, considering their expertise in breast cancer coping (Chart 1).



Chart 1. Users, professionals and managers interviewed by treatment location and workplace. Pernambuco, Brazil, 2023

| Step 1 – Women with breast cancer                             |   |   |  |   |                        |
|---|---|---|--|---|------------------------|
| Treatment<br>Unacon/Cacon                                     | N | Health macro-region<br>the user belongs to          | Code used<br>in the text                                       | Distance from the<br>user’s home to<br>treatment location | Transportation<br>mode |
| Cacon IMIP  | 1 | I - Metropolitan                                    | User #1: Macro 1.  | 8 km  | Private                |
| Cacon IMIP  | 1 | II - Agreste  | User #1: Macro 2.  | 211 km  | OHT                    |
| Cacon IMIP  | 1 | III – Sertão  | User #1: Macro 3.  | 509 km  | OHT                    |
| Cacon IMIP  | 1 | IV – Vale do São Francisco<br>and Sertão do Araripe | User #1: Macro 4.  | 535 km  | OHT                    |
| Unacon HCP  | 1 | I - Metropolitan                                    | User #2: Macro 1.  | 10 km   | Uber ride share        |
| Unacon HCP  | 1 | I - Metropolitan                                    | User #3: Macro 1.  | 18 km   | Bus                    |
| Unacon HCP  | 1 | II - Agreste  | User #2: Macro 2.  | 135 km  | OHT                    |
| Unacon HCP  | 1 | III – Sertão  | User #2: Macro 3.  | 470 km  | OHT                    |
| Unacon HCP  | 1 | IV – Vale do São Francisco<br>and Sertão do Araripe | User #2: Macro 4.  | 682 km  | OHT                    |
| Step 2 – Professionals in oncology services                   |   |   |  |   |                        |
| Workplace   | N | Code used in the text                               |  |   |                        |
| Cacon IMIP  | 1 | Specialist 1 – Oncology service                     |  |   |                        |
| Unacon HCP  | 1 | Specialist 2 – Oncology service                     |  |   |                        |
| Cacon IMIP and<br>Unacon HCP                                  | 1 | Specialist 3 – Oncology service                     |  |   |                        |
| Step 3 – Professionals in the Primary Healthcare Consultation |   |   |  |   |                        |
| PHC professional<br>category                                  | N | User attached to treatment                          | Code used in the text  |   |                        |
| Doctor  | 1 | Cacon IMIP  | Professional 1 – Primary care                                  |   |                        |
| Nurse   | 2 | Cacon IMIP  | Professional 2 – Primary care<br>Professional 3 – Primary care |   |                        |
| Doctor  | 1 | Unacon HCP  | Professional 4 – Primary care                                  |   |                        |
| Nurse   | 1 | Unacon HCP  | Professional 5 – Primary care                                  |   |                        |
| Step 4 – Health managers                                      |   |   |  |   |                        |
| Management  | N | Code used in the text                               |  |   |                        |
| City  | 1 | City management                                     |  |   |                        |
| State   | 1 | State management                                    |  |   |                        |
| Federal   | 1 | Federal management                                  |  |   |                        |

**Captions:** OHT = Out-of-Home Treatment; Cacon = High-Complexity Oncology Center; Unacon = High-Complexity Oncology Unit; IMIP = *Instituto de Medicina Professor Fernando Figueira*; and HCP = *Hospital do Câncer de Pernambuco*.

The women were interviewed by the first author in the study, at the services they attended, for up to 40 minutes. The others had their data collected in a previously arranged location, for up to 40 minutes. The interviews were recorded through the “Recorder”

software available at the Apple Store. The Cockatoo software was used for transcription. The transcribed text was corrected accordingly.

The interview analysis used the content analysis<sup>22</sup> method and, from empirical phenomenology<sup>18</sup>, it was

possible to identify the significance units that express the totality of experience lived by the participants, capturing the essence of the intention of conscience in the experiences related to oncology care integrity in Pernambuco. This theoretical framework was chosen due to its ability of revealing the nuances in the subjects' experience, enabling a deeper understanding of the challenges and fragmentations in the implementation of BCLC and how women navigate the HCN. In the content analysis, the following categories emerged: "Management of Oncology Care: Fragmentation in the Implementation of the Breast Cancer Line of Care in Pernambuco"; and "Challenges in Implementing Navigation for Women with Breast Cancer in the Health Care Network."

This study has been approved by the Research Ethics Committees of the *Instituto de Pesquisas Aggeu Magalhães*, report number 6142468 (CAEE (submission for ethical review): 67124722.2.0000.5190); of the HCP, 6219126 (CAEE: 67124722.2.3001.5205); and the IMIP, 6298573 (CAEE: 67124722.2.3002.5201), in compliance with Resolution 466/2012<sup>23</sup> of the National Health Council.

## RESULTS AND DISCUSSION

The interviewed users were aged 46 to 60 years old, with three of them under 50 years old. Four single and five married women. Only one had no children. The Unacon/Cacon professionals had four to 35 years of experience in the care of women with breast cancer. At the PHC, professionals had 15 to 29 years of experience in primary care. All the managers have over six months' experience in the job.

The average distance in kilometers traveled by the users in Macro-regions I, II, III and IV from their homes to the oncology service were 12 km, 173 km, 489.5 km and 608.5 km, respectively. Women in Macro-regions II, III and IV benefited from the Out-of-Home Treatment (OHT) transportation.

Considering the diversity of participants, it is important to highlight the direction pointed was unanimous among users, health professionals and managers.

### Management of Oncology Care: Fragmentation in the implementation of the Breast cancer Line of Care in Pernambuco

Oncology policy management should be performed by professionals who plan and monitor actions to improve the Oncology Healthcare Network, using a holistic approach to identify the needs and complexities

in managing the disease. The narratives show the absence of specific managers for oncology in the state and municipal levels.

There is the central coordination for women's health [...], a person within the territory that exclusively cares for women's health. She is not exclusively responsible for cervix and breast cancer. She is responsible for women's health generally (Municipal management).

[...] We have the women policy, but for cancer, the oncology policy coordinator hasn't arrived yet (State management).

It's essential to have a specific manager for oncology, aligned to the Women's Health Policy strategies. The overload of neoplasms on the public health system is costly, and strategies that allow for early diagnosis, in addition to increasing survival, represent less expensive treatments for SUS<sup>1,24</sup>. The lack of coordination for oncology care affects the situational diagnosis, planning and organization of HCN actions. The manager can be an agent with several possibilities of connection that can contribute or complicate the network's organization and user access<sup>25-28</sup>. It is crucial to train capable managers for cancer prevention and control, integrating assistance, promotion, prevention, management, education and research, considering the regional and local diversities<sup>27</sup>.

The fragilities in the conception of the oncology action plan have been shown in reports by PHC professionals and tertiary service:

[...] I think the lack of dialog with people in the front line, before defining anything, is the first issue. [...] It's not interconnected, each one is in their corner, their space, their level (Professional #1 – Primary Care).

[...] No one plans, this is the greatest issue (Specialist #3 – Oncology service).

[...] planning should be considered from the bottom up [...], the Ministry of Health doesn't execute the policy at the front line. So, we have a series of difficulties in operating these policies [...], there is a very strong need for States and cities to build their plans based on the local scenario (Federal management).

Policies are executed at the city-level and should be organized around early diagnosis, involving PHC in the planning, as it's intimately involved with the population, making it, in fact, the head of the network<sup>25,29-31</sup>.





When the planning doesn't involve the interested parties, the strategies tend to not faithfully reflect the reality of territory, which risks health professionals not feeling like they belong in the mission enough to fulfill it. To advance planning, it's essential to consider articulations with the stakeholders and strengthen relations with other policies, in addition to women's health, sectors that involve the social health determinants.

Reports indicate fragilities in the oncology care planning, and there are no guarantees in the care coordination, since BCLC is not implemented in the city and state levels, affecting continuity of care in the different HCN sites:

There is no care coordination [...], the patients end up seeking tertiary services (Specialist #1 – Oncology service).

[...] They often leave the network seeking celerity. Then, she ends up leaving the network and we lose track of this woman [...] (City management).

Today, we see a very fragmented cancer line of care, of women's care. There is no access flow, no Line of Care [...], this patient gets lost (State management).

With no adequate flows, users seek, often alone, alternative pathways to access the health services. Ensuring comprehensive care is related to the LC structure<sup>29,32</sup>. Absence of care coordination is a reflex of the network's organization<sup>33</sup>, and the diverse non-institutional flows.

[...] You can only get treatment there if you are referred to [...], so a friend of mine [...] put me there in the UPAE [...] (User #2: Macro 2).

I, myself, follow this flow already, because if I were to wait the, say, regular flow, I would lose more patients (Professional #1 – Primary care).

[...] We feel this difficulty with professionals [...], [a lack of] knowledge of the network itself, knowing the flows, because we sometimes lose time (City Management).

Without the BCLC, the several pathways users follow to access the health services increase inequities and access inequality. Fragilities in the organization of access flows should be overcome<sup>28,34,35</sup>. Professionals' lack of knowledge on the network and the available services may aggravate the situation of users that need to be referred to the next stage in the network and there is no adequate protocol and flow, with effective communication between the levels and guarantee of access. The absence of municipal oncology plans and the significant incoherence between the current State

oncology plan and the reality of HCN, has compromised the implementation of BCLC, flows, timely access and accessibility to oncology care.

[...] To build a specific protocol for Recife, because we have none. [...] (City management).

There is no assistance protocol. [...] The current oncology plan is one that is not integrated, that has no access flow, [...] the user is lose (State management).

The elaboration of a city and state plan for oncology is crucial to coordinate and integrate health services, reduce inequalities in access to diagnosis and treatment, optimize resources, promote early diagnosis and improve the quality of care. The creation and advertisement of the oncology plan is a responsibility of health managers<sup>19</sup>. It is worth measuring the consequences of the lack of an adequate oncology plan and the impacts in women's lives and in SUS, since the early diagnosis increases survival and is less costly to the health system<sup>3,4,24</sup>. Especially when it comes to users of Macro-regions II, III and IV who are not referred to the Unacon of their respective Macro-regions, the TDF adds obstacles due to long distances.

Communication between assistance levels was pointed as fragile due to incipience in the referral and counter referral system.

Terrible, terrible! [...] The patient comes in really lost [...]. Usually just the exams tell the patient's history, but sometimes there are details that need to be said (Specialist #3 – Oncology service).

[...] Nothing is written down to us, and I think it should. So, this referral and counter referral doesn't exist (Professional #4 – Primary care).

Fragilities in referral and counter referral compromise effective communication, delays in diagnosis, therapeutic conduct and time of treatment start due to loss of clinical information. The network organization needs to rely on an effective referral and counter referral system that works and is recognized among professionals<sup>29,36</sup>.

The guarantee of integrity has been a challenge that, added to the lack of care navigation and BCLC makes the user navigate with no help from HCN. The navigation of patients consists of active search and individual follow-up throughout the care journey<sup>37</sup>. Reports from users and health professionals point to a lack of guaranteed care continuity among the several HCN levels, as summarized by the following narratives:

I didn't have this follow-up with the CHA (User #3: Macro 1).

[...] Usually, the treatment site follows up with the patient and we lose this link a bit (Professional #5 – Primary care).

Integral and integrated care action is needed, showing all the paths the patient should follow in primary care, how it's done in secondary care, tertiary care, showing that these are not tight chambers, they have to communicate [...], when the patient comes to the screening, she already lost time due to lack of coordination (Specialist #1 – Oncology service).

There is fragmentation in the coordination of care and in the organization of the network by the PHC within the HCN. The lack of communication between the PHC and the Specialized Care may generate a series of issues, compromising adequate and timely follow-up, in addition to affecting quality and continuity of care, especially in the follow-up of patients in treatment that need care beyond oncology treatment. This scenario directly impacts one of the central attributes of the PHC, which is broad and integral<sup>25,29,35,38,39</sup>. Thus, it's necessary to (re)think how the defined strategies are being actually implemented by PHC, on the conditions that are being given so the primary care executes this role effectively, minimizing inequities in breast cancer control.

The fragilities in care continuity by the PHC do not remove the responsibility of other assistance levels and health managers of ensuring continuity.

In the reports of users and professionals of IMIP's Cacon, the Pink Line was identified. In the first appointment, the woman is inserted in a process of care navigation, with a navigating nurse, responsible for all the flows and access to internal services, while the treatment lasts:

The IMIP screening saw my exams and referred me to the Pink Line (User #1: Macro 4).

It was created in 2013, by us, what we call the Pink Line. [...] There needs to be a coordination of the Line of Care when the patient comes to the hospital, [...] when they come, screening is relatively quick. I think the patient doesn't wait 15 days for a screening. She can wait a little longer, if she has a minor suspicion degree, that is the 4 C. But, if she has BIRADS-5, we schedule her back in 15 days, tops. When she is assisted by the professional, they prescribe all the necessary exams so we can close a diagnosis and the pink line is the coordination of those exams through nurses and bureaucrats, each one has their role. While the patient has cancer and is in treatment, she receives

support from this line, these professionals, that will schedule exams, return appointments, oncology clinic appointments, follow-up with this patient in the oncology clinic during oncology treatment, that will schedule radiotherapy and their follow-up. So, this patient has her care coordinated, receives assistance, because we know if this doesn't happen, they get lost within the institution (Specialist #1 – Oncology service).

While it is limited to the treatment phase, Cacon's Pink Line has navigation attributes<sup>14,15,40</sup>. Navigation facilitates timely access to necessary exams and treatments, minimizing obstacles and communication issues. Studies show it significantly reduces diagnosis time, accelerates access to treatment and improves clinical results, and should be adapted to the needs of users and health systems<sup>12,13,41,42</sup>.

Timely access to health services has also been compromised by the low capacity of the healthcare regulation system and its communication with the HCN.

They throw you out there and leave you more lost than ever. For how long? If the regulation comes to improve things, then it should jump hoops to make it reach the public (User #3: Macro 1).

[...] most hospitals give no easy access, some are regulated by the Health Secretariat and the patient cannot access it spontaneously, neither by referral. [...] I work for the city as well, so, this communication is extremely hard, even when we refer a patient, we have to do it through the regulation, through the city's Secretariat of Health, and the patient doesn't get the access (Specialist #2 – Oncology service).

The waiting line is difficult, it's a matter of volume, really (City management).

Since we don't regulate, there is even greater suffering. Everyone comes to Recife (State management).

The testimonials suggest that the healthcare regulation system is failing in its purpose to improve access to health services, leaving users with no adequate support and increasing waiting time. The lack of efficient regulation results in a centralization of services in the Macro-region I, forcing women of other Regions to make long and costly journeys, which aggravates the regional disparities in the access of treatment. It is necessary to qualify and manage queues in the system, creating criteria that promote equity and transparency for users. Establish the supply-demand relationship, with referral protocols, quotas and waiting lists<sup>19</sup>.



It is essential to discuss the regulation of specialized care, including treatment, so that users in the inner cities receive care from oncology services in their respective health Macro-regions. Decentralization of the regulatory system can be a strategy to get closer to the user, but it requires synergy with centralized processes and greater distribution of services in regions with care gaps<sup>43</sup>.

The state management highlighted the difficulty in regulating oncology treatment due to a lack of governability in managing access queues to Unacon and Cacon.

[...] we have accreditation as a Secretariat, but we had no vacancies management. It was self-managed. [...] We started, this month, to regulate the patient to IMIP. And to the HCP, we already had ten quotas. [And the inner cities' Unacon] too, we don't regulate [...], I don't send patients to the HRA [...] in Arcoverde [...], we can't send them. If I have a patient with an alleged diagnosis in Pesqueira, [...] I don't have the calendar of this outpatient clinic, [...] the house of health, which is in Garanhuns, I, as well the State, don't have an open calendar there. So, that patient that went there by herself, God knows how, or with somebody's help, but it wasn't through the State (State Management).

The difficulties mentioned by the state management contrast with the responsibilities defined by Unacon and Cacon qualification order<sup>19</sup>, which demands effective and equitable management of the Oncology Healthcare Network. To improve access to treatment, it is fundamental that the State implements effective regulation and monitoring mechanisms, ensuring fairer and more organized access to oncology services, with flows between the HCN, and waiting lines managed efficiently and transparently. Thus, it is essential the State empowers the monitoring and assessment strategies of the services offered by Unacon and Cacon, record the origins of users serviced and the flows they follow, according to established quantity and quality criteria<sup>19</sup>.

To increase access and accessibility to oncology treatment, there was an attempt at implanting the *Vale Médio São Francisco* Interstate Health Care Network, along with the State of Bahia, a Pernambuco-Bahia Network (PEBA), to overcome the assistance gaps in Macro-region IV, but the testimonials suggest the strategy was not implemented:

The service at Juazeiro is completely idle, [...] the hospital management is not interested in

opening up more space in their calendars. [...] The PEBA network they talk about is not well structured, [...] a radiotherapy service is yet to be equipped, it needs space, demands high cost, expertise manpower and all. But when you have a place with all that and it doesn't work because the hospital is not interested [...], the solution is right there [...], when you see an underused equipment, not working due to politics and bad management, this worries me (Specialist #3 – Oncology service).

[...] If the State and city cannot provide this diagnosis, we, as a federal management, we can't, we don't manage the line. [...] Regarding the radiotherapy line [...], I reckon that, while the city and State don't reach a consensus, we can't say "yes, there's one more service coming your way, I'm sending it", that's not the Ministry's posture (Federal management).

The gaps recognized in the PEBA network portray the incipience in monitoring and assessing oncology services and measuring the impacts in the lives of users that leave the Macro-regions II, III and IV to undergo chemotherapy and surgery in Macro-region I. In Pernambuco, only two cities offer radiotherapy treatment through SUS, women from Macro-region IV travel 700 km on average to get their treatment at Macro-region I<sup>5</sup>.

Results show that the absence of a BCLC and the lack of navigation, in addition to impacting continuity of care for women in treatment for breast cancer, complicates the effective action of the PHC as coordinator of care, and increase inequities and challenges in implementing strategies of care to women with breast cancer by the PHC and the PEBA network.

## CONCLUSION

The results in this study reveal significant fragilities in oncology management in both city and state levels, as well as in the Primary Healthcare Consultation (PHC), as a coordinator and organizer of the Healthcare Network (HCN). The main fragmentation identified is the lack of a Breast Cancer Line of Care (BCLC), impacting care continuity and increasing challenges of adequate and timely access to health services. Users have been managing their own flows, and health professionals create parallel flows that can lead to inequities in access and accessibility.

Planning of oncology care should involve several actors and policies to cope with breast cancer. It is essential to



bring the PHC to the center of planning, as it is the main form of access for the network user, and to overcome fragmentations that were identified in the care and organization of HCN.

Though there is an extensive search for articles on the lines of care (LC), there is a lack of studies focused on the already implemented LC, which limited the theoretical dive in the discussion and highlighted the need for more research on this perspective.

It is essential to structure the network so that services can meet demand when users need them. To ensure continuity, it is necessary to implement LC with care navigation strategies throughout every level of health care. Improvements in the BCLC management include investments to structure the LC with clear protocols and flows, training professionals in every care level, and implementing patient navigation to ensure continuous access and coordination of services, strengthening regulation and referral/counter referral.

The relevancy of this study is in its ability to highlight the perspectives and experiences of the women, health professionals and managers, offering a deeper understanding of the assistance contexts faced by women with breast cancer. This study is believed to offer significant contributions for management to identify fragilities and critical issues towards breast cancer, providing subsidies to decision-making in the politics, planning and health management areas. This information is essential to improve health politics, assistance practice and coordination of integral care.

### CONTRIBUTIONS

Rosalva Raimundo da Silva has contributed to the study design, analysis and interpretation of the data, wording, and critical review. Mauricéa Maria de Santana has contributed to the data analysis, wording and critical review. Adriana Falangola Benjamin Bezerra and Jurema Telles de Oliveira Lima contributed to the critical review. Tereza Maciel Lyra has contributed to the study design, wording and critical review. All the authors approved the final version for publication.

### DECLARATION OF CONFLICT OF INTERESTS

There is no conflict of interest to declare.

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