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THE IMPACT OF
PATIENT NAVIGATION
ON QUALITY OF LIFE
IN ONCOLOGICAL
PATIENTS UNDERGOING
DEFINITIVE
RADIOTHERAPY IN THE
PUBLIC HEALTH SYSTEM
IN BELO HORIZONTE

Carolina Martins Vieira

Federal University of Minas Gerais (UFMG)

Roberta Xavier Campos

Federal University of Minas Gerais (UFMG)

Clara Sobreira Dias Lopes

Pontificia Universidade Católica de Minas Gerais (PUC Minas)

Angélica Nogueira Rodrigues

Federal University of Minas Gerais (UFMG)



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Abstract: Cancer is Brazil's second leading cause of death, demanding comprehensive and timely treatment approaches. However, challenges in accessing and incorporating new technologies in radiotherapy treatment (RT) have led to delays and hindered patient outcomes. Patient Navigation (PN) has emerged as a potential solution to address these challenges and enhance cancer patient care, particularly in vulnerable populations. To explore and present unpublished data from an original project regarding the role of PN in impacting the quality of life of patients undergoing definitive RT in the public health system of Belo Horizonte, through scores such as Supportive Care Needs Survey Short Form, comparing the same group of patients before and after PN. This pilot study is a prospective, non-randomized clinical trial conducted in collaboration with the Global Cancer Institute/MGH Harvard University in a public teaching hospital. The study evaluates the time from diagnosis to RT initiation and secondary outcomes such as treatment duration, access barriers, patient satisfaction, with significant improvements in patient outcomes. There was an increase in the median SCNS-SF score from 98.5 to 117.5 (p= 0.002) from inclusion in the project to follow-up. Furthermore, PN positively influenced the reduction of time between diagnosis and treatment, healthbehaviors, including conscious health check-ups (53.8% vs. 88.5%, p<0.01), healthier eating habits (67.3%), and sun protection (36.5% vs. 62.7%, p=0.008). PN presents a valuable approach to bridging gaps in cancer care, reducing disparities, and enhancing patient experiences. This analysis findings underscore the importance of Patient Navigation in optimizing cancer treatment outcomes, promoting timely care, ultimately improving patients' quality of life. While the study has inherent limitations, its contribution to improving cancer care for SUS

patients is evident, highlighting the potential impact of addressing social disparities.

Keywords: Patient Navigation; Radiotherapy; Oncology; Cancer Treatment.

INTRODUCTION

Cancer is the second leading cause of death in Brazil, second only to cardiovascular diseases, while in developed countries, it is already the leading cause of mortality. For quality treatment to be available, it must be multimodal, thus including systemic therapy, surgery, and radiotherapy. In Brazil, however, there is significant difficulty in accessing radiotherapy treatment, reflected in inadequate deadlines for it to be performed. Delays in initiating and/or completing radiotherapy treatment can have deleterious effects on patient care, including lower response rates, higher recurrence rates, and shorter survival. ^{3,4}

The challenges related to radiotherapy in the SUS include the availability of human resources to incorporate new technologies in radiotherapy. According to the census carried out in 2022, of the 363 linear accelerators identified, 122 (34%) are considered obsolete by the manufacturer.⁴

Despite advances in cancer treatment in recent years, it is notable that there is less access to new technologies for patients with a low socioeconomic profile and racial and ethnic minorities. This is due to the direct impact of social determinants of health on their care. Delays in initiating and/or completing radiotherapy treatment can have deleterious effects on patient care. These effects include lower response rates, higher recurrence rates, and shorter survival. ^{2,3,4}

Several patient navigation templates can be tailored to the needs of patients and healthcare systems, as discussed in ASCO 2021, including transportation, communication, cultural barriers, financial problems, social

support, compression of information and care resources, in addition to patient-professional communication, directly impairing equitable access for all patients with cancer. ⁵ In recognition of the role of Navigation in the equitable approach to patients, the U.S. Congress passed the Patient Navigation Outreach and Chronic Disease Prevention Act in 2005 and created a funding mechanism designed to support research on the impacts of patient navigation. ⁶

The Brazilian government enacted Law No. 12,732, of November 22, 2012, 37, the 60-day Law, defining that the patient with malignant neoplasm has the right to undergo the first treatment in the SUS within a period of up to 60 days, counting from the day the diagnosis is confirmed in the pathological report. ⁷

Following the approval of this Law, SISCAN (Cancer Information System) was established, responsible for monitoring its implementation, tracking, and recording treatment deadlines, as well as other indicators aimed at future cancer control measures. 8 However, most patients still suffer from delayed receiving a cancer diagnosis and starting treatment. For every ten people who turn to the Federal Public Defender's Office with health-related cases, at least six ask for help to carry out some stage of their journey as a cancer patient. 9,10

As a tool for overcoming bottlenecks to adequate oncological care, Patient Navigation (PN), a patient-focused health service delivery model, can lead to improvements in care. It is a concept centered on the movement of patients through their medical care, including all stages of this broad and diverse *continuum*, starting in the community and continuing through diagnosis, treatment, and survival until the end of their lives. ^{4,5,6} PN can help overcome common obstacles encountered by patients, such as financial barriers and communication barriers (understanding, language/culture),

medical system barriers (fragmented medical system, missed appointments, missed results), and psychological barriers (such as fear and distrust) to accessing treatment. ^{9,10}

The PN programs with cancer have some characteristics in common, such as the existence of a specific network of services necessary to solve that pre-established demand, focus on identifying patient barriers to accessing treatment; to reduce delays in accessing cancer treatment services, with an emphasis on the time from diagnosis to treatment and reducing follow-up losses. Furthermore, PN has a defined endpoint: once the obstacle is overcome, the patient can perform the defined objective (for example: reaching diagnostic clarification or initiating cancer treatment). The navigation process is concluded now, and citizens use the usual healthcare flows. 7,9

Faced with the analysis of the present literature and the scarcity of data regarding the inclusion of Navigation in the panorama of the public health service and its impact on the quality of life of cancer patients, we expose unpublished data from the original study, carried out at the Hospital das Clínicas of UFMG, in front of academic cooperation for program development PN. Data referring to the primary outcome were previously presented. ⁹

According to the World Health Organization (WHO), health is "a complete physical, mental and social well-being and not merely the absence of disease or infirmity." Hence, the application of protocols to measure health-related quality of life (HRQoL) in cancer patients holds great significance. It is known that HRQoL encompasses several aspects of a person's well-being, including the physical, social, functional, and emotional domains. Cancer treatment can significantly impact HRQoL in various domains, underscoring the importance of addressing it in patient care. 14,15

Collecting HRQoL information from cancer patients allows physicians to personalize propaedeutic and positively impact their treatment, increasing their quality of life and general well-being. Therefore, physicians must pay attention to HRQoL in oncological outcomes and use this tool to benefit the patient's therapy. 14,15

OBJECTIVE

Explore and present unpublished data from the original project regarding the role of Navigation in impacting the quality of life in patients undergoing definitive radiotherapy treatment in the public health system of Belo Horizonte.

METHODOLOGY

This is a pilot study in a public teaching hospital, a prospective non-randomized clinical trial, comparative with a historical cohort, in partnership with the Global Cancer Institute/MGH Harvard University. The primary outcome was to assess the time from histological diagnosis to initiation of RT among cancer patients who received RT with curative intent in a PN program. Secondary outcomes included time between the start and end of RT, identifying and describing the main obstacles observed to access and quality of life data, and evaluating patient satisfaction with the PN program. ^{10,11,12}

The study included cervical, rectal, esophageal, anal canal, head and neck, lung, and prostate cancer candidates for neoadjuvant or definitive RT, except for one patient who was excluded from the navigation arm. The pilot study showed benefits for the primary outcome. Between July 2018 and January 2020, 124 patients were included in the retrospective arm, and 73 were included in the navigation arm. Patients in the navigation arm were monitored weekly, received support during radiotherapy, and experienced an

impact on their quality of life. 12

Data collection on quality of life was performed after inclusion in the study (initial assessment), based on original questionnaires (Worry Interface Scale (WIS); PEPPI Scale (Perceived Efficacy in Patient-Physician Interactions); Functional Assessment of Cancer Therapy Scale (FACT-G - Version 4); Supportive Care Needs Survey Short Form (SCNS-SF34), applied in the prospective group. At the time of inclusion of the patient in the study and after the end of the radiotherapy treatment, the information was answered directly on the tablets. The present study aims to explore and present the impact of patient navigation on quality of life through prespecified subanalyses of the original project. 12

RESULTS

The study showed positive results for the primary outcomes, with a reduction in the time from diagnosis to referral for radiotherapy (from 53 to 40.5 days, p = 0.011), from referral to the first RT consultation (from 25 to 13 days, p < 0.001), and from referral to the end of RT (from 98 to 78 days, p < 0.003). 9,10

Of the selected scales, the Worry Interface Scale (WIS) measures the patient's level of concern about cancer. The PEPPI scale (Perceived Efficacy in Patient-Physician Interactions) comprises ten questions to assess understanding and communication in the doctor-patient interface. ¹⁶

The Functional Assessment of Cancer Therapy scale (FACT-G - Version 4) is a questionnaire with 27 items designed to measure four domains of quality of life in cancer patients: physical, social, emotional, and functional well-being. Simultaneously, the Supportive Care Needs Survey Short Form (SCNS-SF34) measures the need for supportive care. This score has already been tested in the Brazilian population, consisting of 34 items distributed in four domains

(Physical and Daily Life, Psychological, Sexuality, and Care and Support). It proved valid and accurate in measuring the care needs of individuals diagnosed with cancer in the Amazon region. ^{16, 17, 18}

The pilot study identified several barriers faced by the NavigatorNavigator; among them, transportation difficulty was reported by 60.6%, and more than half of the patients (56.3%) reported fear as an obstacle. In addition, the difficulty of communicating with the medical team (40.8%) and the low level of education can negatively impact the understanding of medical information; about 21.1% of the patients indicated illiteracy. Other identified problems, such as physical or mental comorbidities, were reported by 19.7% of patients, and work-related issues were reported by 31%.

Below are the tables related to the main applied scales:

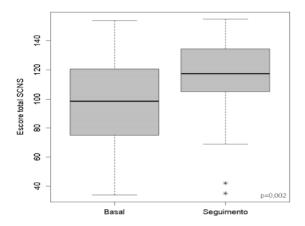


Figura 1 – Score SCNS basal and follow-up

The p-value refers to the Wilcoxon test for paired samples.

Source: elaborated by the author with data extracted from the research

Regarding the concern interface score described in Table 17, there was an increase in the median (19.5 vs. 25, p<0.001) when comparing baseline and follow-up. Another issue addressed regarding the quality of life was communication difficulties with the

medical team, with almost half (41.4%) of the patients undergoing the navigation process reporting this issue. ¹⁹.

Among the main counterpoints that prevent adequate communication are: "the patient does not fully understand all the facts about the treatment; medical information is not provided in a way that the patient can understand; the patient believes that the doctor will tell them the essential facts about the treatment and does not ask questions; the patient is afraid to ask too many questions; the patient is afraid to waste a lot of the doctor's time and does not ask questions. Social issues, such as employment, were reported by 35.2% of patients, and financial problems were reported by 31%. Regarding the patients in the project, a low level of education (21.1% reported literacy deficits) can negatively understanding impact the of medical information.

DISCUSSION

According to Law Organic Law of the SUS (Law n° 8080) ²⁰, one of the fundamental principles includes integrality, where the system carries out individual and collective preventive actions and services, requiring different levels of complexity. Applied to the reality of cancer patients, the system must be prepared to listen to the user, understand them in their social context, and meet the demands and needs of this person. ²¹

Cancer patients experience negative feelings and various difficulties during the diagnostic and therapeutic journey. However, some factors enable reframing the illness and need to be considered by health professionals and managers to minimize the impact of the disease during this journey. ^{15,22} Fear/anxiety is one of the most addressed feelings (about 56.3 percent) reported by patients as an obstacle. Despite optimized medical care, whether chemotherapy or radiotherapy, significant

Statistics	Basal	Follow-up	P-value
Minimum; Maximum	34;154	35;155	0.002
Median (P25%, P75%)	98.5 (75-118,75)	117.5 (105.5-133.8)	
Average (CI 95%)	98.19 (97,39-98,99)	116 (115,34-116,7)	
Standard deviation	29,79	25.42	
Missings	1	21	

Table 16 - Descriptive statistics of baseline SCNS total score and follow-up.

The p-value refers to the Wilcoxon Test for paired samples.

Source: elaborated by the author with data extracted from the research

Statistics	Basal	follow-up	P-value
Total score Concern interface			< 0.01
Minimum; Maximum	7; 30	7; 35	
Median (P25%, P75%)	19,5 (11; 25)	25 (22; 27,25)	
Average (CI 95%)	18.1 (17,8; 18,23)	24.27 (24,13; 24,41)	
Standard deviation	7,77	5,12	
Missings	2	20	

Table 17 - Descriptive statistics of the total baseline concern interface score and follow-up.

The p-value refers to the Wilcoxon test for paired samples.

Source: elaborated by the author with data extracted from the research

Variables	Basal	Follow-up	P-value
Periodic health check			<0,001
Less/maintained	24 (46,2%)	6 (11,5%)	
More	28 (53,8%)	46 (88,5%)	
Eat healthy foods			<0,001
Less/maintained	29 (55,8%)	9 (18%)	
More	23 (44,2%)	41 (82%)	
Use sunscreen*			0,011
Less/maintained	40 (76,9%)	26 (51%)	
More	12 (23,1%)	25 (49%)	
Try to lose weight*			0,228
Less/maintained	41 (80,4%)	37 (72,5%)	
More	10 (19,6%)	14 (27,5%)	
Avoid sun exposure*			<0,001
Less/maintained	36 (69,2%)	17 (33,3%)	
More	16 (30,8%)	34 (66,7%)	
Wear clothes to protect yourself from the sun*			0,008
Less/maintained	33 (63,5%)	19 (37,3%)	
More	19 (36,5%)	32 (62,7%)	
Make an effort to manage stress*			0,136
Less/maintained	35 (67,3%)	27 (52,9%)	
More	17 (32,7%)	24 (47,1%)	
To exercise*			0,773
Less/maintained	44 (86,3%)	42 (84%)	

More	7 (13,7%)	8 (16%)	
Rest*			0,153
Less/maintained	23 (45,1%)	16 (30,8%)	
More	28 (54,9%)	36 (69,2%)	
Spend time with family and friends.			0,677
Less/maintained	32 (62,7%)	30 (58,8%)	
More	19 (37,3%)	21 (41,2%)	
Spend time with recreation and leisure*			0,663
Less/maintained	36 (69,2%)	32 (62,7%)	
More	16 (30,8%)	19 (37,3%)	
Avoid Alcohol			
Less/maintained	37 (72.5%)		
More	15 (28.8%)	16 (32%)	
Go to church or spiritual activities			0,646
Less/maintained		35 (67,3%)	
More	14 (27,5%)	17 (32,7%)	
Avoid Cigarrette			0.502
Less/maintained	37 (72,55)	34(68%)	
More	14 (27.5%)	16 (32%)	

Table 18- Descriptive questionnaire statistics on changing health habits, baseline, and follow-up.

Table made with only the 52 patients who answered the two questionnaires.

The p-values refer to the McNemar chi-square test.

Source: elaborated by the author with data extracted from the research

Variables	Basal	follow-up	P-value
I felt that my health concerns were	understood		1,000
Disagree/Neutral	2 (3,8%)	2 (3,8%)	
Agree/fully agree	50 (96,2%)	50 (96,2%)	
I was able to get the advice/answer issues/questions	s I needed about my health		1,000
Disagree/Neutral	1 (1,9%)	2 (3,8%)	
Agree/fully agree	51 (98,1%)	50 (96,2%)	
I was treated with courtesy and res	spect.		-
Disagree/Neutral	-	-	
Agree/fully agree	52 (100%)	52 (100%)	
I felt included in decisions about my health.			0,371
Disagree/Neutral	4 (7,7%)	1 (1,9%)	
Agree/fully agree	48 (92,3%)	51 (98,1%)	
I felt like I had enough time with n	ny Navigation.		-
Disagree/Neutral	1 (1,9%)	-	
Agree/fully agree	51 (98,1%)	52 (100%)	

^{* &}quot;I do not know" answers were considered missing.

I felt supported by my NavigatorNavi	igator.		-	
Disagree/Neutral	-	-		
Agree/fully agree	52 (100%)	52 (100%)		
Booking an appointment was easy			0,289	
Disagree/Neutral	7 (13,5%)	2 (3,8%)		
Agree/fully agree	45 (86,5%)	50 (96,2%)		
I knew what the next step in my care	would be.		0,221	
Disagree/Neutral	6 (11,5%)	1 (1,9%)		
Agree/fully agree	46 (88,5%)	51 (98,1%)		
I feel confident in how my Navigator deal with the healthcare system.	Navigator has helped me		-	
Disagree/Neutral	-	1 (1,9%)		
Agree/fully agree	52 (100%)	51 (98,1%)		
I knew whom to contact when I had a question				
Disagree/Neutral	2 (3,8%)	3 (5,8%)		
Agree/fully agree	50 (96,2%)	49 (94,2%)		
I am satisfied with the help I received	l .		-	
Disagree/Neutral	-	1 (1,9%)		
Agree/fully agree	52 (100%)	51 (98,1%)		
Please rate your overall browsing experience from 1-10, 1 being a very poor experience and 10 being an excellent experience.				
Minimum; Maximum	7; 10	7; 10		
Median (P25%, P75%)	10 (10, 10)	9 (9; 10)		
Average (CI 95%)	9,69 (9,67; 9,72)	9,29(9,26;9,32)		
Standard deviation	0,70	0,78		
Missings	1	1		

Table 19 - Descriptive statistics of the navigation satisfaction questionnaire, baseline, and follow-up.

Table made with only the 52 patients who answered the two questionnaires.

P-values without indication refer to the McNemar chi-square test, and the p-value with the symbol W refers to the Wilcoxon test for paired samples.

Source: elaborated by the author with data extracted from the research

numbers of cancer-related deaths in the country perpetuate this feeling. 10,15,22

Physical and/or mental comorbidities were reported as barriers by 19.7 percent of patients. Considering that cancer and oncological treatments can exacerbate previous illnesses, it becomes crucial for several medical specialties to act in an integrated manner. The lack of interconnected health systems in Belo Horizonte (and the region) can also pose challenges. Even within the Hospital das Clínicas, Universidade Federal de Minas Gerais (HC UFMG), communication between doctors and patients presents obstacles due to the need for computerized hospital records.

Deepening the data on quality of life, there was an increase in the median SCNS-SF34 score from 98.5 to 117.5 (p= 0.002) from project inclusion to follow-up, as seen in Table 16. However, the medians remained in the lowneed category. The scores found, in general, are consistent with the profile of patients who, despite having life-threatening illnesses, could still receive outpatient treatment with the prospect of disease control (no patient had a high need).

Furthermore, Table 18 provides descriptive statistics for the questionnaire on changes in health habits at baseline and follow-up. Regarding periodic health check-ups: after follow-up, there was a significant increase in patients reporting having more periodic health check-ups (from 24 at the study's inception to 46 at follow-up, approximately 53.8%). Concerning healthy eating habits: more patients reported consuming healthy foods at follow-up (from 23 at the study's inception to 41 at follow-up, approximately 67.3%). Regarding sun protection: a higher percentage of patients reported sunscreen at follow-up (from 12 at the study's inception to 25 at follow-up). Regarding other lifestyle habits, we did not obtain statistically significant data, which can be attributed to the number of patients to conclude such data.

When comparing habits between baseline and follow-up assessments, there was an increase in the habits of having periodic health examinations (53.8% versus 88.5%, p<0.01), taking vitamins and supplements (44.2% versus 82%, p<0.01), using sunscreen (23.1% versus 49%, p=0.011), avoiding exposure to the sun (30.8% versus 66.7%, p<0.001), and wearing clothes to protect themselves from the sun (36.5% versus 62.7%, p=0.008). This demonstrates that longitudinal follow-up led to awareness about adopting healthier lifestyle habits. However, there is still much room for optimization. For example, there was no improvement in drinking habits, smoking, weight loss, and physical activity. Controlling these habits after a cancer diagnosis is associated with lower rates of cancer recurrence and a lower incidence of second primary neoplasms. The healthcare team should actively encourage patients to adopt healthier habits.

Growing evidence links these modifiable risk factors (obesity, smoking, consumption, physical inactivity) to cancerrelated outcomes. This linkage has been extensively studied in common cancers such as breast, colon, prostate, and lung cancer through observational studies and is now being evaluated prospectively in interventional studies. Survivors are highly motivated to improve their overall health after a cancer diagnosis. Healthy lifestyle recommendations from oncology providers can be a reliable tool to motivate survivors to adopt health behavior changes. Ways to encourage these behavioral changes could be the adoption of educational booklets, periodic lectures within the outpatient clinic, and discussing the most challenging cases in multidisciplinary groups. It should be noted that changing habits can be challenging, especially for cancer patients,

without support from multidisciplinary teams.^{5,24,25}

During the project, an attempt was made to mitigate financial impacts that could contribute to increasing this discrepancy. were instructed about rights, which include withdrawal from the Severance Indemnity Fund for Length of Service (FGTS), withdrawal of PIS/PASEP (via Caixa Econômica Federal and Banco do Brasil), monthly sick pay for insured persons temporarily unable to work due to illness for more than 15 consecutive days, retirement in case of disability, assistance support (or Continuing Provision Benefit), and income tax exemption. Repayment of home financing (if provided for in the contract) was also discussed. 23

One of the main counterpoints that prevent adequate communication is that patients do not fully understand all the facts about the treatment, and medical information is not provided in a way that patients can understand. Patients believe that the doctor will tell them the essential facts about the treatment and do not ask questions, they are afraid to ask too many questions, and they are afraid to waste their time and not ask questions.

Table 19 presents descriptive statistics for the navigation satisfaction questionnaire at baseline and follow-up. The table displays the variables and the number of patients who indicated "Disagree/Neutral" or "Agree/ Fully agree" for each satisfaction aspect. Additionally, the table includes the overall rating of the browsing experience on a scale from 1 to 10. The key points to consider are the inclusion of patients as part of the treatment, described as "I felt included in decisions about my health," with 92.3% agreement at baseline and 98.1% agreement at follow-up. It also reinforces understanding concerning the statement: "I was able to get the advice/ answers I needed about my health issues/

questions," with 98.1% agreement at baseline and follow-up.

Furthermore, the statement: "I knew what the next step in my care would be" received a high percentage of agreement or complete agreement from patients, both at baseline (88.5%) and follow-up (98.1%). "I felt supported by my navigation": All patients agreed or fully agreed with this statement at baseline and follow-up (100%). This demonstrates how Navigation can be fundamental in welcoming and involving patients, transcending socioeconomic and cultural barriers.

Finally, patient satisfaction with patient navigation was measured, as described in Table 19. Both at baseline and at follow-up, the experience was reported as highly positive. The median overall score was ten at inclusion and nine afterward (p=0.003). Despite the statistically significant difference in this comparison, as both values were very high, it is impossible to infer that there was a worsening in the degree of satisfaction.

CONCLUSION

Patient navigation provides individualized support during the care of cancer patients, granting access to necessary treatment resources and implementing measures to enhance the quality of life.

Although the original study presents potential limitations, such as nonrandomization with the control arm being the historical cohort, difficulties in collecting data referring to the prospective study due to the lack of computerized medical records, and challenges posed by patients in answering questionnaires due to their low educational level, it is known that patient navigation is a valuable tool. It was first implemented in the 1990s, and its approaches are now capable of reducing social disparities in SUS patients with cancer. 26.27,28

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