Cancer Patient Navigation by Nurses in Brazil: History, Concepts, and Models

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História, Conceitos e Modelos da Navegação de Pacientes Oncológicos por Enfermeiros no Brasil

Historia, Conceptos y Modelos de Navegación del Paciente Oncológico por Enfermeros en el Brasil

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ABSTRACT

Introduction: Cancer patient navigation aims to eliminate barriers in cancer treatment by offering support and facilitating access to therapeutic care. It originated with Harold Freeman's theory and has spread to other countries, including Brazil, where it has been adapted to the local context. **Objective:** To identify the theoretical conceptualization and navigation models adopted by nurse navigators of cancer patients in Brazil, to compare theory and practice based on COFEN resolution 735/2024, and to verify the perception of nurses about the repercussions of theory on daily practice. **Method**: Qualitative research, with interviews conducted with 27 nurse navigators, selected by snowball sampling. Data collection included semi-structured interviews, and the data was analyzed using Bardin's content analysis technique. **Results**: Freeman's principles are the basis for navigation programs in Brazil. However, the theoretical models are not well described in the practice of nurses, who often confuse the structure of the program with the navigation model. The personalization of action, according to institutional and patient needs, is frequently mentioned. **Conclusion**: The study confirms the application of Freeman's principles but highlights the lack of standardization and knowledge about theoretical models. The navigation of cancer patients in Brazil is constantly evolving and is moving towards complying with COFEN regulations, with the need for greater integration with the SUS to reduce disparities in access to healthcare.

Key words: Patient Navigation/trends; Nursing; Oncology Nursing; Practice Patterns, Nurses'; Oncology Service, Hospital.

RESUMO

Introdução: A navegação de pacientes oncológicos visa eliminar barreiras no tratamento do câncer, oferecendo suporte e facilitando o acesso aos cuidados terapêuticos. Surgiu com a teoria de Harold Freeman e se expandiu para outros países, incluindo o Brasil, onde foi adaptada ao contexto local. **Objetivo:** Identificar a conceituação teórica e os modelos de navegação adotados por enfermeiros navegadores de pacientes oncológicos no Brasil, confrontar teoria e prática com base na Resolução COFEN n.º 735/2024 e verificar a percepção de enfermeiros sobre as repercussões da teoria na prática cotidiana. Método: Pesquisa qualitativa, com entrevistas realizadas com 27 enfermeiros navegadores, selecionados por amostragem do tipo bola de neve. A coleta de dados incluiu uma entrevista semiestruturada, e os dados foram analisados pela técnica de análise de conteúdo de Bardin. **Resultados:** Os princípios de Freeman são aplicados como base para programas de navegação no Brasil. No entanto, os modelos teóricos não são bem descritos na prática dos enfermeiros, que frequentemente confundem a estrutura do programa com o modelo de navegação. A personalização da atuação, conforme as necessidades institucionais e dos pacientes, é frequentemente mencionada. **Conclusão:** O estudo confirma a aplicação dos princípios de Freeman, mas destaca a falta de padronização e conhecimento sobre modelos teóricos. A navegação de pacientes oncológicos no Brasil está em constante evolução e caminha para corresponder à regulamentação do COFEN, com a necessidade de maior integração com o SUS para reduzir disparidades no acesso à saúde.

Palavras-chave: Navegação de Pacientes/tendências; Enfermagem; Enfermagem Oncológica; Padrões de Prática em Enfermagem; Serviço Hospitalar de Oncologia.

RESUMEN

Introducción: La navegación del paciente con cáncer pretende eliminar las barreras en el tratamiento del cáncer ofreciendo apoyo y facilitando el acceso a la atención terapéutica. Se originó con la teoría de Harold Freeman y se ha extendido a otros países, incluido el Brasil, donde se ha adaptado al contexto local. **Objetivo:** Identificar la conceptualización teórica y los modelos de navegación adoptados por los enfermeros navegadores de pacientes oncológicos en el Brasil, comparar la teoría y la práctica con base en la resolución 735/2024 del COFEN y verificar las percepciones de los enfermeros sobre las repercusiones de la teoría en la práctica cotidiana. **Método**: Investigación cualitativa, con entrevistas realizadas a 27 enfermeros navegadores, seleccionados por muestreo de bola de nieve. La obtención de datos incluyó entrevistas semiestructuradas, y los datos se analizaron mediante la técnica de análisis de contenido de Bardin. **Resultados**: Los principios de Freeman se aplican como base de los programas de navegación en el Brasil. Sin embargo, los modelos teóricos no están bien descritos en la práctica de los enfermeros, que a menudo confunden la estructura del programa con el modelo de navegación. La personalización de la acción, de acuerdo con las necesidades institucionales y del paciente, se menciona con frecuencia. **Conclusión**: El estudio confirma la aplicación de los principios de Freeman, pero destaca la falta de estandarización y conocimiento sobre los modelos teóricos. La navegación de los pacientes oncológicos en el Brasil está en constante evolución y avanza hacia el cumplimiento de las normas del COFEN, con la necesidad de una mayor integración con el SUS para reducir las disparidades en el acceso a la asistencia sanitaria.

Palabras clave: Navegación de Pacientes/tendencias; Enfermería; Enfermería Oncológica; Pautas de la Práctica en Enfermería; Servicio de Oncología en Hospital.

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INTRODUCTION

Cancer patient navigation (CPN) is a health field of action in which the professional aims to identify and overcome barriers so the patient's therapeutic itinerary can flow continuously, more seamlessly, and effortlessly as possible, adding agility to actions, better crisis management planning, and creating processes and emergency actions inside and outside the hospital context. This patient-centered scheme is created according to the bond established between the ill person and their support network, the navigator, the multidisciplinary team involved, and the institution or network that manages the treatment[1-3].

Patient navigation emerged from Harold Freeman's disquiet with the difficulties in accessing cancer treatment services in the United States and later expanded to Canada, Australia, and other healthcare systems. Currently, patient navigation encompasses not only assistance in accessing treatments but also prevention, diagnosis, and continuity of the journey until the outcome. It can be performed by laypeople or professionals, presenting different objectives and modes of action according to the navigator's abilities and competencies[4,5].

The nurse as navigator has their attributions associated directly with flow management and/or directing the clinical assistance, as well as developing indicators, which requires understanding the patient's journey from diagnosis or admission to the institution to the end of their path with the disease, whether it is discharge, rehabilitation, palliation, or death[6,7]. It is therefore essential that the professional knows the theoretical models to base and guide their action[8,9].

In Brazil, CPN by nurses has been built over the years based on foreign guidelines and has been improved and adapted little by little[7,10]. In 2022, the National Patient Navigation Program for People with Malignant Breast Neoplasm was legislated, which, despite representing an advancement, did not inspire many practical changes in the National Health System (SUS). Recently, in December 2023, the National Cancer Prevention and Control Policy and the National Patient Navigation Program for People with Cancer Diagnosis were instituted in SUS, so, there was a regulation in January 2024 by the Federal Council of Nursing which established the action in the field as an advanced nursing practice and delimited the scope to nurses who perform this function[11-13].

In this context, reflecting on the theoretical framework that grounds this practice is relevant to understanding that the work of nurses in the health field is influenced by its medium and by the relationships faced by multiple situations, which confer singularities and renormalizations to the process, configuring a dialectics between the job in paper and the actual job[14,15].

This article is a framing of a study developed by the authors who sought to unveil the practices of CPN performed by nurses in Brazil. The present study aims to identify the theoretical conceptualization of navigation models used by cancer patient navigator nurses in the active programs in Brazil; compare theory and nurse-described practice in light of the Federal Nursing Council (COFEN) Resolution of January 17, 2024[13]; and verify the perception of navigator nurses on the repercussions of these findings in their daily practice.

METHOD

Descriptive investigation and qualitative approach. To ensure methodological quality, transparency in data collection, and robustness of data analysis, the present study was conducted in light of the Consolidated Criteria for Reporting Qualitative Research (COREQ)[16]. Adopting COREQ allowed us to structure each step of the study systematically and in line with international best practices for qualitative research. This study initially selected 30 practicing navigator nurses, aiming to achieve richness of detail in the interviews[17-20]. This participant's dimensioning was grounded in Dworkin's theory[17], which recommends a sample size of 25-30 participants to ensure that information from interviews can provide a quality answer to the research question.

The professionals' approach was non-probabilistic by convenience, a snowball sampling type, in which initial participants indicated new participants, who in turn indicated other participants, and thus continued until the proposed quantity was reached or data saturation was achieved[18-20].

Researchers conducted recruitment through a messaging app, which was also used to provide the Informed Consent Form and schedule the interview.

A total of 39 answers were collected in the interest questionnaire, and data collection was closed once the proposed number of participants was reached. After removing one duplicate, two revocations of expressions of interest, and nine exclusions due to a lack of response within the proposed period, 27 interviews were included and anonymously coded from P1 to P27.

The interviews were conducted by the oncologist nurse researcher, who works in the multiprofessional residency program of a national reference institute, remotely via a video call application, and recorded for audio consultation. Data collection instruments, including an interest manifestation questionnaire and preferred interview dates, were employed. The interviews followed

a semi-structured script containing topics on their professional journey, tools, knowledge, abilities, practice description, use of theories, obstacles, and impacts in the work, based on the research interest in aspects of the practice, and also to allow contributions from participants that could add details to the activities description.

The interviews were analyzed following Bardin's content analysis technique, which allowed us to infer the pattern of the navigator nurse in Brazil based on the discourse that addresses the subjectivity of practice from the perspective of the actors under critical, non-intuitive analysis and with methodological rigor that makes it pertinent. That provided us with a valid approach to consider the possibility of generalizing the description of the navigator nurse practice[21].

The interviews were transcribed in full and the three degrees of content analysis were applied, consisting of pre-analysis (fluctuating reading, research *corpus* delimitation, formulation of hypotheses and objectives, reference to indices and elaboration of indicators, and preparation of material); exploration of material (definition of units of record (UR), units of content (UC), categories, and themes); and data treatment and interpretation[21].

The study was previously submitted to the Research Ethics Committee, thus respecting the legal aspects of studies conducted with human beings ruled by Law N. 14.874/24[22], ensuring the safety, dignity, and well-being of participants. Study approved under number 6.962.337 (CAAE (submission for ethical review): 79826224.6.0000.5274), in compliance with Resolution N. 466/2012[23] of the National Health Council.

RESULTS

A total of 27 cancer patient navigator nurses, working in public, private, and philanthropic institutions, participated in the study, recruited through convenient snowball sampling. Most were female (96.3%), predominantly aged 29-44 years (85.16%). A considerable number of participants graduated between 2012-2016 (40.72%) and had an oncology specialization (88.89%); 29.63% had a Master's degree, and none had a Doctorate. Time working in navigation varied from 2 years (48.15%) to up to 8 years (7.41%). The average weekly workload varied from 30 to 40 hours. Regarding practice, most worked in private institutions (62.96%) and had no specificity regarding cancer topography (44.44%). The most frequently navigated care pathway was the treatment phase (70.37%).

This article will discuss the first category of a study that aimed to unveil the CPN practices by nurses in Brazil, named "History, concepts, and model of Cancer Patient Navigation". This category was established based on the understanding that there is relevance in knowing the fundamental bases and models used in current navigation programs, so that it is then possible to describe the models and their relationship with practices.[5,8]. This fact is justified by the option to previously define categories, as recommended by Bardin[21] and Minayo[24].

HISTORY, CONCEPTS, AND MODEL OF CANCER PATIENT NAVIGATION

The present category has 353 units of record, representing 9.39% of UR. It is divided into 2 subcategories ("History and Fundamental Theoretical Concepts" and "Cancer Patient Navigation Model"), composed of 5 named UC: Harold Freeman, importation of navigation models, structure and format of the navigation program, navigation process and model, and creation and implementation of the navigation program.

HISTORY AND FUNDAMENTAL THEORETICAL CONCEPTS

The historical background of CPN was built on the observation of disparities in access to health and implementations of strategic measures to alleviate difficulties found in the treatment of people in vulnerable situations in the region of Harlem, in New York (USA). Therefore, the work of the navigator had an impact on the journey of the assisted, initially during the diagnosis period, and later throughout their whole journey[4,25].

With the expansion of CPN, the nine patient navigation principles written by Harold Freeman have become the main pillar for building navigation programs currently. They are: patient-centered care (1), full care to patient, seeking access and fluidity in their journey (2), elimination of barriers on the journey (3), well-defined scope of action different from those of other team members (4), cost-effectiveness (5), compatibility of navigator abilities and competencies with the support level in the assisted phase of the journey (6), well-defined patient admission and discharge moments (7), integration and bond between the patient and the healthcare system (8) coordination or supervision structure within the program (9)[4].

In Brazil, there has been an exponential growth of CPN programs, and, in this scenario, Freeman's theory has been observed in the participants' testimonies:

> The main one, that everybody uses, I guess, is Harold Freeman's model. His nine steps are what we base our work on... We actually put him in our project when we made it, exactly hi[s principles]m (P7).

> Actually, and this goes for all models, we must base ourselves on the essence of navigation, which are the principles. So, first, getting to know the nine navigation principles. Then, this is the basis of any [navigation] program, regardless of the model you use (P16).

Thus, the presence and similarity of discourses suggest the existence of a commonly grounded basis in the historical originator aspect of navigation to build CPN by nurses in Brazil.

In addition to the clear association of Freeman's principles with the creation of programs, navigator nurses reported applying these principles when putting the patient at the center of the navigation process, focusing on eliminating barriers for each case, with actions within the defined scope.

> We survey the barriers they face. Barriers like transportation, support, financial issues, health literacy, communication difficulties, difficulties understanding the diagnosis, and understanding the journey. We survey all these barriers they face. Then, we draw a plan (P20).

> So, we act as a link to the patient; if they bring us an issue, we'll talk to, say, the nutritionist, and intermediate the communication (P26).

These testimonies consequently express an appropriation of the Brazilian scope defined in 2024 by COFEN, which, to achieve Freeman's objectives, relies on the use of scales, consultations, flow organization, bonding with the patient, integration with the multidisciplinary team, communication, and health education.

CPN MODELS

The context of the CPN's historical origins means that the acquired bases and models, as well as the execution of pioneering long-term studies, were created and carried out in the North American continent, providing an opportunity for the creation of Brazilian programs to have as a starting point and inspiration the importation of these models.[7].

Starting from understanding the premise that navigation should be structured and executed according to the public to which it assists, the needs to be met and the barriers to be most often found and eliminated, the CPN program should be developed with institutional adaptations respecting the previously established theoretical model, to meet the demands of the public, valuing to maintain the limits of the scope of action recently provided by law and well-defined navigator skills, thus aiming at the quality and flow of ordering, according to principles 4 and 6 of the Harold Freeman patient navigation[4,5,7,8]. This topic was approached in the speech fragments:

> If we're not curious, do not develop critical thinking on what is relevant to adapt to my reality, we can't just copy and paste the USA references to our context; we must adapt these references from one program to another. Because it's different patient profiles, different programs, different missions, visions, and institutional values (P21).

> For not having a model, you end up adapting it according to the institution. Yes, I think you have to adapt it according to the institution, but you must have a model [to start from]. (...) Nursing is science (P8).

Thus, the perception of the navigator nurse on adjusting the program formats to the theoretical models highlights the customization aspect of the practice and the importance of customizing the action, as well as reports the need for a theoretical model that standardizes and guides the focus of the work to the patient.

Regarding the models, patient navigation can be described according to the competency of the navigator, who can be a layperson, an academic, a professional (social service or nursing), or multidisciplinary, culturally competent, bicultural, and/or bilingual. It can still be classified by its form of action, emphasis, or location of the practice, as seen in Chart 1, which gathers the most used descriptions in the literature[4,5,9]. The models are frequently described with one or more of these aspects.

The CPN programs were commonly described as separated by the *continuum* phase, when the work of the navigator is restricted to the stage in which the patient is, either prevention, screening, diagnosis, or rehabilitation/survival. They were even described according to the work process, such as, for example, navigation associated with a specific diagnosis by topography or navigation by type of patients assisted based on the medical professional[5]. Thus, the predominant model identified in the research, according to the interviewees, was clinic professionals assigned per journey phase. However, when asked about the navigation model used, participants often struggled to provide a straightforward answer and confounded the program's structure with its format, describing the work of the navigator, navigated pathology type, and work process.

> We build it according to the clinic's needs, but theoretically I'm in the diagnosis phase until the start of treatment, that's the phase I cover... (P3).

Chart 1. Summary of the patient navigation models

Patient navigation model	Description
Lay	Performed by lay navigators, who work as journey facilitators with no specific clinical knowledge or attributions. More aimed at information reproduction, expansion, and recruiting for health care
Academic	Performed by navigator students in the health field, who function as journey guides and facilitators
Professional	The navigator has professional training in the field they intend to work. Some eligibility criteria for this work, in addition to training, are familiarity with the public, the chosen field, and competencies for each navigation level. In this model, nurses and social workers can excel
Full journey	Involves the navigator's work throughout the journey stages from the moment of admission to the navigation program. It can start at the time of disease detection and follow up with the disease already identified, up to rehabilitation, survival, or death
Per journey phase	Involves the work of a navigator at a certain stage, either for a patient who has just identified the disease or who is following up from a previously diagnosed disease. Guides the patient through prevention, screening, diagnosis, treatment, rehabilitation, or survival
Per patient profile	Considers the type of vulnerability found and the required assistance for each public. Aims for better resourcefulness to overcome the barriers found
Clinic	Care targeted at needs and symptoms, health education, information, help with decision-making, emotional support, and coordination of care throughout the journey. For this model, nurses are preferred
Non-clinic	Targeted at social, logistical, and organizational barriers. Usually done by lay navigators or social workers
Community	Classified by location of practice, usually in community groups, therapeutic communities, or clinics with an established coverage territory
Culturally concordant/ bilingual	Considers the cultural and logistical competency essential to the role, to achieve better accessibility, understanding, and adherence results

Source: Elaborated by the authors based on Wells and Nuhaily[5], Pautasso et al.[9], and Freeman[25].

> As is our model. The patient goes to treatment, chemotherapy treatment, they get there, let's say it's their first treatment. So, we go there and talk to that patient. We introduce ourselves, explain the whole treatment, how it's going to be, if it's on the blood vessel, if it uses a catheter, if there is a pump, no pump, we explain everything, signs, symptoms, care (P17).

When reflecting on the rapid growth of CPN in Brazil over the last few years, it is possible to infer that recently implemented programs are subject to changes and adjustments to adapt the practice and workflows. This is demonstrated by how frequently the creation of the navigation program comes up in the testimonies. Fifteen out of 27 interviewees reported participating in the creation and implementation of the program over the last few years, totaling 66 UR (1.76%). They talked about the process from their own experiences:

> So, we started developing a project that would become this navigation. (...) So, nowadays we work on it, we've been creating, maturing it. We started it in October after stitching everything together. And we still have those moments where we stop, improve, so it's a dynamic job, we learn a lot (P3).

Thus, the improvement and flexibility of navigation program structures throughout their activities may be considered a finding of this study, highlighting even more the process of patient navigation development in Brazil.

DISCUSSION

The analysis of interviews demonstrated that the origin of CPN, grounded in Harold Freeman's principles, is the foundation of the navigation programs in Brazil. The Harlem population, where Freeman implemented the first navigation experience, is marked by deep social inequalities in terms of race/color, poverty, and gender. It must be highlighted that these characteristics are directly related to the greater cancer incidence, prevalence, and mortality, being evidently similar to the current Brazilian scenario, in which social inequalities interfere with timely access to diagnosis and oncology treatment. This scenario reinforces the importance of applying the nine navigation principles that are perfectly applicable to the Brazilian reality, especially when it comes to fighting health inequalities[25-28].

However, data from this study reveal that navigation programs in Brazil are concentrated, mostly, in private institutions. Such a distribution restricts the reach of navigation to part of the population who already have some easy access to the health system, excluding, mostly, people in extreme poverty who would benefit the most from these strategies of care coordination and support provided by patient navigation. Thus, maintaining a navigation model centered in the private sector paradoxically contributes to perpetuating disparities in the health field.

Therefore, it becomes evidently necessary for government health authorities to invest in the implementation of navigation programs within SUS, as a structuring strategy to promote a more equitable, efficient, and integral therapeutic journey. By acting as facilitators of access and organizers of care, nurse navigators can play a crucial role in reducing the geographic, institutional, clinical, emotional, and socioeconomic barriers experienced by cancer patients across the country.

Regarding theoretical navigation models, the collected data reveal that these models were scarcely mentioned or understood by professionals. Instead, they predominantly referenced the *continuum* care phase of action (diagnosis, treatment, follow-up). Although the literature indicates that the absence of formalized theoretical models does not necessarily compromise program outcomes[5], this gap represents a risk to the methodological consistency and quality of the care, especially when aiming for scalability and institutionalization of practices.

Adherence to Freeman's principles, such as effective communication, health education, coordination of care, and integration into the care network, actually constitutes a solid ground for the practice. However, the absence of a structured theoretical model limits the navigation potential as a systematized and reproducible care technology, impairing its evaluation, expansion, and adaptation to different contexts. The COFEN N. 735/2024[13] Resolution reinforces the need for a well-defined scope, in line with specific competencies, which requires more investment in the critical and technical training of professionals working in this field[29]. This resolution thoroughly describes the work of the navigator nurse, which, given its extension, will not be thoroughly addressed in this study. However, it was possible to show an equivalence between practice and legislation, since the management of care, health education, and overcoming biopsychosocial barriers were well described.

Moreover, results suggest that navigation program formats, although diverse and shaped by specific institutional realities, are not necessarily incompatible with theoretical models. On the contrary, the customization of care and articulation with the healthcare system are aspects that can and should be integrated into existing models, promoting their adaptation to local demands with no harm to their conceptual consistency.

Finally, although the observed programs presented positive results even in the absence of explicit theoretical models, this does not diminish the importance of their implementation. Structured references are essential to ensure standardization, continuity, quality, and sustainability of navigation programs, especially in the public sector, in which practice institutionalization requires theoretical, normative, and scientific support[5,29].

CONCLUSION

The main finding of this study was the use of Harold Freeman's nine principles as the guiding basis for CPN programs in Brazil, which reinforces the applicability and adaptability of this theoretical framework to the national context. However, a significant lack of knowledge was observed on the part of the nurses interviewed regarding formal theoretical navigation models. Such a realization reflects the absence of standardized care in current programs. Still, this lack of knowledge does not impair the initiatives' work, nor compromises achieving the patient-centered objectives or fulfilling the guidelines established by COFEN N. 735/2024[13] Resolution.

CPN in Brazil has a journey marked by progressive advancements. Over the last few years, the field has gained more visibility, incentives, and investments, which tends to broaden the reach of navigation benefits to the Brazilian population. These advancements, in turn, can be followed up, furthered, and assessed through new studies.

As a limitation, we highlight the predominance of participants from private health institutions, which may restrict the representativeness of realities experienced by

public institutions. Although verifying this institutional distribution was not the focus of this study, we acknowledge that this framing may influence the generalization of the obtained results.

CONTRIBUTIONS

Gleyce Kelly Cordeiro Maia has contributed to the study design, planning, acquisition, analysis, and interpretation of the data, as well as the wording. Raquel de Souza Ramos, Fernanda Felipe Pautasso, and Carla Maria Castro do Santos contributed to the study design, planning, acquisition, analysis, and interpretation of the data, as well as critical review and intellectual contribution. All the authors approved the final version for publication.

DECLARATION OF CONFLICT OF INTERESTS

There is no conflict of interest to declare.

DATA AVAILABILITY STATEMENT

The generated data sets analyzed during the current study are available at the Ninho repository, under the electronic address: https://ninho.inca.gov.br/jspui/handle/123456789/17451.

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