The Painful Journey for Treatment: the Experience of Women with Breast Cancer in a Northeastern Brazilian State

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O Doloroso Percurso por Tratamento: Experiência de Mulheres com Câncer de Mama em um Estado do Nordeste do Brasil

El Doloroso Recorrido por el Tratamiento: la Experiencia de Mujeres con Cáncer de Mama en un Estado del Noreste de Brasil

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ABSTRACT

Introduction: Breast cancer is one of the biggest public health challenges in Brazil and worldwide due to its high rates of incidence, prevalence, and mortality. **Objective:** To analyze the comprehensiveness of care for women with breast cancer in the Health Care Network of the State of Pernambuco, considering the integral nature of the human being. **Method:** Qualitative research conducted with women undergoing breast cancer treatment in different State Health Macroregions, using semi-structured interviews. **Results:** Significant fragilities in the comprehensiveness of care were identified, especially in addressing frequently neglected biopsychosocial needs, particularly in contexts of socioeconomic vulnerability. Women reported challenges related to long distances for treatment, lack of adequate logistical support, financial difficulties impacting food and family sustenance, and the absence of continuous support at different levels of care. **Conclusion:** The barriers faced by women highlight the need for strategies that ensure comprehensive care, such as navigation programs, the implementation of care pathways, and improved care coordination. The importance of health education is also emphasized as a critical tool to empower women in securing their rights and comprehensive care.

Key words: Breast Neoplasms; Comprehensive Health Care; Women; Delivery of Health Care.

RESUMO

Introdução: O câncer de mama é um dos maiores desafios de saúde pública no Brasil e no mundo em razão de suas altas taxas de incidência, prevalência e mortalidade. **Objetivo:** Analisar a integralidade do cuidado às mulheres com câncer de mama na Rede de Atenção à Saúde do Estado de Pernambuco, considerando a dimensão do ser integral. **Método:** Pesquisa qualitativa conduzida com usuárias em tratamento de câncer de mama nas diferentes Macrorregiões de Saúde do Estado, utilizando entrevistas semiestruturadas. **Resultados:** Evidenciaram-se fragilidades significativas na integralidade da assistência às mulheres, especialmente no enfrentamento de necessidades biopsicossociais frequentemente negligenciadas, sobretudo em contextos de vulnerabilidade socioeconômica. Usuárias relataram desafios relacionados a longas distâncias para o tratamento, falta de apoio logístico adequado, dificuldades financeiras que impactam na alimentação e sustento familiar, e ausência de suporte contínuo nos diferentes níveis de atenção. **Conclusão:** As barreiras enfrentadas pelas mulheres reforçam a necessidade de estratégias que garantam a integralidade do cuidado, como programas de navegação, implementação da linha de cuidado e uma melhor coordenação assistencial. Também se destaca a importância da educação em saúde como ferramenta crítica para empoderar as mulheres em busca de seus direitos e cuidados integrais.

Palavras-chave: Neoplasias da Mama; Assistência Integral à Saúde; Mulheres; Atenção à Saúde.

RESUMEN

Introducción: El cáncer de mama es uno de los mayores desafíos de la salud pública en el Brasil y en el mundo debido a sus altas tasas de incidencia, prevalencia y mortalidad. **Objetivo:** Analizar la integralidad del cuidado de las mujeres con cáncer de mama en la Red de Atención a la Salud del Estado de Pernambuco, considerando la dimensión del ser integral. **Método:** Investigación cualitativa realizada con mujeres en tratamiento de cáncer de mama en las diferentes Macrorregiones de Salud del Estado, utilizando entrevistas semiestructuradas. **Resultados:** Se evidenciaron debilidades significativas en la integralidad de la atención a las mujeres, especialmente en el enfrentamiento de necesidades biopsicosociales frecuentemente desatendidas, especialmente en contextos de vulnerabilidad socioeconómica. Las mujeres reportaron desafíos relacionados con las largas distancias para el tratamiento, la falta de apoyo logístico adecuado, dificultades financieras que impactan la alimentación y el sustento familiar, y la ausencia de apoyo continuo en los diferentes niveles de atención. **Conclusión:** Las barreras enfrentadas por las mujeres refuerzan la necesidad de estrategias que garanticen la integralidad del cuidado, como programas de navegación, la implementación de la línea de cuidado y una mejor coordinación asistencial. También se destaca la importancia de la educación en salud como herramienta crítica para empoderar a las mujeres en la búsqueda de sus derechos y cuidados integrales.

Palabras clave: Neoplasias de la Mama; Atención Integral de Salud; Mujeres; Atención a la Salud.

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INTRODUCTION

Breast cancer is one of the most serious public health challenges worldwide, highlighted as the main cause of death from cancer among women in Brazil, except in the North Region, where it ranks second after cervical cancer. Apart from non-melanoma skin cancer tumors, the most frequent cancer type in the country, for the 2023-2025 triennium, 73,610 new cases a year are estimated in Brazil, 2,880 of those in the Pernambuco State. In 2023, the disease caused 20,054 deaths in the country, including 865 in Pernambuco[1,2].

It is a complex disease in which early diagnosis plays a crucial role in successful treatment, increasing survival rates and reducing treatment costs in the Brazilian National Health System (SUS). However, once diagnosed, women face a series of challenges that go beyond physical complications, encompassing psychological and social aspects as well. Mastectomy, a common treatment procedure, can generate stigmas and deeply affect female identity and social relations, intensifying feelings of vulnerability[3]. This stigma can create emotional barriers, like shame and isolation, creating difficulties for recovery and adaptation to this new reality. Moreover, women in socioeconomic vulnerability usually face more obstacles during cancer treatment, not just financial limitations, but also lack of access to information on their rights, which impairs their full exercise of citizenship and access to proper care[4].

Identifying individual needs and considering the social context of each user becomes essential for integral care[5]. Health care for women with breast cancer should include not only medical treatment, but also psychological support, rehabilitation and support network, like navigation programs that consist in organized interventions to guide and support users throughout their healthcare system journey, essential to identify barriers in access to care, improve follow-up and strengthen the continuity of care[6,7].

Integrity, a fundamental principle of SUS, proposes care that encompasses the totality of the individual[8]. Guided by people's health needs, integrity transcends biomedical needs and includes the life context and emotional conditions of each individual[9]. This principle aims to provide a holistic view with the expression "look at the person" (not at the disease), considering the lives and experience of individuals and involving intersectoral articulations to cater to their needs more comprehensively[10,11]. SUS should be regarded as a synonym for consolidation of humanized and contextualized assistance, overcoming the reductionist view of the disease and strengthening inclusive and integral care[12].

The objective of this study is to analyze the comprehensiveness of care for women with breast cancer in the Health Care Network (HCN) of the State of Pernambuco, focusing on the integral nature of the human being.

METHOD

Qualitative research based on the integrity principle and dimensions of the integral human being[9]. The study was based on the theoretical-methodological framework of empirical phenomenology[13], from the perceptions and experiences of users with breast cancer.

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

The selection of women was intentional, based on criteria that ensured the representativeness of the four Health Macroregions of the State of Pernambuco. Nine women in treatment for breast cancer were interviewed, five from the High-Complexity Oncology Unit (Unacon) of the *Hospital de Câncer de Pernambuco* and four from the High-Complexity Oncology Center (Cacon) at the *Instituto de Medicina Professor Fernando Figueira* (Chart 1).

These units were chosen because they assist users with breast cancer from all the municipalities in the State, which enables a broad view of the journey of care until oncological treatment. The nine women interviewed were in different moments of the breast cancer treatment, which allowed us to encompass diverse experiences throughout the care journey. Three of them had undergone chemotherapy, surgery, and radiotherapy, and went to the healthcare service for consultations with multiprofessionals and retrieve medication. Other three had undergone chemotherapy and surgery and were about to start radiotherapy. The three remaining participants were in chemotherapy treatment and scheduled to undergo surgery after concluding this step. Semi-structured interviews were conducted with women in treatment at hospitals, in a private space for recording, using the free Recorder software (Apple Store) and transcribed in the Cockatoo[14] software, with corrections to ensure integrity of the content. Additional consultation of medical records was performed to deepen the understanding of the interviewees' care journey.

The women's testimonies were analyzed following Bardin's[15] content analysis technique, along with the empirical phenomenology approach by Giorgi[13]. This methodological combination allowed us to capture, systematically and rigorously, the meanings attributed by users to their experiences throughout their journey of care in breast cancer treatment. Initially, testimonies were

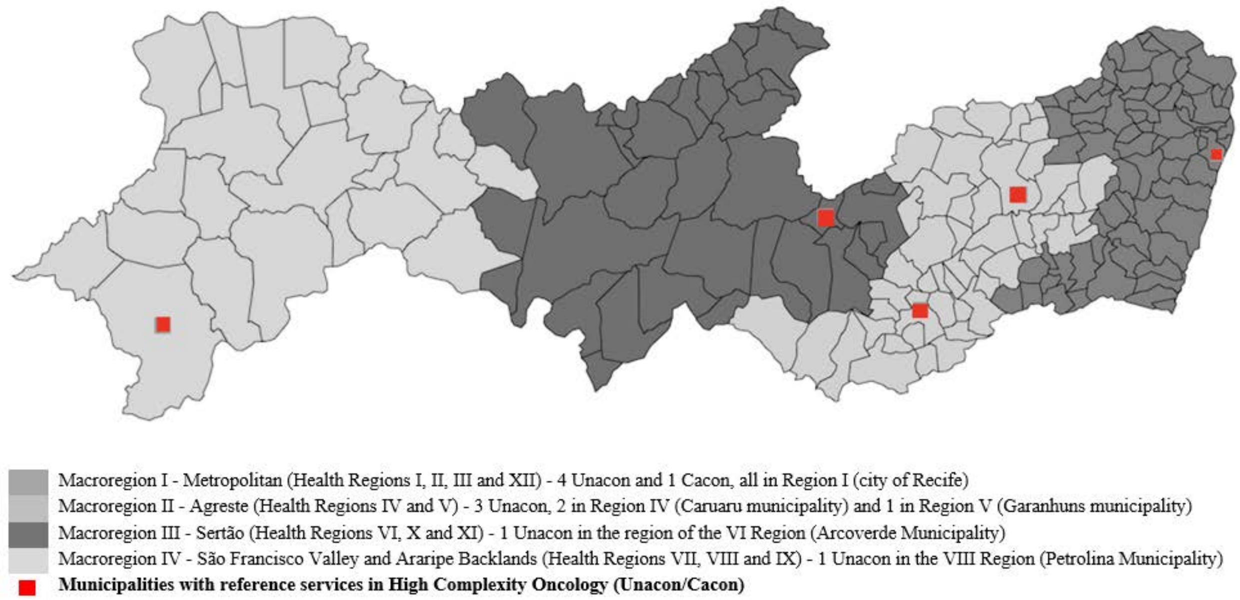

Figure 1. Health macroregions in the State of Pernambuco and Unacon and Cacon distribution. Pernambuco, Brazil, 2023
Captions: Unacon = High Complexity Oncology Care Units; Cacon = High Complexity Oncology Care Centers.

Chart 1. Distribution of users by service, Health Macroregion, and identification code. Pernambuco, Brazil, 2023

Health Macroregion	Unacon HCP	Identification code	Cacon IMIP	Identification code
I	2 users	U1-M1; U2- M1	1 user	U3-M1
II	1 user	U1-M2	1 user	U2-M2
III	1 user	U1-M3	1 user	U2-M3
IV	1 user	U1-M4	1 user	U2-M4

Captions: HCP = *Hospital do Câncer de Pernambuco*; IMIP = *Instituto de Medicina Professor Fernando Figueira*.

transcribed in full and submitted to fluctuating reading, so researchers could be immersed in the content and identify units of meaning. Next, based on the content analysis procedures, data was codified, considering the context of testimonies, repetition of themes, and emotional load of the accounts. This step allowed the identification of relevant nuclei of meaning. These nuclei were then grouped in analytical categories, anchored on the integrity dimensions proposed in the Basic Care Booklet (*Caderno de Atenção Básica*)[12], which guided the study's interpretive axis: perception on health-disease, knowledge, and culture dimension; work conditions and income dimension; and physical and organic conditions dimension.

This study has been approved by the Research Ethics Committees of the *Instituto de Pesquisas Aggeu Magalhães* (CAAE (submission for ethical review): 67124722.2.0000.5190); the *Hospital do Câncer de Pernambuco* (CAAE: 67124722.2.3001.5205); and the *Instituto de Medicina Professor Fernando Figueira* (CAAE: 67124722.2.3002.5201), under report numbers 6142468, 6219126, and 6298573, according to Resolution no. 466/12[16] of the National Health Council (CNS).

RESULTS AND DISCUSSION

Of the nine participants, three were under 50 years old and six were aged between 50-60 years. One identified as black, four as white, and four as brown (*parda*). The terms used in the study followed their self-declaration, respecting the way each of them expressed their racial identity. Four were single and five married, eight mentioned having children. Regarding education, three had completed higher education, three had completed high school, and three had incomplete elementary school.

The users who live in Macroregion I presented an average displacement distance of 12 km, with an average displacement time estimated in 47 minutes. The users in Macroregions II, III and IV, who sought care in Macroregion I, faced much longer journeys, of 173 km (~4 hours), 489.5 km (~9 hours) and 608.5 km (~10 hours) on average, respectively.

PERCEPTION ON HEALTH-DISEASE, KNOWLEDGE, AND CULTURE DIMENSION

Understanding the perception of women in health-disease in the malign breast neoplasm includes addressing their education level and knowledge on the course of the disease, considering interventions in susceptibility (health awareness), pre-clinical (screening), clinical (treatment) and residual inability (palliative) phases. Despite differences in education, most had no regular access to health services for preventive follow-up, as demonstrated by the following narratives:

> It's been a long time since I went to the doctor. A long time indeed (U2-M1).
> I never used to go, ever, not even to health centers, nothing. I never saw a doctor, didn't use to go to them (U3-M1).

It is the Primary Health Care (PHC) responsibility[5] to identify and actively visit people who do not regularly seek the service, in addition to strengthening health education aimed at promotion and prevention. Understanding the factors that delay breast cancer diagnosis helps to develop effective interventions. Proper information facilitates timely decisions to seek care. All participants had initially ignored their symptoms, attributing to stress, overweight and transitory problems, as shown by the testimonies.

> First, I noticed it on my armpit, then I told my husband, and he said 'no, it must be because you're overweight, that must be it.' Then one day, I noticed it on my breast. Then he said, 'you better go see a doctor.' Then I said, 'ok, I'll see about that later.' And I think this lasted about six months (U2-M2).
> Then a lump appeared in my armpit, and it hurt. I worked at a school, making lunch for 300-500 students, when I complained, the sister, who was a nurse, said, 'no, you keep reaching for the bucket, that's why you're in pain' [...] I scheduled a breast ultrasound on my expenses [the user paid for the exam], she [the doctor] said I had a very large nodule (U2-M3).

Testimonies stress the importance of users being able to recognize the signs and symptoms of the disease and making timely decisions in seeking healthcare services. A study with women with breast cancer identified the association of symptoms with other problems[17]. Lack of knowledge can delay the search for diagnosis, resulting in advanced stages, greater costs, and fewer chances of survival[5-13,15,17,18]. Information should reach the entire population, as families and friends influence women's decisions[19].

Besides knowledge, facts such as family responsibilities and life conditions impact the search for healthcare. One user delayed seeking care because she was caring for her husband who had been in an accident.

> It was when my husband had an accident, he almost died. So, I could not treat the lump. Or I treated my husband, or I treated myself. Then we started measuring it every night, me, and him, using our hands. This was within a year. Just feeling it, we both just measuring the size of the lump. […] Then, it began to bother me. So, one day it hurt a lot, then I went to the doctor, and he kept giving me morphine every 4 hours. When he gave me the morphine I felt like he caught the pain and threw it away, but in 4 hours I couldn't take it anymore [...] I had been with this tumor for two years (U1-M3).

By taking on the role of caregiver, the woman neglected her self-care in favor of her spouse. This negligence reflects structural flaws, like the absence of regular PHC visits, which could have early identified her problem. The gap in this active search and continuous care highlights a shared responsibility between PHC and gender dynamics. Traditional role division, which imposes to women the responsibility of care, often superimposes to their personal needs, especially where there are economic difficulties and lack of proper support[20], leading them to prioritize others. This reinforces the need to discuss the impact of gender norms in health and of having a more active PHC to reduce the individual overload in breast cancer control.

All the users highlighted the need to broaden access to information, especially for less educated women, as summarized by U2-M4:

> People who have no knowledge, no information, refrain from caring for themselves. So, every day is the day, every hour is the hour to care for yourself, to protect yourself and care for yourself. And there's this common thought that 'oh, you had cancer because you wanted it, you didn't take care of yourself.' No. But if you have prevention, if you have follow-up, clearer and simpler information, at the level of people who really need it, the treatment, the service, because for me it was easy, I have the information, the knowledge, I know where to look for, where to search, what I need to alleviate the treatment, everything. But there are many people, most of them don't have this understanding. Then they die more in their minds. Because their minds don't help them do the treatment. Because you say cancer, cancer is fatal, cancer kills. But sometimes it's not cancer, it's misinformation.

The report highlights the importance of disseminating information on diseases in an accessible language. States and municipalities must develop local health education plans to improve breast cancer awareness, prevention, and treatment. Educational spaces aligned to the National Policy for Popular Education in Health (*Política Nacional de Educação Popular em Saúde*) are effective strategies[21].

Participants positively evaluated the Pink October (*Outubro Rosa*) campaign but highlighted the need to clarify the meaning of allusive colors and promote awareness all year round, not just in October.

> I believe that [there should be] more information, at basic health units, provided to women. Diseases have no color months, diseases have no months, they have people, human beings. People advertise: "do your mammogram on 'pink October'". They go that month and if they can't, they won't go anymore because they'll think it's over (U2-M4).

This report highlights the need for objective and continuous awareness campaigns, to avoid people considering the allusive month as the only time for preventive exams. The campaign should consider geographic disparities to reach populations that are historically affected by lack of access to healthcare, since inequalities may intensify the emotional load in vulnerable groups[20]. Navigation programs can increase the efficacy of care, especially among the most vulnerable[6,7].

All the users reported having received proper guidance on the disease and treatment.

> Guidance is complete [...] both the mastologist and the oncologist said that I would have to start with chemo to check the tumor, how it would react, regress [...] they told me it would be a long treatment. I would have to do the mastectomy, lose a breast, also empty the armpit, and then radiotherapy. It was all very well explained, I got there knowing what I had to do (U1-M1).

Assertive communication is essential in breast cancer treatment, ensuring clear orientation on procedures and duration. Women seek information on prognoses, impacts on routine, and returning to daily life[22,23]. As the treatment advances, new doubts arise, demanding adapted educational materials and space for clarification[24]. Network navigation programs strengthen continuous care and communication between users and health services, identifying individual needs[6,7]. Training professionals for effective communication, understanding of diseases and knowledge of HCN strengthens trust and promotes empathetic care, focused on the person[24].

In addition to knowing the disease, users highlighted the importance of understanding their rights as people with cancer, as reported by a user from Macroregion 3.

> The doctor said that those who have cancer can work, and I said, 'but without seeing properly, how can I work?' I've lost my sight [...] We don't get the benefit, they take it away, then those who don't know how to seek a lawyer end up not getting it (U2-M3).

Integral approach is a user right, but fragmenting care between assistance levels has compromised its effectiveness. PHC, main care coordinator, should ensure continuous follow-up, regardless of the HCN, considering individual characteristics during treatment[24].

Lack of knowledge on rights, in addition to fragmentation between assistance levels, may negatively impact the lives of women, as reported by a user of Macroregion 2:

> First, I came by bus. I've had many expenses, the ticket was 90.00 per person. And my husband always came with me. Then, I mean, it was 180.00 one way, and 180.00 the other way back. I was on this scheme from October to May. Then I found out about OHT (Out-of-home treatment) (U2-M2).

The testimony shows discontinuity of care by the PHC and absence of navigation programs, essential to identify barriers like limited access, not knowing your rights, and financial difficulties. These programs can positively impact the lives of women, ensuring them adequate support and respect to their singularities[6,7]. Limitations in access to services and legal information is a significant obstacle, since many women have no knowledge of their medical and legal rights[4]. In this perspective, social assistance during treatment plays a fundamental role in guidance and support to women in coping with cancer[23-25].

The perception on health-disease, knowledges, and culture dimension in the interviewed women suggested that women's education level had no influence on self-care, prevention, and immediate search for assistance when noticing symptoms, highlighting the need for reviewing health education approaches in all levels of care. Strengthening health education can be achieved through Popular Education in Health in the different levels of healthcare, and through practical processes (action-reflection-action), since the change in practices goes beyond simply conveying information, involving reflection on autonomy and empowering the individual as an essential part of integral healthcare.

WORK CONDITIONS AND INCOME DIMENSION

Work conditions and income influence integral care, affecting access to health services and treatment adherence. Among new users, two public workers obtained breast cancer license; two autonomous workers accessed the health benefit of the National Social Security Institute; one received the benefit through the Organic Law of Social Assistance (*Lei Orgânica de Assistência Social* - LOAS); another, member of a rural union, receives half a salary, subject to reassessments; two were out of income and benefits; and one kept her professional activities during the treatment.

> My condition is terrible. I got nothing out of my disease. I'm trying [to obtain] the health benefit. Financial conditions are very bad (U1-M3).
>
> I spoke to the people from the family agriculturists association [...] I scheduled an evaluation in Petrolina. I went at night and spend the night at the bus terminal, early on the other day I went to the INSS [...] she asked me if I had a sick note, I showed her all my papers [...] then she said, 'have you received yet?' [...] I got half a salary [...] 'just that?', and I said: yes. 'But did he [the doctor] already know you were with cancer?' Yes. Then she looked at everything and said that I should receive the benefit by March. The benefit is not permanent, it's only temporary (U1-M4).
>
> I chose to keep working, because it was better for my psychological state, not to be at home [...] I used to do chemo on Thursday and have Friday off (U3- M1).

Financial difficulties faced by women with breast cancer during treatment deeply impact their quality of life, especially for autonomous workers, who reported greater challenges than the employed ones[25].

Some users tried to access the LOAS benefit, but only one succeeded after seeking legal advice to ensure her rights.

> I haven't yet managed to get my retirement through LOAS. I can't prove my poverty, since I have no income, I have no way to prove it. I live on someone else's expenses (U1-M1).
>
> Just the health benefit, which became my retirement, I got through the legal system, because they stopped providing it in the pandemic when we needed it the most. I spent a year and three months with no income. During that time, my family helped. We took it to court and were denied, then I got the benefit again as if coming from the LOAS, which is a faster process.
>
> It took a while, then was denied, then we took it to court again, and now it became a retirement pension (U2-M3).

LOAS is a federal law that ensures a monthly minimum wage for elders with no income (starting at 65 years) and people with disabilities unable to work, with biennial re-evaluation and medical report from the INSS (social security)[26]. Testimonies highlighted the need to integrate Unacon/Cacon social assistance into municipal health departments to strengthen the care of people with cancer. Individual analysis is essential to reduce inequalities, inequities, and mitigate the impacts of the disease. Social support improves quality of life during treatment, preventing anxiety and uncertainty[27-28].

One of the users who did not get the health benefit reported sequelae due to the treatment, and is having trouble getting back to the workforce:

> I couldn't return to work. Due to my arm deficiency, I lost my hand movement, I can no longer work [...] we get a lot of guidance from the hospital, go back to school, if you can, go back to the workforce. But the job market doesn't have this perspective, they're not the hospital (U1-M1).

Women who do not go back to work after breast cancer present a greater drop in quality of life when compared to those who remain employed[29]. Going back to work requires integrated support from hospitals, employers, civil society, public policies, and families, with actions towards rehabilitation, inclusion, and professional autonomy to prevent prolonged inability and meet individual needs[30].

The lack of proper financial support impacts access and treatment adherence. Six women breadwinners reported concerns with resource shortage, as reported by user U2-M3: "The little money I make I spend with groceries [...], we are five people at home".

These circumstances show that lack of proper financial support creates barriers for these women to receive integral care that respect their biopsychosocial needs and life conditions[30].

Although Out-of-Home Treatment (OHT) is ensured for users in Macroregions II, III and IV, they have all faced extra expenditures. Four reported that municipal transportation is only to the support house, and the displacement inside the city is at their own expense, which generates financial difficulties.

> They drop me in the support house. And we come with our own money [...] we spend to go from the support house to here (U1-M4).
>
> The inbound trip is in the city hall car. It leaves us here but doesn't collect us at the hospital. To return, we must gather at the support house. Today, for instance, I have only 30.00 to go back. I pay 20.00 for an Uber ride from here to the support house,

> which leaves me only 10.00 to get home. They were supposed to have a car to take us from the hospital to the support house, the patient shouldn't need to spend their money. Because many people don't have it. We refrain from eating on the way so we can pay for the car to the support house (U1-M3).

OHT should be used when there are no treatment alternatives in the municipality or macroregion of origin[31]. The absence of clear guidelines for access and organization of OHT between municipalities contributes to increasing inequalities in healthcare, mainly affecting patients in greater social vulnerability situations. Precarious or absent proper public transportation compromises adherence to oncological treatment, especially among SUS users who cannot afford frequent displacements. Moreover, deficient screening strategies and assessment of oncology services and access flows result in wearing and often unnecessary displacements[32]. To mitigate these impacts, health departments need to monitor the profile of users and optimize assistance flows[31].

Understanding work and income conditions is key to ensure that women with breast cancer do not face additional obstacles imposed by the fragmentation and disorganization of the HCN. Although guidelines state that treatment occurs preferably within their original macroregion, many women spontaneously choose reference centers like the *Hospital do Câncer de Pernambuco* and the *Instituto de Medicina Professor Fernando Figueira*, that concentrate chemotherapy, radiotherapy, surgery, and multiprofessional teams. This choice reveals the pursuit of integral and resolutive care, and exposes fragilities in the Macroregions II, III and IV Unacon. This reinforces the urge to strengthen decentralized assistance, without compromising integrity and continuity of oncological care.

PHYSICAL AND ORGANIC CONDITIONS DIMENSION

Receiving a breast cancer diagnosis is a tough experience that generates varied reactions, including fear, anger, and anxiety.

> When I found out I was desperate, groundless, frightened. To receive such news, if I could bury myself that instant, I would have done it. [...] if you're not strong enough, you crumble (U1-M2).

Professionals' preparedness and psychological support are fundamental, as the consequences of the diagnosis can be devastating[28-33]. The disease staging influences the therapeutic conduct; five users were diagnosed in advanced stage, two of them with metastasis.

> It had already reached my bones, it wasn't just in the breast, I was limping from my right leg [...] I had to remove the whole breast and undergo axillary emptying (U2-M1).
> She said it was in my liver, that I had metastasis (U1-M3).

Reports reinforce the importance of early diagnosis, essential for survival[1,2,5,6]. Most women highlighted psychological problems, anxiety being the most mentioned.

> Besides the disease, fear, anguish, anxiety, all the bad stuff (U1-M2).
> Sometimes depression hits, I get very anxious, I gained 9 kg (U1-M4).
> Also, I was so nervous that, when I went to the psychologist, I almost didn't let him talk (U1-M2).

Continuous psychological support is fundamental since the fear of death and uncertainties cause great anguish[28-34]. Only one user did not have access to the service, while the others had at least one consultation, but half did not follow through. Continuity of psychological support in all phases of treatment is vital for integral care, preventing lack of assistance, as in the case of the user who did not have psychological appointment. Psychological implications should be addressed in every step of care[35]. Although fear of dying worries users, the determination to overcome the disease and the support received from their families motivate them to follow the treatment.

> I don't wanna give up, I'm gonna win! [...] I don't wanna give in [...] I'm afraid of dying, leaving my family [...] I have a daughter with special needs, who's gonna take care of her? My husband is injured and sick... […] (U1-M3).

This testimony highlights the importance of a multiprofessional approach since fear of dying and concern about the family intensify suffering[36]. On the other hand, one user reported that cancer gave new meaning to her life, offering her more autonomy:

> No fear. We have life before cancer and after cancer. [...] to see life with other eyes [...] I'm not scared because my life is today. You only go if you must go (U2-M4).

This statement reinforces resilience and personal growth strategies observed in women who coped with the disease[37].

Regarding physical changes due to oncological treatment, some women reported challenges with losing their hair and breast:

> There were so many challenges. My hair started falling. During this time when I had no hair, I couldn't look at myself in the mirror. Now I can, a little, but I can't look to where my breast was. I haven't managed it yet; I don't touch or look at it (U2-M2).
>
> I have a friend who has removed both breasts. And she's done it five times. And her body rejects it. I don't wanna be cut open anymore, I don't wanna be poked, I don't want any more of that. Maybe I'll change my mind later, but for now, I don't want it (U2-M2).

Understanding the perception of women with breast cancer on their body image and the impacts in quality of life may guide health professionals in interventions, minimizing negative effects, since psychosocial and sociocultural factors influence body image[38]. Fear of rejecting a prosthetic led a woman to not accept breast reconstruction. It should be emphasized that reconstruction is a women's right[39] and the decision should consider guidance from the multiprofessional team on the risks and benefits, respecting each women's desire and clinical condition. Fear of losing a breast again may discourage reconstruction surgery, since some women believe they shouldn't risk complications for aesthetic issues[35].

The social context was observed to impact the organic condition of users in Macroregions II, III and IV. Two women highlighted that long distances generate additional costs that compromise their basic needs, like eating during their displacements to Macroregion I for treatment.

> [...] you get hungry [...] because you have no money to eat [...] if you can't eat right, then how [the treatment] will react well to your body? (U1-M2).
>
> I'm diabetic, I go a long time without eating. I can do without food, but not without water, I feel too thirsty. One small bottle of water is 3.00. If I don't eat for too long, I get sick, [...] I have traveled a lot while hungry (U1-M3).

States, municipalities, and oncology services must deploy access protocols and guide professionals in adequately referring users, considering the network's design and services closer to their homes. Moreover, OHT use strategies should be reassessed, considering travel costs, feeding and overnight, to ensure adequate financial and physical support during treatment.

Other difficulties with long trips were mentioned by Macroregions II, III and IV users.

> We leave at 9 pm and arrive here at 5 am. It's very exhausting (U1-M3).
>
> I leave at 5 pm, get here at 4 am [...]. I must come back on the same day (U1-M4). It's a 10-hour trip, 10 and a half hours (U2-M3).

Logistic barriers in access to treatment may compromise well-being and continuity of oncological care. Long trips to the State capital to receive treatment directly affect these women's physical and organic conditions, requiring a significant effort from them, who are already physically vulnerable due to the oncological treatment. In addition to exhaustion, these trips frequently involve extended periods without adequate rest, need to eat on the way, which is not always possible, given that many users report not having financial resources to eat well during the journey.

Treatment out of their macroregion imposes biological, psychological, and financial challenges to women with breast cancer. In countries like the United States and Japan, 90% of oncological patients live within an hour of treatment services[40,41]. Despite long distances and additional costs to go to Macroregion I, users highlighted positive perceptions on the service provided at the *Hospital do Câncer de Pernambuco* Unacon and the *Instituto de Medicina Professor Fernando Figueira* Cacon, recognized by the offer of integral oncological treatment[42], with access to a complete multiprofessional team, essential to cope with the disease.

> [...] it must be noted that we have an amazing follow-up, everything we need we find here [...] not having this group would be complicated. We have access to dental, psychology, nutrition, and social service that receive us. […] I have friends doing this treatment in other hospitals and they don't get what I have here (U1-M1).

Lack of regulation in access to oncology treatment, associated to the logic of spontaneous demand, leads many women to seek, either by themselves or referred by health professionals out of the formalized regulatory flow, referral centers that concentrate all the therapeutic steps in a single location. This movement reflects how disconnected the network is and the absence of a structured care pathway, while imposing relevant challenges to oncological services, especially to Unacon located in Macroregions II, III and IV. These units present limitations on the offer of integral care and in access to multiprofessional teams, favoring concentration of demand in Macroregion I. Such scenario highlights the need to strengthen the resolutive ability of decentralized services, as well as the strategic roles of PHC in coordinating care and organizing assistance flows[42].

The Physical and organic conditions dimension in breast cancer treatment is important to assess the quality of life of patients during the several steps of treatment. The conditions in the Health Macroregions and agreements between municipalities require a situational diagnosis and assessment of available oncological care services. Thus, it is essential to create assistance flows that consider territorial inequalities, macroregions' installations, and coordination between different Regions, aiming to ensure integral and equal care.

CONCLUSION

Integrity of care transcends the healthcare sphere, requiring professionals to broaden their perspective on the demands of their users, humanizing practice beyond the disease. The current structure of the care network and oncological planning imposes additional barriers to women with breast cancer, like the absence of adequate assistance flows, resulting in access inequities and difficulties identifying multiple needs of women.

Despite the existence of oncology services in each macroregion, OHT ends up being more used than needed due to the lack of a structured HCN. This strategy needs to be reassessed, considering that women face challenges beyond geographical distances, affecting even basic needs, like the right to have a dignified meal.

Integrity should consider specific needs and equity of access to users, especially in cases of high suspicion and metastasis, which require a differentiated care pathway and quick strategies to avoid delays in tests, since cancer is time sensitive. Cancer coping strategies should include educational and communication processes based on popular education in health.

Cancer coping should be a priority on the public agenda, with political willpower to ensure proper care in the cancer assistance network and priority that affected people deserve. Ensuring continuous follow-up during treatment is essential to promote integrity. Results indicate the urgent need for network navigation programs to overcome clinical and socioeconomic barriers, catering to the singularities of women. We recommend creating navigation teams that work out of the hospital environment, with clearly defined roles and continuous training.

This study, however, presents limitations. By prioritizing three integrity dimensions, this study left out other equally relevant dimensions, like psychological, family, spiritual, in addition to aspects related to return to work and social reinsertion. Intersectoral perspectives that involve social assistance, work, transportation, and feeding policies were also not contemplated. Deep diving into those dimensions is essential for a broader understanding of integrity and may be the object of future investigations.

Results have social and scientific relevance and can contribute to planning the Cancer Prevention and Control Network. Necessary improvements can benefit not only oncological treatment, but also other conditions by organizing the network of care considering the biopsychosocial needs and complexity of care, which must transcend the disease.

CONTRIBUTIONS

All the authors have substantially contributed to the study design, acquisition, analysis and interpretation of the data, wording, and critical review. They approved the final version for publication.

DECLARATION OF CONFLICT OF INTERESTS

There is no conflict of interest to declare.

DATA AVAILABILITY STATEMENT

Given ethical and confidentiality issues, data can be requested to the corresponding author with reasonable justification.

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