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NAVIGATION NEEDS IN PATIENTS WITH ADVANCED CANCER: A CROSS-SECTIONAL STUDY*

NECESSIDADES DE NAVEGAÇÃO EM PACIENTES COM CÂNCER AVANÇADO: ESTUDO TRANSVERSAL

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RESUMO

Objetivo: Avaliar as necessidades de navegação em pacientes com câncer avançado. **Método:** Estudo transversal com 52 pacientes oncológicos em estadiamento avançado. Utilizou-se um formulário de dados sociodemográficos e clínicos e a Escala de Avaliação da Necessidade de Navegação, estratificada em seis categorias. As pontuações geradas foram analisadas por teste de Shapiro-wilk, Qui-quadrado e modelo de regressão linear. **Resultados:** A média de necessidade de navegação foi de 9,21 pontos, com desvio padrão de 2,25; 61,54% sem necessidade de navegação e 28,85% com nível 1. As categorias foram: entendimento parcial da trajetória do tratamento (73,08%), dificuldade de organização para o tratamento (51,92%, p=0,00001), e de apoio/suporte familiar parcial (50%, p=0,023). Os fatores que indicam maior nível de navegação foram: idade (gl=2; wald= 13,94; p=0,001), menor renda familiar (gl=2; wald=16,88; p=0,000), baixa escolaridade (gl=1; wald=7.84; p=0,005), ausência de prática de atividade física (gl=1; wald=13,01; p=0,000), tabagismo (gl=1; wald=5,24; p=0,022) e o uso do sistema público de saúde (gl=1; wald=0,87; p=0,0003). **Conclusão:** As necessidades de navegação avaliadas, relacionaram-se a fatores sociodemográficos e clínicos, como idade avançada, baixa escolaridade, menor renda familiar, ausência de prática de atividade física, tabagismo e uso do sistema público de saúde, reforçando a importância de estratégias direcionadas que promovam acesso precoce e continuidade do cuidado oncológico.

Descritores: Navegação de pacientes; Enfermagem oncológica; Neoplasias; Cuidado centrado no paciente.

ABSTRACT

Objective: To assess the navigation needs in patients with advanced cancer. **Method:** Cross-sectional study with 52 oncologic patients at advanced staging. A sociodemographic and clinical data form and the Navigation Need Assessment Scale, stratified into six categories, were used. The scores generated were analyzed using the Shapiro-Wilk test, chi-square test, and linear regression model. **Results:** The average navigation need score was 9.21 points, with a standard deviation of 2.25; 61.54% without navigation needs and 28.85% at level 1. The categories were: partial understanding of the treatment trajectory (73.08%), difficulty organizing treatment (51.92%, p=0.00001), and partial family support (50%, p=0.023). Factors indicating higher navigation levels were age (df=2; wald=13.94; p=0.001), lower family income (df=2; wald=16.88; p=0.000), low education level (df=1; wald=7.84; p=0.005), lack of physical activity (df=1; wald=13.01; p=0.000), smoking (df=1; wald=5.24; p=0.022), and use of the public health system (df=1; wald=0.87; p=0.0003). **Conclusion:** The assessed navigation needs were related to sociodemographic and clinical factors such as advanced age, low education level, lower family income, lack of physical activity, smoking, and use of the public health system, highlighting the importance of targeted strategies to promote early access and continuity of oncologic care.

Descriptors: Patient navigation; Oncology nursing; Neoplasms; Patient-centered care.

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INTRODUCTION

Patient Navigation (PN) in oncology refers to a care delivery model that has the capacity to support patients' access to timely and quality care throughout the cancer treatment process by providing individualized assistance to patients, families, and caregivers. It began in 1990 at Harlem Hospital in New York, in partnership with the American Cancer Society (ACS), with the goal of ensuring continuity of treatment for individuals with chronic diseases. This concept originates from a process in which a professional, called a patient navigator, guides individuals with confirmed or suspected diagnoses of chronic diseases, helping them overcome socioeconomic, financial, cultural, bureaucratic, and emotional challenges[1-2].

The basic and fundamental principles of PN followed up to the present day are: (1) navigation must be patient-centered and ensure continuity of care; (2) facilitate integration of health systems creating a continuous flow of care; (3) eliminate barriers that hinder access to health services; (4) define the scope and role of navigators in this multidisciplinary team; (5) accessibility to navigation services; (6) navigators with appropriate training and skills; (7) establish clear criteria for starting and ending navigation; (8) create connections between health systems; and (9) ensure the effectiveness of the navigation process. Although the model was initially conceived for oncology patients, its applicability can be expanded to other chronic diseases[3].

Historically, in Brazil, the existence of PN programs is still recent, as the first publication on the topic in Portuguese was only released in 2018. The first article highlighting the development of a PN program for patients with head and neck cancer in an oncology center was published in 2020, structured for the Brazilian reality, along with the Navigation Needs Assessment Scale (NNAS)[3].

Regarding cancer treatment, better prognoses are associated with diagnoses at early stages. Thus, as the disease progresses and affects other organs, therapeutic complexity increases, resulting in reduced survival and changes in treatment goals. In advanced stages (stage IV), the therapeutic focus shifts from cure to tumor control, symptom relief, and quality of life improvement[4].

The oncologic patient's journey is often marked by challenges such as difficulties accessing the health network, misinformation about the therapeutic process, and lack of family support, which are necessary for continuous follow-up throughout the patient's trajectory. Therefore, the Oncology Nurse Navigator (ONN) assumes an important role in managing the patient's journey, acting as a care facilitator and ensuring swift access to health services. Their functions include not only coordinating oncologic care but also interpersonal communication skills and the ability to coordinate with multidisciplinary teams[5-6].

PN is a personalized strategy to meet the needs of oncology patients at all stages of the disease, from screening, diagnosis, reducing the time to start treatment, during treatment, minimizing side effects, complications, hospitalizations, and directing care with timely attention, aiming to improve the journey of oncology patients[7]. Its impact promotes facilitated access to health services, improves adherence to the therapeutic plan, evaluation and monitoring, patient and family education through clarifying doubts and support, optimizing access to oncologic care and reducing inequalities in healthcare[6,8-9].

In this context, the guiding question of this study was to demonstrate what are the navigation needs of patients with advanced cancer? Thus, the study is considered relevant as it sought to assess the navigation needs of patients with advanced cancer. The evaluation data allow professionals and health services to plan specific actions through navigation, focusing on reducing access barriers, improving follow-up organization, and strengthening support for the patient at all stages of the disease.

METHOD

This study was described following the recommendations of the STROBE instrument (Strengthening the Reporting of Observational Studies in Epidemiology), this checklist being used to ensure completeness and quality in the presentation of the study's methods, results, and discussions, promoting reproducibility and reliability of the findings[10].

Cross-sectional study[11] conducted in an oncology treatment center at the outpatient level in the state of Paraná. Fifty-two participants diagnosed with malignant neoplasia at stage IV, according to the Tumor, Node, Metastasis (TNM) classification, adopted to define the clinical stage of the disease, were selected[12].

Participants were selected by purposive sampling, based on individuals' availability to participate in the study. A non-probabilistic sampling method was used, in which population elements do not have the same chance of being included in the sample[11], drawing from electronic medical records between December 2023 and June 2024. Out of the 55 eligible patients selected from clinical data in the electronic medical record, one refused participation due to residing in another municipality and having fixed transportation times, and two, when approached, had altered levels of consciousness and scored 50% on the Palliative Performance Scale (PPS) version 2[13]. The data collection location and time were prearranged with the team and the patient, in a reserved and individual manner. The study proposal was presented to the selected participant, and the Informed Consent Form (ICF) was read and signed together.

Users diagnosed with any histopathological type of cancer at stage IV were considered eligible. However, in the sample obtained, there were no patients with hematologic tumors. Exclusion criteria included users with decreased level of consciousness or emotional disorganization, evaluated using the PPS[13].

For data collection, the sociodemographic and clinical data form and the NNAS[3] were used. The NNAS consists of six evaluation categories: patient understanding in relation to diagnosis, communication ability, understanding of treatment trajectory, capacity to organize treatment, access to health services/system, family support. It contains key questions directed to patients and evaluation criteria that generate a score, which, when summed at the end, indicate the need for navigation. The minimum score is 6 and the maximum is 17 points, with scores from 6 to 9 indicating no need for navigation, 10 to 12 indicating level 1 navigation need, and 13 to 17 indicating level 2 navigation need. Level 1 navigation should be conducted by an academic navigator and a professional navigator, with support from the nurse navigator. Level 2 navigation requires navigation by the nurse. The scale identifies individual navigation needs directed to personalized strategies[3].

The collected data were analyzed using the Statistical Package for the Social Sciences (SPSS) version 21. Description and summary of the collected data were performed through the construction of frequency tables (categorical variables) and calculation of descriptive statistics (quantitative variables). The Shapiro-Wilk test was applied to verify the assumption of data normality. To evaluate the relationship between NNAS levels and sociodemographic and clinical variables, the Chi-square test or Fisher's exact test (when the sample was small) was applied.

To profile patients needing navigation, a Generalized Linear Model (GLM) was adjusted. The application of Generalized Linear/Nonlinear Models allows analyzing linear and nonlinear effects for any number and type of predictor variables on a discrete or continuous dependent variable. The GLM uses maximum likelihood (ML) methods to build models and to estimate and test hypotheses about model effects. The Akaike Information Criterion (AIC) is used as the criterion for selecting the best model.

The study complied with the standards of Resolution No. 466/2012 of the National Health Council (CNS), and Resolution No. 738/2024, which regulates the use of databases for research involving human beings, being approved by the Ethics and Research Committee of the Federal University of Paraná, with CAAE No. 74758923.1.0000.0102 and Opinion Number 7.118.615.

RESULTS

The study sample consisted of 52 participants, of whom 35 (67.31%) were female. Ages ranged from 29 to 84 years, with a mean of 54.25 years. The majority, 33 (67.30%), resided in Ponta Grossa, PR, with 48 (92.31%) living in urban areas; 34 (65.38%) were married, and 45 (86.53%) were on leave from work for disease treatment. Among those with individual income, 24 (46.15%) earned between 1 and 2 minimum wages, while 12 (23.07%) earned between 2 and 4 minimum wages. Regarding health care coverage, 40 (76.92%) had private health insurance, whereas 12 (23.08%) depended exclusively on the Unified Health System (SUS). Concerning education level, 16 (30.77%) had completed high school and 12 (23.07%) had higher education (Table 1).

Regarding clinical data, the most prevalent initial diagnoses varied between the genders. Among women, breast cancer accounted for 13 (25.0%), followed by cervical cancer 5 (9.62%) and colorectal cancer 4 (7.69%). Among men, colorectal cancer was most common with 4 (7.69%), followed by tongue cancer 2 (3.85%), pancreas cancer 2 (3.85%), brain cancer 2 (3.85%), and secondary neoplasms in bones and marrow 2 (3.85%). Less frequent diagnoses were not described individually, only the most prevalent diagnoses by gender were reported, which do not represent the total cases included.

Regarding staging, performed according to the TNM classification, 26 (50%) presented stage IV from the initial diagnosis, progressing to advanced stages with metastases related to the primary site of the disease. In women with breast cancer, metastases were in bones, lungs, and brain; in colorectal cancer, metastases occurred in the retroperitoneum and liver, and participants with cervical and ovarian cancer presented with pelvic lymphadenopathy.

All participants were undergoing cancer treatment: 32 (61.54%) chemotherapy, alone or combined with other therapies such as radiotherapy 15 (28.85%), monoclonal antibodies 14 (26.92%), and immunotherapy 9 (17.31%). These protocols were associated with the treatment of breast and colorectal cancer.

Participants reported symptoms related to advanced disease and effects caused by antineoplastic treatments, including fatigue 43 (82.69%), pain 41 (78.85%), nausea 35 (67.31%), peripheral neuropathy 32 (61.54%), diarrhea 23 (44.23%), constipation 16 (30.77%), anxiety 34 (65.38%), depression 18 (34.62%) and fear 16 (30.77%). Regarding maintenance of daily activities, 12 (23.08%) stopped physical activities and 31 (59.62%) stopped leisure activities due to symptoms such as pain 41 (78.85%) and fatigue 43 (82.69%) associated with treatment.

Continuous medication use was common among 50 (96.15%) participants, highlighting non-opioid analgesics 27 (54.0%), opioids 19 (38.0%), antihypertensives 15 (30.0%), and antidepressants 15 (30.0%).

Regarding the assessment of navigation needs, most participants 38 (73.08%) understood their disease diagnosis. Concerning understanding of the treatment trajectory, 38 (73.08%) reported partial understanding. The ability to organize attendance at multiprofessional consultations and treatments was a challenge for 27 (51.92%) participants, who reported needing support managing schedules and access to health services. In the family support category, half had partial support and follow-up 26 (50.0%).

Regarding the navigation level classified by the NNAS score, among the 52 patients, the mean was 9.21 with a standard deviation of 2.25, ranging from 6 to 15 points. In this regard, 32 (61.54%) had no need for navigation. The highest scoring categories included partial understanding of the treatment trajectory 38 (73.08%), difficulty organizing for treatment 27 (51.92%), and partial family support 26 (50%), as shown in Table 2.

Statistical analyses were performed to assess the association between sociodemographic and clinical variables and levels of navigation needs, as shown in Table 3.

Through the applied multivariate model, the factors considered significantly related to the NNAS score were: age, with higher age resulting in a higher score; family income, with lower family income resulting in a higher score; education, with lower education resulting in a higher score; smoking, with smokers and former smokers having a higher score; physical activity, with lower physical activity resulting in a higher score; organizational skills, with lower organizational skills resulting in a higher score; and family support, with lower support resulting in a higher score. It is noteworthy that the factors influencing navigation levels were considered significant when $p < 0.05$.

The following factors were consistent: age, family income, education, smoking, physical activity, organizational skills, and family support. The multivariate analysis indicated that the participant's age has a relevant impact on navigation levels, including specific age ranges and different levels of support. The level of education emerged as a determining factor associated with greater navigation capacity in the health system.

Table 1 – Sociodemographic characterization of the participants. Curitiba, PR, Brazil, 2024

Sociodemographic varibles	f	%	Standard deviation
Gender			
Female	35	67.31	
Male	17	32.69	
Age			
Mean	54.25		
n	52		
Standard Deviation			14.08
Minimum	29		
Maximum	84		
Marital status			
Single	6	11.54	
Married	34	65.38	
Divorced	4	7.69	
Widowed	2	3.85	
Common-law marriage/Consensual relationship	6	11.54	
Education			
Completed Elementary Education	8	15.38	
Incomplete Elementary Education	3	5.77	
Completed High School Education	16	30.77	
Incomplete Higher Education	4	7.69	
Postgraduate Studies: Specialization	8	15.38	
Postgraduate Studies: Master's Degree	2	3.85	
Technical Education	3	5.77	
Occupation			
Active	7	13.46	
Inactive	8	15.38	
Retired	14	26.92	
On leave for treatment	23	44.23	
Primary Caregiver			
Wife	30	57.69	
Son	11	21.15	
Parents	1	1.92	
Family (other)	9	17.31	
Other	1	1.92	
Health Insurance Plan			
SUS	12	23.08	
Other Health Insurance Plans	40	76.92	
Origin			
Municipality where the research was conducted	35	67.30	
Other	17	32.70	
Living Space			
Urban	48	92.31	
Rural	4	7.69	
Individual Income Value			
One to two minimum wages	24	46.15	
Two to four minimum wages	12	23.07	
Five or more minimum wages	9	17.31	
No response (when there was no income)	7	13.46	
Average Family Income			
One to two minimum wages	5	9.62	
Two to four minimum wages	22	42.31	
Five or more minimum wages	17	32.69	
No answer (not available)	8	15.38	

Source: prepared by the authors, 2025.

DISCUSSION

The predominantly female sample over 50 years of age referred to the analyzed service differs from national studies that indicate a higher prevalence between 60 and 80 years of age, with a predominance of males in metastatic neoplasms[14-15]. Participants reported smoking, alcohol consumption and low frequency of physical activity, factors that corroborate national and global studies on the main risk factors for the development of cancer, with smoking being the main potentiator of carcinogenic activity[16].

Regarding the sociodemographic profile, the findings regarding the level of education are aligned with previous studies developed in Brazil[9,17-18] showing that patients with lower education and income have a greater need for navigation due to difficulties in understanding the treatment and the logistical barriers faced, which may also reflect on shared decision-making, fundamental for the quality of treatment[19-20]. It is observed that more informed patients have better adherence to treatment and a higher quality of life[21].

Table 2 – Assessment of Navigation Needs by NNAS. Curitiba, PR, Brazil, 2025

Categories	f	%
Category 1: Patient understanding regarding the diagnosis		
Understands your diagnosis	38	73.08
Partially understands your diagnosis	9	17.31
Does not understand	5	9.62
Category 2: Communication skills		
No communication difficulties	39	75.00
Experiencing some communication difficulties	13	25.00
Unable to communicate	0	0
Category 3: Understanding the treatment trajectory		
Understands the treatment path well	7	13.46
Understands the treatment path partially	38	73.08
Does not understand the treatment path	7	13.46
Category 4: Organizational skills for carrying out the treatment.		
Patient is able to organize themselves to attend appointments, treatments, and exams.	25	48.08
Patient has difficulty organizing themselves to attend appointments, treatments, and exams and needs assistance with this.	27	51.92
Category 5: Access to health services / system		
Has easy access to the service via transportation (public or private) and knows how to locate the place (hospital or other service) for their treatment.	30	57.69
Has easy access to public or private transportation to get to the health service but has difficulty locating the hospital/service for their treatment.	13	25.00
Difficulty accessing transportation (public or private) to get to the hospital/service for treatment and difficulty getting to the location (hospital/sector) for treatment.	9	17.31
Category 6: Family support		
There is full support and monitoring: the family/caregiver participates in decisions and care and accompanies the patient at all times during treatment.	26	50.00
There is partial support and monitoring: family/caregiver participates in decisions and care and accompanies the patient at some points during treatment.	26	50.00
Navigation level		
6 to 9 points: no navigation required	32	61.54
10 to 12 points: navigation level 1 required	15	28.85
13 to 17 points: navigation level 2 required	5	9.62

Source: prepared by the authors, 2025.

Table 3 - Generalized linear regression model (GLM) for navigation levels. Curitiba, PR, Brazil, 2025

Variable	Gl	wald	p
Intercept	1	9299.66	0.0
Gender	1	2.01	0.156
Age	2	13.94	0.001
Dependents	1	1.41	0.235
Family income	2	16.88	0.0
Primary care provider	1	0.06	0.809
Health insurance	1	0.87	0.35
Education level	1	7.84	0.005
Smoking habits	1	5.24	0.022
Physical activity	1	3.65	0.0
Organizational skills	1	34.24	0.0
Family support	1	45.55	0.0

Source: prepared by the authors, 2025.

Regarding treatment adherence, it was found that SUS users reported greater difficulty in scheduling appointments, obtaining medications, and interdisciplinary support, corroborating studies[18] that highlight the vulnerability of patients without private health insurance, being assisted in a radiotherapy health service that serves 50% through the SUS. In addition, access to health services and the quality of treatment are directly related to sociodemographic factors, such as income and educational level[22]. Patient navigation, coordinated by nurses, has the potential to minimize these inequalities, ensuring more timely and effective care[23].

The navigation needs in this study were related to understanding the treatment trajectory, organizational capacity, and family support. The importance of the family as a link is one of the fundamental factors in the patient's journey, therefore family involvement is an essential determinant for treatment adherence[19-20]. Family support helps organize daily demands and positively impacts the patient's emotional stability, increasing the feeling of being welcomed and secure[24-25]. However, the approach to prognosis and palliative care faces cultural and emotional challenges, both in Brazil, as demonstrated in an Asian study[26], where professionals avoid this discussion for fear of causing emotional distress, compromising the patient's autonomy and their right to information.

Regarding tracking up to the start of treatment, the nurse navigator acts as a central link in the coordination of care, reducing delays in the start of treatment and providing more effective and humanized follow-up at all stages[27-28]. As for the diagnostic phase, in turn, it is often cited as one of the critical moments of the oncological journey, marked by stress and uncertainty. Studies[29-30] have shown that efficient navigation at this stage reduces the time between diagnosis and the start of treatment, minimizing disease progression

and ensuring individualized support for the patient. Another relevant finding was the correlation between lower education and greater need for navigation. Socioeconomic inequalities directly impact access to and quality of care[18], reinforcing the importance of a structured navigation model for advanced cancer patients[3].

It is therefore evident that there is a need for public policies that encourage the expansion of Patient Navigation Programs in Brazil, guaranteeing more equitable, structured and dignified access to cancer treatment[31]. The ENO is thus consolidated as an essential element in the cancer patient's journey, from diagnosis, treatment, survival, including palliative care, providing a more dignified, compassionate and person-centered path[32-33].

One of the challenges and limitations of this study was the absence of a Patient Navigation Program at the local institution of the study, as well as the lack of integrated action by the multidisciplinary palliative care team, due to institutional restrictions. Another limitation was groups with diverse access, both those with private insurance and those using the SUS, with the resulting inequalities observed in this study.

CONCLUSION

It is concluded that although most participants did not present an indication for formal navigation according to the NNAS (Brazilian Oncology Assessment Scale), partial needs were observed, related to understanding the treatment trajectory, organizational capacity, and family support. Advanced age, low education level, lower family income, lack of physical activity, smoking, and exclusive use of the public health system stood out as significant predictors of a greater need for navigation. These findings reinforce the importance of implementing structured Patient Navigation programs in oncology, aiming at the early identification of barriers and the formulation of individualized strategies that promote access, continuity, and comprehensiveness of care. Additionally, the results offer relevant support for the planning of health interventions, as well as encouraging further research on the effectiveness of navigation programs in the Brazilian oncology context.

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CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

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AUTHORSHIP CONTRIBUTIONS
Study conception: Pio EAM, Mercês NNA, Tracz R. Data acquisition: Pio EAM. Data analysis: Pio EAM, Mercês NNA, Tracz R. Data interpretation: Pio EAM, Mercês NNA, Tracz R. All authors are responsible for drafting the manuscript, critically revising its intellectual content for the final published version, and ensuring the study's accuracy and integrity with regard to ethical, legal, and scientific aspects.