Acta Scientific CANCER BIOLOGY (ISSN: 2582-4473)

Volume 10 Issue 4 April 2026

Review Article

Between Laws and Struggles: Dimensions of Patient Navigation in Breast Cancer Control in Brazil

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Received: June 19, 2026

Published: June 29, 2026

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Abstract

This article presents important dimensions of a Patient Navigation Program (PNP) for breast cancer (BC) based on a diagnostic hub of the Rio de Janeiro State Health Department, Brazil, focusing on access to treatment initiation within 60 days, as required by the "60-Day Law" (Federal Law No. 12,732/2012) of the Brazilian Ministry of Health. This law establishes that treatment for any type of cancer for patients in the public health system must begin within 60 days of definitive diagnosis. The article also examines the patient's experience throughout the entire navigation process and their satisfaction with the relationship and services provided by the Patient Navigator (PN).

I invite all readers to understand that health challenges may deserve "better solutions" through collective production for populations in areas where access to healthcare is fragmented and health systems may be fragile and underfunded. In the Brazilian context, a PNP may represent an opportunity to properly implement existing legislation and, as such, has great potential to favor the functioning of the health system through a healthcare network, strengthening the oncology care pathway, regulation, and health governance.

Keywords: Patient Navigation; Breast Cancer; 60-Day Law; SUS; Public Health; Health Equity

Introduction

A cancer diagnosis is often described by patients as the worst moment of their lives. Uncertainties regarding treatment and potential chances of cure are compounded by doubts about the next steps to be taken. Which specialist should I seek? What exams should I undergo? For how long will this disease paralyze me? In their journey against a previously unknown illness, users of the Unified Health System (SUS)—75% of the Brazilian population uses the public system [1]—also encounter difficulties in navigating the care flow, referrals, and scheduling, which often leads to delays and disease progression [2].

Despite all efforts, advanced-stage diagnoses with high mortality rates still prevail, as shown by a recent study analyzing data from the Unified Health System (DATASUS) between 2013 and 2022 [2]. An increase was observed in the proportion of cases diagnosed at advanced stages (III/IV) across all age groups, and in more than 50% of cases, the time between diagnosis and treatment initiation exceeded 60 days across all age groups [2].

From the recognition of this demand for speed and efficiency, without neglecting the need for humanization in approaches, Patient Navigation Program (PNP) for Breast Cancer (BC) started in 2019 at the Heloneida Studart State Women's Hospital (HM), in São João de Meriti, Rio de Janeiro, Brazil [3].

The concept of oncology patient navigation to correct disparities and improve care dates to the 1990s was developed in the United States [4]. In Rio de Janeiro, this work began as a pilot project in 2016, at a state diagnostic hub, Rio Imagem Centro [5]. However, it was implemented more effectively when it entered HM. The primary objective was to facilitate patient access to the services necessary for diagnosis and treatment [6] of the most incident type of cancer among Brazilian women. The Brazilian National Cancer Institute [7] (INCA) estimates 78,600 new cases for 2026, with an estimated risk of 71.57 per 100,000 women.

The 60-day law and its challenges

The goal is compliance with the "60-Day Law", Federal Law No. 12,7328, of 2012, which determines that oncology treatments, regardless of type, must begin in the SUS within a maximum of 60 days after definitive diagnosis. As is known, the law is often violated in Brazil.

Critical data point

Over the last 10 years, the 60-day treatment deadline has only been met in 31% of cases in Brazil, with an average delay of 128 days—more than double the legal requirement [9].

Follow-up in the PNP is coordinated by a breast oncology specialist from the moment the patient arrives at HM with suspicion or confirmation of cancer. It extends to staging exams, to locate the tumor and determine its extent, and to all other necessary exams. Because they know the system from the inside, Patient Navigator (PN), a trained social worker in close harmony with the physician, is able to overcome potential barriers in the oncology journey that the SUS user alone could not overcome, whether due to socioeconomic, cultural issues, or natural lack of knowledge about the subject.

PN becomes the figure who centralizes communication between the patient and the healthcare professionals assisting her and guides her to schedule appointments with important specialists at this stage, such as psychologists, nutritionists, cardiologists, and dentists. The patient is inserted into the State Regulation System (SER), so that she can be referred for treatment initiation at the most appropriate specialized unit.

Patient voices: The human impact

PNP coverage does not stop there. Welcoming nature is a differential. Proximity to the team continues until treatment initiation, whether by telephone, messages, or in person. By overcoming barriers and softening a moment that is complex and painful by nature, the program is seen as a lifeline by hundreds of women treated.

One thing is certain, without PNP to guide me throughout these years of treatment, perhaps I would not be here to tell my story. Throughout my entire journey, I was never alone; I was accompanied throughout my treatment, from diagnosis. That made all the difference. — Aline, 57 years old, in remission.

Aline (fictitious name), now 57 years old, learned about PNP during the COVID-19 pandemic, at the end of 2020. She had discovered, shortly before, a tumor in her right breast. "The diagnosis of breast cancer that the doctor gave me on February 18, 2021, I will never forget. I left the breast surgeon's office straight to the navigator social worker's appointment, who enrolled me in PNP and helped me schedule exams that would be requested at the high-complexity hospital to which I would be referred to begin the actual treatment. At HM, I had appointments in psychology, nutrition, dentistry, cardiology (where I underwent electrocardiogram and echocardiogram for surgical risk), laboratory exams (blood and urine), and imaging (chest X-rays and ultrasounds)".

She highlights all the qualities of PNP, including the care in empowering the patient herself to better understand what she is experiencing. PNP identifies the social determinants of cancer and acts to eliminate barriers to diagnosis and treatment for each patient. It is a humanized approach, in which the patient, in addition to being the object of care, becomes the subject of caring [10]. Health education, one of the program's pillars, gives patients autonomy for this. "Today, what bothers me most in these almost 5 years of treatment is the fact that I cannot make plans, as my life revolves around treatment and other comorbidities derived from the disease. There is also the ghost of recurrence, with which I will have to live for the rest of my life. Still, when I realized that treatment would not be as brief as I imagined, I resumed my studies and as soon as I graduate, I will return to work, because I still have many dreams to fulfill," reflects patient Aline.

Evidence and outcomes

International experience shows the efficiency of this type of approach, which increases patient adherence to diagnostic and treatment protocols. Oncology patient navigation is a scientifically grounded intervention that, for more than 30 years, has shown us that identifying and reducing the barriers faced by patients contributes to better management of their oncology journey [11]. Speed in early diagnosis, timely and quality treatment initiation, and improved patient satisfaction in using health services reassures patients. They understand that they are not alone in this very difficult journey, and become proactive in their healthcare, with greater treatment adherence. This increases overall survival and reduces mortality rates [12].

- 2× Higher mortality risk for patients not complying with the 60-Day Law [12]
- 27% → 85% Increase in law compliance rate (2019–2020) at HM[3]
- 38 days Average time to treatment initiation in 2020 (pandemic peak)[3]

The compilation of follow-up data from PNP's 5 years of operation showed that complying with the "60-Day Law" saves lives. Those who did not comply with the law had 2× more chances of dying from breast cancer [12].

Barriers and navigation strategies

Patients encounter numerous obstacles to undergo diagnostic exams. And, when they confirm having cancer, difficulty in initiating treatment. This was the case with patient Lilian (fictitious name), 43 years old, who discovered a tumor in her left breast in 2019. She arrived at HM already in an advanced stage of the disease, due to the delay in biopsy through the SUS.

One day I was working, PN called me and advanced the appointment for the breast biopsy result with the specialist doctor. The next day, I went to the hospital, and he gave me the worst news of my life. Not only did I indeed have cancer, but it was already large and could no longer be operated on. But I moved forward. I am immensely grateful to PNP, because the team guides and supports you from beginning to end. — Lilian, 43 years old.

"From the doctor, I was immediately referred to by PN and already underwent 2 more exams. I was taken to the psychologist, because I was very shaken, and then to the dentist. The next day, I already did the other exams I needed and scheduled the rest. PN guided me into the vacancy regulation system, and I soon started chemotherapy. When I arrived at the oncologist to begin, 15 days later, I had already had all the exams ready. PNP was a watershed moment in my journey".

At 41 years old, HM social worker Maicon Rocha has a legion of admirers for the work he develops as a PN. He emphasizes that the focus of the work is to facilitate transit through the system, without failing to welcome the pain of those who are fragile due to the disease, physically and emotionally.

Humanization, care, and affection go hand in hand with the speed and efficiency that cases require. My main work is to identify and eliminate the barriers these women encounter to begin treatment within the 60 days recommended by the law. These are emotional, financial, cultural, religious, family barriers, communication barriers with the team. — Maicon Rocha, Patient Navigator.

Former INCA employee, where she worked for 23 years, Lucia Brigagão, social worker and PN, enumerates the specificities of the role.

It is an extremely challenging program, which requires the professional to have extensive knowledge about breast cancer, understanding of treatments, patient fragility, the disease itself, what it represents in the patient's life and family's life. The main objective of navigation is to facilitate, break down barriers, because there are many. In the thousands of appointments I have done, there is one super common thing, which is the fear that cancer brings. Patients arrive terrified, because, for them, it is still a death sentence. They think: 'I have cancer, I am going to die'. And we work so that they think: 'I have cancer, I am going to treat it.'— Lúcia Brigagão, Patient Navigator.

From local initiative to national policy

Lírio Cipriani, consultant and member of the Advisory Board of the Union and Support in the Fight Against Breast Cancer (UNACCAM), closely followed PNP since its inception in Rio de Janeiro. He recalls that the initiative can effectively enforce the 60-Day Law.

Since when cancer is suspected, exams must be done within 30 days. And treatment, no more than 60 days after diagnosis. And navigation does exactly this: accompanies the woman to face and overcome existing barriers, ensuring that the law is complied with and that diagnosis is earlier and more effective. — Lírio Cipriani, UNACCAM Advisory Board.

Currently in remission, Marina (fictitious name), 62 years old, agrees. She was diagnosed in 2020, at HM, with an advanced tumor in her left breast. "What you hear during diagnosis is crucial. Therefore, it is necessary for the doctor to have tranquility, delicacy, and care when speaking. We need to hear that it is curable, to be able to breathe and think: 'I will fight for this cure.' Through PNP, I received all the necessary exam requests. I ended up writing a book about the self-esteem of breast cancer patients, and I had support for that too. The book launch was at the hospital, in August 2024".

For all these reasons, PNP has proven to be a powerful mechanism for shortening paths in the SUS, improving the quality of oncology care, and reducing follow-up and monitoring failures. This was proven right at the beginning of its implementation at the HM. In 2020, at the height of the pandemic, the treatment initiation time reached 38 days at the unit. The compliance rate with the 60-Day Law increased from 27% in 2019 to 85% in 2020, for example [3].

Psychological and social barriers

The success of navigation can indeed be a matter of life or death for breast cancer patients. In our experience, the two main barriers to breast oncology care are fear and fatalistic thoughts. Patients hide the report in the drawer, do not tell their family members, are afraid of treatment due to the possibility of breast mutilation, hair loss, or feeling pain. Many have suicidal ideation, fear abandonment and the stigma of the disease. All of this contributes to delays in treatment initiation. The disease progresses, and curative treatment becomes compromised.

Currently, medicine has evolved greatly, and breast cancer is a disease that has prevention, treatment, cures, and control. Even for metastatic disease, new treatments provide increased survival and quality of life. But unfortunately, many patients still believe that a breast cancer diagnosis is a death sentence. Patient navigation and the navigator's assistance contribute to addressing all patients' fears, leading to favorable clinical outcomes for these women [13].

Patient experience survey results

100% of patients agree or strongly agree that: they felt treated with courtesy and respect, felt supported, knew what the next step in their care would be, and knew who to contact when they had a question. All patients reported an excellent experience with PN services [5].

Recognition and scale-up

All these good results have been recognized and presented at national and international congresses, such as in Chicago at the American Cancer Society (ASCO) Meeting, the San Antonio Breast Cancer Symposium (SABCS), and several editions of the Union for International Cancer Control (UICC) World Cancer Congress.

Awards and recognition

- "Transforming My Square" Trophy (2017) — Rio de Janeiro City Hall
- Innovative Initiatives in Breast Cancer Control Award (2019) — BBCS & FEMAMA
- Cancer Prevention and Control Award (2021) — Brazilian Ministry of Health
- Marcos Moraes Award (2021) — Cancer Foundation (two categories)
- Pedro Ernesto Medal (2021) — Rio de Janeiro City Council
- Best Projects Award (2025) — FórumCCNTs

In 2021, with PNP already operating at HM, after extensive discussion with public policy formulators, managers and health professionals, civil societies, and patients, Municipal Law No. 7,197/2021 [14] was approved, which provides for oncology patient navigation in the public sector. This was the first law on the subject in national territory. The discussion advanced rapidly in the Federal Chamber and Federal Law No. 14,450 [15] on patient navigation for people with breast cancer was sanctioned on September 21, 2022. And currently, patient navigation is part of the New National Policy for Cancer Prevention and Control, since December 2023 [16].

Program metrics and expansion

The scale gain that would come from transforming PNP into comprehensive public policy can therefore enforce the legislation for thousands of patients and save lives daily. At HM, from 2019

to 2024, with limited resources and staff, 3,987 breast biopsies were performed, a monthly average of 60. There were 1,501 (40%) confirmed malignancy cases. Had obstacles, such as contractual issues, not hindered their flow, the numbers could have been much higher. The obstacles are not few. The main difficulties are constant political changes and unsustainable funding. But the good results of the PNP and the incorporation of the theme into the new National Cancer Control Policy are mitigating these difficulties.

PNP initiative, in 2016, was brought from Boston, with support from the Avon Foundation, under the coordination of clinical oncologist Paul Goss, professor at Harvard and founder of the Global Cancer Institute [17]. Currently, PNP has become an official program of the Rio de Janeiro State Health Department. It was named NavegaRJ and operates in 3 major diagnostic hubs in the State of Rio de Janeiro with 5 specialist doctors and 4 PNs, among social workers and nurses. The reach will be for 1,500 patients diagnosed with breast cancer per year in these units [18].

Conclusion

Much more than awards, presentations at congresses, and legislative recognition, the most rewarding aspect is professional and human fulfillment. Working with patient-centered care management allows us to see what was invisible. It allows us to understand that there are barriers beyond those of the health system. Health assistance professionals are also responsible for strategies to reduce health inequalities. Patient navigation showed that it is possible to work in a healthcare network on behalf of the patient. Dialogue between different federal entities is possible. Cancer control and combat are a responsibility of the State and society.

However, the most important thing was the usefulness of PNP in promoting the empowerment of these women. Bringing health education and helping them overcome barriers in a complex, fragmented, and underfunded health system gave hope to all of them. There is life after cancer. Many returned to studying, to working. They built a great community, helped each other. They actively participated in the construction of public policy for patient navigation in Brazil in a great movement of citizenship.

It is amazing to see all the engagement of these women, united by such a frightening disease. But all of them are writing a new story for their lives, with better choices. With this experience, we can have hope. Now, we can aspire to make the world a better place.

Ethical Considerations

This study was approved by the Research Ethics Committee of the National Cancer Institute (INCA) at the time of the pilot project, under CAAE No. 62728616.5.0000.5274, in accordance with Resolution No. 466/2012 of the National Health Council. Currently, the patient navigation service of the State Health Secretariat is a regular service with the agreement of patients to participate in the patient navigation program, with the signing of the consent form and free and informed consent to the service. There are no conflicts of interest for the author.

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