



# The path to implementing a patient navigation program in oncology: an experience report

# Trajetória para implementação de programa de navegação de pacientes na oncologia: relato de experiência

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Submission: 31-Aug-2023 Approved: 04-Dec-2023 ABSTRACT

**Objective:** To describe the process of implementing a Navigation Program for cancer patients. **Method:** Descriptive study, type of experience report carried out in an Oncology Center in Southern Brazil. **Results:** The process of implementing navigation took place in four stages: the first began with the implementation of navigation for private patients with head and neck cancer; the second involved piloting the navigation program for breast cancer patients to understand the main barriers faced by patients; the third stage, was to draw up and approve the Institutional Navigation Program Policy. In the last stage, the Breast Care Navigation Program was implemented for patients with neoadjuvant indications. A 70% reduction was achieved in the median time between indication and first oncology consultation, 28.6% between symptom and diagnosis, and 26.0% between diagnosis and start of treatment. **Conclusion:** Implementing a Navigation Program for cancer patients requires dedication and institutional commitment, leading to better cancer care, with nurses playing a leading role in managing and implementing this process.

**Descriptors:** Nurses, Male; Medical Oncology; Patient Navigation; Breast Neoplasms; Program; Oncology Nursing.

#### RESUMO

**Objetivo:** Descrever a trajetória para a implementação de um Programa de Navegação para pacientes oncológicos. Método: Estudo descritivo, tipo relato de experiência realizado em um Centro de Oncologia do Sul do Brasil. Resultados: O processo de implementação da navegação ocorreu em quatro etapas: a primeira iniciou com implementação da navegação para pacientes privados com câncer de cabeça e pescoço; a segunda envolveu o piloto do programa de navegação de pacientes com câncer de mama para entender as principais barreiras enfrentadas pelas pacientes; a terceira etapa, foi elaborar e aprovar a Política do Programa de Navegação Institucional. Na última, o Programa de Navegação da linha de cuidado da mama foi implementado para pacientes com indicação de neoadjuvância. Obteve-se redução de 70% na mediana de tempo de indicação e primeira consulta oncológica, de 28,6% no tempo entre sintoma e diagnóstico, 26,0% no tempo entre diagnóstico e início de tratamento. Conclusão: A implementação de um Programa de Navegação para pacientes com câncer exige dedicação e comprometimento institucional onde se evidencia um melhor cuidado oncológico, tendo o enfermeiro como protagonista da gestão e efetivação do processo.

**Descritores**: Enfermeiros; Oncologia; Navegação de Pacientes; Neoplasias da Mama; Programa; Enfermagem Oncológica.

#### INTRODUCTION

In Brazil, in almost all regions except the North, where cervical cancer has the highest mortality rate, breast cancer is the leading cause of cancer death in women<sup>(1-2)</sup>. For the three years 2023-2025, 73,610 new cases of the neoplasm are estimated<sup>(2)</sup>, which justifies political and organizational strategies aimed at the control and early diagnosis of the disease in order to achieve lower mortality rates and improve the quality of life of patients<sup>(3-5)</sup>.

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Survival rates for breast cancer, about diagnosis, are around 80% in early stages, 30 to 50% in intermediate stages, and 5% in advanced stages<sup>(3-4)</sup>. Faced with this scenario, to maximize the therapeutic impact, the extension of modalities and time optimization must be considered, as well as the provision of services and timely  $access^{(4,6)}$ .

Even though it is considered a neoplasm with a good prognosis when diagnosed and treated promptly, the delay in accessing health services is one of the reasons that unfavorably influences the mortality rate from breast cancer, which remains high in Brazil<sup>(6)</sup>. This causes the disease to be diagnosed at more advanced stages, reducing survival and increasing morbidity and mortality<sup>(4,6)</sup>. The reason for this is that there is still a significant disparity in the supply and use of screening, diagnosis, and care services for people with cancer between the country's regions, compromising accessibility to treatment in order to achieve the best outcomes<sup>(4,6-8)</sup>.

An effective strategy used internationally to promote the best clinical outcomes in breast cancer is patient navigation (PN). Developed in the United States in 1990 by physician Harold Freeman at Harlem Hospital in New York, PN is an evidence-based practice<sup>(9-10)</sup>. Defined as a systematized process carried out by a professional called a patient navigator, it involves assessing needs, planning, and implementing actions to coordinate care focused on helping patients overcome the barriers that hinder their access to health care<sup>(11)</sup>. It is one of the most efficient ways of putting person-centered care into practice, i.e. regarding their needs and priorities<sup>(8-10)</sup>. Through this process, the navigator can work with patients with a diagnosis or suspicion of cancer, focused on eliminating the barriers that hinder their access to health services and the necessary assistance promptly (8,12)

Since its inception, the PN has multiplied beyond the USA, consolidating itself in Canada and Australia<sup>(12-13)</sup>. It is currently being implemented globally, but it has only been about eight years since it was strengthened in Latin America<sup>(14)</sup>. In Argentina, for example, the National Breast Cancer Patient Navigation Program was implemented by the National Cancer Institute in 2018<sup>(15)</sup>. In more developed and emerging countries, nurses stand out as NPs, earning the status of nurse navigators<sup>(12)</sup>. This professional certifies satisfactory clinical results in oncology<sup>(16)</sup>, improving time to diagnosis and treatment, patient satisfaction, and articulating multidisciplinary work<sup>(17)</sup>.

In Brazil, the existence of PN programs is still incipient, and only in 2018 was the first publication on the subject published in Portuguese<sup>(12)</sup>. In 2020, the first article was published that showed the development of a PN program for patients with head and neck cancer in a high-complexity oncology center (CACON), fully structured for the Brazilian reality, along with the Navigation Needs Assessment Scale (EANN)<sup>(12)</sup>. In September 2022, NPs became regulated through the approval of Law No. 14,450, which created the "National Patient Navigation Program for People with Malignant Breast Neoplasia"<sup>(18)</sup>.

Currently, the existence of the Nurse Navigator (NN) is considered a differential for patient care in oncology services<sup>(14)</sup> and, therefore, is related to advanced nursing practice since PN corresponds to a way of managing and providing care in which the NN will need a list of competencies that are both clinically advanced in the specialty to be navigated and eminently relational, in order to make the objectives of the PN process feasible<sup>(12)</sup>.

In Brazil, both scientific and empirical/practical knowledge about PN and the role of nurses in this process are incipient, making it relevant to describe successful experiences that can expand this model of professional practice. This article aimed to describe the process of implementing a Navigation Program for cancer patients.

## METHOD

This is a descriptive study of the experience report type. The Revised Standards for Quality Improvement Reporting Excellence (SQUIRE 2.0) checklist was used for its preparation<sup>(19)</sup>, seeking transparency and reproducibility in the content of the scientific report.

The study site was an oncology hospital in Porto Alegre, part of a philanthropic hospital complex that treats patients from the Unified Health System, the Supplementary Health System, and private individuals. Considered a High Complexity Oncology Care Center (CACON), it is one of three CACONs in Rio Grande do Sul, Brazil. This institution cares for cancer patients of all specialties, with elective outpatient consultations, diagnostic and treatment services, inpatient units, surgeries, and referral of critically ill patients to Intensive Care Centers. The implementation of the NP Program for breast cancer patients took place from October 15, 2019, to August 15, 2022, and has continued to this day.

This report describes the professional experience of the first author of this article. The results are presented in stages, following the chronology of the facts and respecting the description of processes and workflows, routines, and intervention strategies related to NP in the program of the field of study. To make the experience reproducible, in addition to a narrative description of the process of implementing the NP program, we sought to illustrate the processes inherent in this action using CANVA software. As it did not require any form of data collection or display, it was unnecessary to submit the study to the ethics committee.

#### RESULTS

Implementing patient navigation in the study institution took time. The following are the stages: 1. attempted implementation of patient navigation; 2. pilot of the breast cancer patient navigation program; 3. structuring of the institutional patient navigation program policy; and 4. implementation of the breast cancer patient navigation program.

#### Patient Navigation implementation attempted

It began in 2019, when the nurse, the first author of this article, took over the nursing and operations supervision of CACON's oncology outpatient clinics and tried to implement a PN program developed during her master's degree. Senior managers intended to understand and introduce NPs in the outpatient sectors. However, the human resources to implement the proposed model were limited, and more support was needed. In October 2019, this nurse manager started the PN with private head and neck cancer patients, dedicating approximately two hours of her daily workday attending only those patients directed by the surgeons of this specialty. It was impossible to continue quickly, as the short time dedicated to the role limited the PN process.

In 2020, with the COVID-19 pandemic, there was an attempt to resume care for patients with head and neck cancer by nursing teleconsultation, but once again, due to the worsening scenario itself, the strategy was not implemented.

At the end of 2020, an international foundation

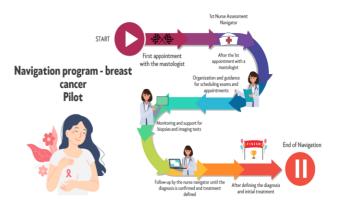
launched a call for projects from Brazilian health institutions to improve care for lung cancer patients. The nurse manager and another oncology nurse drew up a project proposing the development and structuring of a PN program for lung cancer, which was submitted to the call in January 2021 and selected to receive funding for its implementation over two years.

During this period, a clinical oncologist took over as head of the mastology service and, in a meeting aimed at planning strategies, proposed structuring an NP program in this specialty linked to the Unified Health System (SUS).

# Pilot of breast cancer patient navigation program

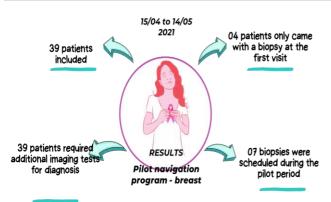
The nurse manager and two care nurses structured the breast cancer PN program and presented it to the CACON management and the SUS outpatient clinic team, with approval to carry out a pilot project for thirty days. The aim was to understand why patients arrived at their first appointment with the mastologist, via municipal regulation, without a diagnosis, with delays in getting complementary imaging tests and a confirmatory breast biopsy.

Before starting the pilot, the nurses were trained. It was established that the navigation process should begin with assessing patients' need for navigation immediately after their first appointment with the mastologist at CACON, as described in Figure 1.



**Figure 1** – Flow of the pilot patient navigation program. Porto Alegre, RS, Brazil, 2022

The pilot program ran from April 15 to May 14, 2021. During its implementation, the nurse manager and her two care colleagues assessed and monitored 39 patients, according to the flow illustrated in Figure 2.



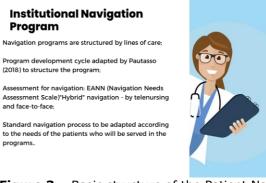
**Figure 2** – Main results of the pilot navigation program. Porto Alegre, RS, Brazil, 2022

With the pilot test results, it was possible to identify the main barriers faced by SUS patients when entering the cancer care service via municipal regulation. The fact that all the patients needed complementary imaging tests for diagnosis and that the majority did not arrive at the service with a biopsy defining a diagnosis of breast cancer was confirmed as one of the factors justifying the delay in defining the treatment and starting it, as there was a limited supply and capacity of care compared to the number of patients. These results were later presented to service managers, triggering an analysis to improve processes in the areas.

Despite the alarming results, unfortunately, due to the demand for care in the outpatient clinics after the pilot, it was impossible to continue with the program. As the care nurses and the manager were dividing their specific activities between their positions and carrying out the navigation, the growing demand for care and management was eating up their working hours, making it impossible to follow through with the effective implementation of the proposed program.

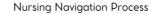
### Structuring the Institutional Patient Navigation Program Policy

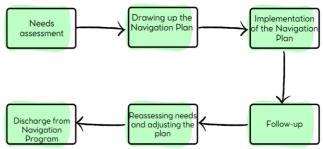
In July 2021, the nurse manager was invited to dedicate herself to the project for which they had been awarded funding from the international foundation. The proposal was to structure a navigation program for patients in the lung cancer care line, enabling the integration of primary and tertiary care and focusing on qualifying the assisted population's access to screening, diagnosis, and treatment. He, therefore, stopped supervising the cancer outpatient clinics to devote himself entirely to the project. At the beginning of 2022, the "Value Office" sector of the hospital complex began its activities, and the manager of this unit coordinated the project. The office coordinator and the hospital complex's director of operations, seeing the results and possible benefits of the PN, recognized its importance and understood that this type of program should be implemented in the institution in an organized and structured way. In this way, the basic structure of the Institutional Navigation Program policy was drawn up and later approved by the executive board. It was decided that the PN programs in the units of the hospital complex should follow the structure shown in Figure 3.



**Figure 3** – Basic structure of the Patient Navigation Program Policy. Porto Alegre, RS, Brazil, 2022

The nursing navigation process was also standardized (Figure 4) and could be adapted according to the peculiarities of the patients assisted in the institution's navigation programs. To this end, it was established that the EANN would be used to assess patients' need for navigation.





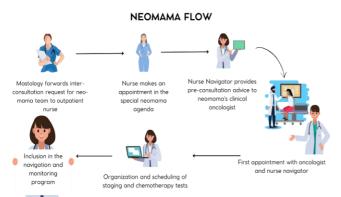
**Figure 4 -** Stages of the Institutional Nursing Navigation Process. Porto Alegre, RS, Brazil, 2022

#### Implementation of the Breast Cancer Patient Navigation Program

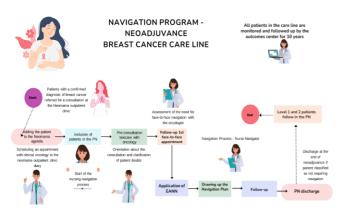
After the institutional policy was established, it was decided that the first program to be struc-

tured and implemented should be for breast cancer patients. This was because breast cancer is one of the institution's strategic lines of care and is included in the monitoring of outcomes. During this same period, the head of the mastology service at CACON pointed out barriers in the flow of care for patients with indications for breast neoadjuvant therapy, consisting of inadequate time between consultations with specialties, access to diagnostic complementation and a lack of systematization in discussions about conduct, aggravated by a lack of multidisciplinary integration, indicators of direct interest to the essence of PN.

This set of barriers could lead to unfavorable outcomes and worsening quality of life both during and after treatment. It was felt that a strategy should be planned to change this scenario, so the Neomama outpatient clinic (Figure 5) was structured, and the Breast Care Line Navigation Program began, focusing on patients diagnosed with breast cancer and with an indication for neoadjuvant treatment (Figure 6).



**Figure 5** – Flow of the Neomama Outpatient Clinic. Porto Alegre, RS, Brazil, 2022



**Figure 6** - Flow of the Navigation Program for patients in the breast cancer care line and indication for neoadjuvant treatment. Porto Alegre, RS, Brazil, 2022

The criteria for including patients in the program were defined as follows: having a diagnosis of breast cancer and an indication for neoadjuvant treatment to be carried out at the institution. Exclusion criteria: treatment outside the institution.

The pre-consultation teleconsultation with oncology aimed to guide the patients about the consultation, ensuring they came better prepared. They were put on a specific agenda at the Neomama outpatient clinic and after starting their treatment, they went to the general clinical oncology team. The aim was to ensure patients received prompt care and started treatment quickly.

The Navigation Program for patients with an indication for neoadjuvant treatment and the Neomama outpatient clinic began on May 19, 2022. In August 2022, the Navigation Program was expanded to include patients from all breast cancer treatment modalities.

At the end of 2022, the project funded by the international foundation came to an end, and due to the positive results related to this project and the Navigation Program of the breast cancer care line, the Director of Operations approved the structuring of the "Outcomes Center" and the "Patient Navigation Center". With the project's resources, it was possible to readjust the value office to accommodate the two Centers physically. Finally, the "Patient Navigation Center" was officially inaugurated in March 2023.

With the implementation of the program, it was possible to significantly reduce the journey times of breast cancer patients, especially those with neoadjuvant indications: there was a 70% reduction in the median time between indication and first consultation with clinical oncology (from 105 to 31.5 days); a 28.6% reduction in the time between symptom or first consultation and diagnosis (from 21 to 15 days); a 26% reduction in the time between diagnosis and start of neoadjuvant (from 77 to 57 days); and the time between treatment indication and start of neoadjuvant (from around 30 to 8 days). From May 2022 to May 2023, more than 200 patients were navigated, with an average of 98 patients per navigator.

#### DISCUSSION

Although there have been important advances in breast cancer diagnosis methods and treatment options in recent years, women who have been diagnosed still face a complex and tortuous emotional journey<sup>(20-21)</sup>. Even though breast cancer can have a high cure rate and successful treatment, in Brazil, around 12.78 women per 100,000/year still die from the disease, and delay in diagnosis and/or treatment is one of the most plausible causes of this rate<sup>(22-24)</sup>. In view of this, the PN programs seek, among other things, to eliminate and/or reduce this inequity, which is the delay in timely care, while at the same time promoting a critical look by the multidisciplinary team in 2021, allowed us to identify and understand the main barriers faced by these women when they enter the oncology service to undergo their treatment. This data provided the basis for opportunities for improvement and was essential for restructuring various institutional processes to smooth out this arduous journey of dealing with cancer. It also highlighted the urgent need to structure and implement an institutional navigation program focused on these patients to improve care, welcome, and provide comprehensive support throughout the treatment continuum. This provided input for the establishment of the Navigation Policy in the services. Corroborating the literature indicates that developing policies, procedures, guidelines, and processes is essential to formalize the navigation program in health service <sup>(25)</sup>. Implementing the Neomama Outpatient Clinic

and the NP for patients in the breast cancer care line, with the nurse navigator's role, made it possible to improve the care provided by ensuring efficient care coordination and focusing on the needs and peculiarities of each patient. This was directly reflected in the results, ensuring that these women had timely access to treatment through the nursing navigation process. This resulted in a 26% reduction between diagnosis and the start of treatment. This data and the multidisciplinary integration qualification promoted have a definite potential impact on clinical outcomes. This corroborates the impression of international literature, highlighting the growing and innovative role of nurse-led PNs<sup>(24)</sup>.

The NN is the professional who constantly communicates with patients, carries out health education, and identifies the barriers each may face during their journey through cancer treatment<sup>(12,24)</sup>. Implementing these programs involves a series of actions that must be planned collectively to ensure success in supporting vulnerable patients and improving outcomes<sup>(11,25)</sup>. This combination of clinical and managerial skills is emblematic of the nature of the professional nurse<sup>(14)</sup>, and, therefore, it is only fitting that he should be legitimized to lead the programming and implementation of the PN in different lines of care, such as breast cancer.

The involvement of the head of the mastology service, care professionals, coordinators, and the institution's executive management were defining points for the successful implementation of the PN. All the main stakeholders must be involved, such as managers, executive directors, and professionals, so everyone can have an overview of the processes and be realistic in structuring the program's actions, observing the needs and peculiarities of the patients and the health service<sup>(25)</sup>.

The main objective of the Nursing PN is to identify and remove barriers that may prevent or hinder access to treatment and care<sup>(22,24)</sup>. The PN's role in the program, through assessing the need for navigation using the EANN12, made it possible to obtain the main results related to improving access times to treatment. The PN's role in the program, through assessing the need for navigation using the EANN12, made it possible to obtain the main results related to improving access times to treatment. The PN's

According to a qualitative study involving seven nurse navigators in Queensland, Australia, by contributing to a culture of care integration, these professionals can support integrated care practices that strengthen relationships between health professionals<sup>(26)</sup>. This enhances the understanding of nurse navigation as an integrated care model, illustrating the complexity, diversity, and breadth of nurses' roles and their ability to contribute to defragmenting the entire health system<sup>(26)</sup>. In one year, more than 200 patients were seen by a single PN, and all of them had their care coordinated, considered their needs, and wishes, and integrated them with the entire multi-professional team.

Finally, among the various strategies used to improve the coordination of care and reduce the challenges arising from the complexity of cancer care, the PN is an intervention that shows considerable benefits for the outcomes of breast cancer patients<sup>(20,22,24)</sup>, and this was also evidenced by the operationalization of the PN described and the results presented in the report in such a short time of operation. Despite this, it is vital to recommend robust studies so that PNs, especially those led by nurses, are given a better scientific status. As a limitation of this report, it is important to note that the article describes only one specific case in a single CACON within the diverse and heterogeneous context of the Brazilian reality. On the other hand, the study is innovative and influential for disseminating PN, facilitating the implementation of other PNs, and consolidating nurses as protagonists in these promising forms of professional practice.

### CONCLUSION

The report highlights the difficulties in implementing a Navigation Program for cancer patients. The path was arduous and time-consuming, but when it was implemented, it improved cancer care, with nurses playing a leading role in managing and implementing this process.

The experience reported illustrated the path to implementing a Navigation Program for oncology patients. The process lasted around two and a half years and was carried out in four stages. In all phases, nurses played a leading role in the planning, management, and execution of the PN. Preliminary results from the im-

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plementation of the program indicate that the breast cancer patients navigated are already showing an improvement in the times related to the stages of the treatment journey. Thus, we believe in the innovation of the study and the applicability of the PN as a way of qualifying the care provided to patients and connecting the health system and services in favor of person-centered care.

Finally, it is hoped that, from this report, health professionals and managers can become aware of PN, in the sense of seeing it as a means of improving cancer care in the country and encouraging other services to implement this strategy. In these implementations, it is recommended that nurses be considered key players both in program management and in implementing the navigation process. In order to do this, this professional must meet a set of advanced clinical competencies in addition to their inherent managerial skills.

### **CONFLICT OF INTERESTS**

The authors have declared that there is no conflict of interests.

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