

The Role and Contribution of Psychology in the Navigation of Oncology Patients

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Abstract: Introduction: Patient navigation (PN) is a model of care in which a professional helps the patients overcome difficulties during their treatment. Although established in oncology, the profession does not have regulations, and the training varies in each program. Data about navigators' formation is scarce, but nurses were the most prevalent professionals in a literature review. Since cancer patients can feel more imbued in expressing feelings, understanding, and coping with the disease, a psychologist could also be capable of navigating. **Objective:** Explore and recognize PN within the field of psychology. **Method:** A psychology student was selected for the project "Role of PN in improving time to start and finish radiotherapy (RT) in patients treated by the public health system in Belo Horizonte." Questionnaires to identify obstacles to the treatment were applied, and training granted by the Global Cancer Institute (GCI) guided the navigation. **Results:** From July 2018 to January 2020, 73 patients that needed RT were closely guided by weekly contacts, receiving help with documentation, appointment schedules, and information about their rights. Common points were difficulties in transportation, dialogue, and family support. As observed by caregivers, anxiety and stress levels were identified in all patients. As the treatment proceeded, there was a decrease in these levels (measured through questionnaires), with high rates of patient satisfaction with the navigator role ($\geq 9/10$ for all the patients). **Conclusion:** Beyond clinical care, the psychologist may exert other roles in an oncological team. This emphasizes the importance of psycho-oncology in core education and a new field of specialization due to its unique way of aiding patients' insecurities. In addition to initial training for skill development, an experienced and accessible institution such as GCI is essential to make navigators feel empowered and secure to perform their roles.

Key words: Patient navigation, psychology, clinical oncology.

1. Introduction

Patient Navigation (PN) is a patient-focused healthcare service delivery model. It is a concept centered on supporting the patient throughout their healthcare movement, including every step of this broad and diverse continuum, starting in the community and continuing through testing, diagnosis, and survival to the end of their life [1]. PN can overcome some obstacles that are often encountered, such as financial barriers, communication barriers (such as lack of understanding, language/culture), medical system barriers (fragmented medical system,

missed appointments, lost results), and psychological barriers (such as fear and distrust).

The conception of idea of navigation came from a retrospective study at the Harlem Hospital Center, in New York, in the United States of America, by Dr. Harold P. Freeman. The study was carried out with 708 patients with breast cancer, followed from January 1964 to December 1986 [2], demonstrating that the survival rate of black women was lower than that of white women. In 1989, the American Cancer Society (ACS), then chaired by Dr. Freeman, called public meetings, and the same conclusions as to mortality were found. The results were reported in a paper in which it was argued that underserved US populations received suboptimal health services [3].

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The navigation concept was then created to improve cancer care for the underprivileged.

The pioneering study by Dr. Freeman was performed at the same hospital in Harlem between 1995 and 2000. Historically, only 6% of patients with breast cancer were diagnosed at an early stage, with a median five-year survival rate for patients with this neoplasm of 39%. Between 1995 and 2000, 324 patients were followed up in a PN program in Harlem, with significant improvements in diagnosis (41% were diagnosed in early stages) and overall 5-year survival, from 39 to 70% [4]. A percentage of 87.5% of the patients underwent the recommended breast biopsies, compared to 56.6% of the non-navigated patients, also with an impact on the time taken to perform the biopsies [4, 5].

PN programs can overcome barriers, including cancer screening, as shown in several other studies [6-8], which even motivated US legislative changes. In 2005, the Patient Navigator Act (HOUR 1812) was signed into law in the United States [9], and since the first successful experience in Harlem, many other navigation programs have been initiated.

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

Nine principles related to PN were established, namely: patient-centered model focused on promoting continuity of care on time; ability to integrate a

fragmented and complex health system, showing a flow for the patient's journey; elimination of barriers as a primary function through the relationship based between the navigator and the patient; a clear definition of the role and responsibilities of the navigator, who must be integrated into the team that promotes patient care; cost-effective tool, including proper navigator training; navigator determination based on the necessary skills for that project, which can be a nurse, social worker or even a member of the community; definition of navigation start and end points; need to connect diverse health systems, including primary, secondary, tertiary and quaternary care services; need for project coordination [10]. Even today, PN is not a regulated profession. Even though several professionals can perform it, it is usually incorporated into the scope of nursing actions.

Even though it is a low-cost tool with high potential for use within public health systems, there is a scarcity of published data on PN for cancer treatment in Latin America (LA).

The Global Cancer Institute (GCI) is a non-profit organization operating worldwide, linked to Harvard University, and focused on improving survival rates and quality of life for patients diagnosed with cancer in vulnerable situations. The main objective of the GCI is to reduce the discrepancy between cancer deaths in underdeveloped countries compared to those in the United States through programs and interventions that can accelerate diagnosis, access, and cancer treatments in low- and middle-income countries (LMICs) [11].

In the Brazilian context, the PN may represent an opportunity to implement existing legislation properly and, as such, would have great potential for integration into federal, state, and local health systems.

Given the GCI's previous experience with PN and the need for better access to radiotherapy treatment for cancer patients at HC UFMG, academic cooperation

was established to develop a PN program.

2. Methodology

In June 2018, after approval of the project: “Role of Patient Negotiation in Improving the Deadlines for Starting and completing definitive radiotherapy treatment in the public health system of Belo Horizonte, a selection was opened for a scholarship intern for the project.” Students from undergraduate courses in health (speech therapy, social work, nursing, and psychology), duly enrolled and with satisfactory school performance, were evaluated.

Training provided by the Global Cancer Institute (GCI) was planned, based on theoretical classes and simulation of clinical cases, based on previous experiences of the Institution. In addition, the intern would have adequate time to familiarize herself with the questionnaires applied to patients during the project.

The original questionnaires (created by the GCI and modified for this research) collected primary sociodemographic data, clinical data, and patient satisfaction. They were answered directly on tablets at the time of patient enrollment in the study. The data-informed about the navigation process helps to understand the patients’ barriers, social situations, and attitudes towards the program and establish actions to overcome the identified obstacles.

On the date of inclusion of the patient in the study, in addition to the application of the questionnaires, a conference was held to verify that the patient had all the documentation necessary to carry out the radiotherapy treatment, including identity document, National Register of Individuals (CPF), proof of address, SUS card, biopsy report and medical report indicating Radiotherapy (RT). If the patient did not present any of these documents, the navigator would advise how to acquire them.

After checking the documentation, the patient was instructed to take the documentation to the Municipal Commission of Oncology (CMO) (resident of Belo

Horizonte) or the Health Department of the city of origin. In the first contact, the patient could also receive clarification on the rights of cancer patients, especially those that could directly impact treatment adherence.

After inclusion in the project and these first guidelines, telephone contacts were made at least once a week until the end of treatment. If during these weekly contacts, an obstacle was identified, monitoring was intensified through even daily connections with patients and their families, CMO, RT services and health secretariats, assistant physicians, Halfway houses, social services, and non-governmental organizations (NGOs). The direction of the contact occurred according to the identified obstacle. In addition, an open and free-demand communication channel was established so the patient could make contact if necessary.

Patients should be followed up until the end of the radiotherapy treatment when information about the quality of life is collected and final instructions are given. The visits for the project were reconciled with consultations previously scheduled at the Borges da Costa Ambulatory by the assistant oncologist to avoid further patient displacements. The patient could be contacted again later to collect survival data, but he maintained follow-up with his assistant team, with intervals and exams defined by the same.

The present work aims to explore and recognize NP in psychology through pre-specified sub analyses of the original project [12].

3. Results

After evaluating the curricula during the interview phase, a psychology student was identified as having the best educational profile for the project during the interview phase. Thus, the bond and training were established (as described in the methodology).

A total of 73 patients were prospectively evaluated for inclusion in the study from July 2018 to January 2020, of which 71 were included. The study was

positive for its primary endpoint: PN reduced the median time from biopsy result to initiation of RT by 34 days (108 days X 74 days, $p < 0.001$), which may be clinically relevant [12].

Among the barriers found by the PN's barriers, more than half of the patients (56.3%) reported fear as an obstacle. Communication difficulties with the medical team and the low level of education can negatively impact the understanding of medical

information. Employment issues were reported by 35.2% of patients, and financial problems by 31%. Physical and mental comorbidities were reported by 19.7% of patients (Table 1).

Finally, patient satisfaction with the PN was measured. At both baseline and follow-up, the experience was reported as highly positive. The median global score was 10 at inclusion and 9 afterward.

Table 1 Main barriers cited by patients in the prospective study.

Barrier	Proportion of people n (%)
Lack of transportation	43 (60.6%)
Fear	40 (56.3%)
Social support	36 (50.7%)
Communication with the medical team	29 (40.8%)
Financial Problems	25 (35.2%)
Employment issues	22 (31%)
Literacy	15 (21.1%)
Physical or mental comorbidities	14 (19.7%)
Others	22 (31%)

Font: elaborated by the author with data extracted from the research.

4. Discussion

The lack of integration of the system as a whole, associated with a lack of information on the part of patients and difficulties in accessing them, can contribute to delays in starting treatment. Furthermore, the lack of awareness about the importance of treatment adherence also contributes to absenteeism, which can result in worse oncological outcomes.

If patients were more aware of the importance of their attendance and consultations were confirmed, absenteeism would probably decrease. Among all its positive aspects, PN is undoubtedly associated with better adherence, and if it were implemented more widely, it would bring gains in this context.

Continuing with the obstacles, more than half of the patients (56.3%) reported fear as an obstacle. Depending on their clinical condition, the individual can reverse the neoplastic condition by performing the appropriate treatment of RT, chemotherapy, or surgery. However, even with medical care, this disease still has

many deaths. That is why the disease causes feelings of fear and anxiety [13]. Both fear and anxiety are aggravated by the fact that cancer is a feared disease due to its history of treatment, which can even weaken the individual. During the experience of the diagnostic and therapeutic itinerary, people with cancer experience negative feelings and many difficulties. However, some factors make it possible to reframe the illness and need to be considered by health professionals and managers to minimize the impact of the disease during this journey [14].

Almost half (41.4%) of the patients who underwent the navigation process reported communication difficulties with the medical team. Given patient and family involvement differences, communication about concerns and decision-making is essential during all cancer treatment and supportive care phases. Studies show many positive outcomes exist when patients and doctors communicate well during cancer treatment. Patients are generally: more satisfied with the care, more likely to follow through with treatment, and

more inclined to participate in clinical trials when available [15]. Among the contexts that prevent adequate doctor-patient communication, the following can be mentioned: 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.

Regarding the project's patients, the low level of education (21.1% reported literacy deficits) can negatively impact the understanding of medical information. Some strategies can improve communication, such as: keeping a notebook with the patient's medical information; pre-list questions and concerns; taking notes during the consultation to be consulted later; bring a family caregiver or friend to the appointment so they can remember important information after the visit.

5. Conclusions

Besides clinical care, the psychologist can perform other functions in an oncology team. This emphasizes the importance of psycho-oncology in primary education and a new field of specialization due to its unique way of helping patients' insecurities. In addition to initial training to develop skills, the presence of an experienced and accessible institution such as the GCI is significant for sailors to feel empowered and confident to carry out their duties.

Navigation strategies can have an important impact on LA, including Brazil, where care is still fragmented despite expanding access to health. Data recording has improved dramatically in the region, but most countries still have, at best, only a partial idea of the cancer challenge they face and how it is evolving.

References

- [1] Freeman, H. P. 2012. "The Origin, Evolution, and Principles of Patient Navigation." *Cancer Epidemiol Biomarkers Prev* 21 (10): 1614-7.
- [2] Freeman, H. P., and Wasfie, T. G. 1989. "Cancer of the Breast in Poor Black Women." *Cancer* 63 (12): 2562-9.
- [3] AMERICAN CANCER SOCIETY. 1989. "A Summary of the American Cancer Society Reports to the Nation: Cancer in the Poor." *CA Cancer J Clin* 39 (5): 263-8.
- [4] Freeman, H. P. 2006. "Patient Navigation: A Community-based Strategy to Reduce Cancer Disparities." *J Urban Health* 83 (2): 139-41.
- [5] Freeman, H. P., Muth, B. J., and Kerner, J. F. 1995. "Expanding Access to Cancer Screening and Clinical Follow-up among the Medically Underserved." *Cancer Pract* 3 (1): 19-30.
- [6] Nash, D., Azeez, S., Vlahov, D., & Schori, M. 2006. "Evaluation of an Intervention to Increase Screening Colonoscopy in an Urban Public Hospital Setting." *J Urban Health* 83 (2): 231-43.
- [7] Raich, P. C., Whitley, E. M., Thorland, W., et al. 2012. "Patient Navigation Improves Cancer Diagnostic Resolution: An Individually Randomized Clinical Trial in an Underserved Population." *Cancer Epidemiol Biomarkers Prev* 21 (10): 1629-38.
- [8] Markossian, T. W., Darnell, J. S., and Calhoun, E. A. 2012. "Follow-up and Timeliness after an Abnormal Cancer Screening among Underserved, Urban Women in a Patient Navigation Program." *Cancer Epidemiol Biomarkers Prev* 21 (10): 1691-700.
- [9] Patient Navigator Outreach and Chronic Disease Prevention Act of 2005. Available at: <https://www.congress.gov/109/plaws/pub118/PLAW-109-publ118.pdf>. Accessed on: 27 Sept. 2019.
- [10] Vargas, R. B., Ryan, G. W., Jackson, C. A., et al. 2008. "Characteristics of the Original Patient Navigation Programs to Reduce Disparities in the Diagnosis and Treatment of Breast Cancer." *Cancer* 113 (2): 426-33.
- [11] The Global Cancer Institute. Available at: <http://globalcancerinstitute.org>. Accessed on: 1st Jul. 2017.
- [12] Vieira, C. M., Diniz, P. H. Z., Dizon, D. S., & Nogueira-Rodrigues, A. 2023. "Patient Navigation (PN) Support to Timely Access to Radiotherapy in the Brazilian Public Health System." *Support Care Cancer* 31 (3): 182. doi: 10.1007/s00520-023-07615-8.
- [13] Correa, A. C. C., Maia, T. S., and Pereira, T. B. 2018. "Coping Strategies Used as Resources to Reduce Fear and Anxiety Caused by Oncological Treatment: Literature Review." *Hos Pal Med Int Jnl* 2 (2): 82. doi: 10.15406/hpmij.2018.02.00060.
- [14] Teston, E. F., Fukumori, E. F. C., dos Santos Benedet, G. M., et al. 2018. "Feelings and Difficulties Experienced by Cancer Patients Along the Diagnostic and Therapeutic Itineraries." *Escola Anna Nery* 22 (4): e20180017. doi:

10.1590/2177-9465-EAN-2018-0017.

- [15] NATIONAL CANCER INSTITUTE. Communication in Cancer Care (PDQ[®])—Patient Version. National Cancer

Institute, 27 Mar. 2015. Available at: <https://www.cancer.gov/about-cancer/coping/adjusting-to-cancer/communication-pdq>. Accessed on: 15 Jun. 2019.