Patient Navigation to Improve Access to Breast Cancer Care in Brazil

Alexandra Bukowski
Sandra Gioia
Yanin Chavarri-Guerra
Enrique Soto-Perez-de-Celis
Jessica St. Louis
Eduardo Paulino
Angelica Nogueira-Rodrigues
Paul E. Goss

Author affiliations and support information (if applicable) appear at the end of this article.

Corresponding author: Paul E. Goss, MD, PhD, Avon Breast Cancer Center of Excellence, Massachusetts General Hospital Cancer Center, 55 Fruit St, Lawrence House, Boston MA 02114; e-mail: pgoss@mgh.harvard.edu.

Noncommunicable diseases, such as cancer, are surpassing infectious diseases as the most pressing health care threat in low- and middle-income countries (LMICs).[1] By 2025, 59% of new cancer cases and 68% of all cancer deaths will occur in LMICs,[2] and health care systems in these countries are struggling to respond to this changing landscape.[3] In Brazil, breast cancer is the most common cancer and the leading cause of cancer death among women, with 14,206 deaths in 2013[4] and 57,960 new cancer diagnoses estimated for the year 2016.[5]

Recognizing the need for cancer control strategies, the Brazilian government issued Ministry of Health Law No. 12.732/12, also called the Law of 60 Days, in 2012. This law states that treatment of any cancer for patients in the public health system must start within 60 days of definitive diagnosis.[6] Shortly after the Law of 60 Days was enacted, the Cancer Information System (or SISCAN, the Brazilian acronym) was instituted to monitor the implementation of the law by tracking patient treatment times, appointments, diagnostic tests, and targets and indicators for future cancer control actions.[7] However, even years after the institution of the law, a large proportion of patients still do not receive timely treatment, and SISCAN has not been effectively used. Innovative solutions are needed to ensure that the law is properly implemented. In this context, an intervention such as patient navigation (PN) could potentially allow for appropriate implementation of the law.[8] Although PN programs have shown demonstrable success among underserved populations in the United States, their global implementation has been limited. Here, we discuss the potential role of PN in alleviating health system barriers and supporting adherence to the Law of 60 Days in Brazil, which in turn could improve the outcomes of women with breast cancer throughout the country.

HEALTH SYSTEM DELAY IN BRAZIL

A delay in breast cancer care leads to more advanced stages at presentation and worse survival.[9] Delay can be divided into the following two intervals: a patient interval and a health system interval. The health system interval—the time between first consultation and treatment initiation—is significantly longer in LMICs compared with high-income countries (HICs; Fig 1).[10] For example, whereas HICs report a median health system interval of 10 to 42 days for patients with breast cancer, the median interval reported in Mexico City is 5 months.[11] Other studies from Brazil and Mexico show that it takes a patient with breast cancer between 6 and 7 months to receive a definitive diagnosis after her first consultation with a physician.[3] A study from Rio de Janeiro, Brazil, found that the median time from first consultation to diagnosis was 6.5 months and that 80% of patients experienced a health system delay of more than 3 months.[12]

In LMICs, long delays frequently result in clinical upstaging. In the United States, 60% of breast cancers are diagnosed at an early stage of disease, whereas in Brazil, this is true for only 20% of breast cancer diagnoses.[3] In a study of 87,969 Brazilian women with breast cancer, 53.5% were considered to have advanced-stage disease (≥ stage IIB).[13] In another study cohort, 78.8% of women had stage II to IV breast cancer.[14] The latest report from the Breast Health Global Initiative highlighted the importance of clinical downstaging and developed guidelines for the early detection, diagnosis, and treatment of breast cancer to ultimately reduce mortality.[15]

Even within Brazil, staging and survival statistics vary according to sociodemographic characteristics, such as type of health insurance.[16-19] There are two insurance modalities within the Brazilian health care system; insurance can be obtained through the public system, Sistema Único de Saúde, or through private providers. Approximately 75% of Brazilians receive coverage solely through Sistema Único de Saúde, and although progress toward universal health coverage has been made throughout the country, large disparities affecting cancer care remain.[20] Women treated in the public system present with more advanced disease than women in the private sector, and public sector patients have worse cancer-specific, disease-free, and overall survival (which can be partially attributed to longer delays

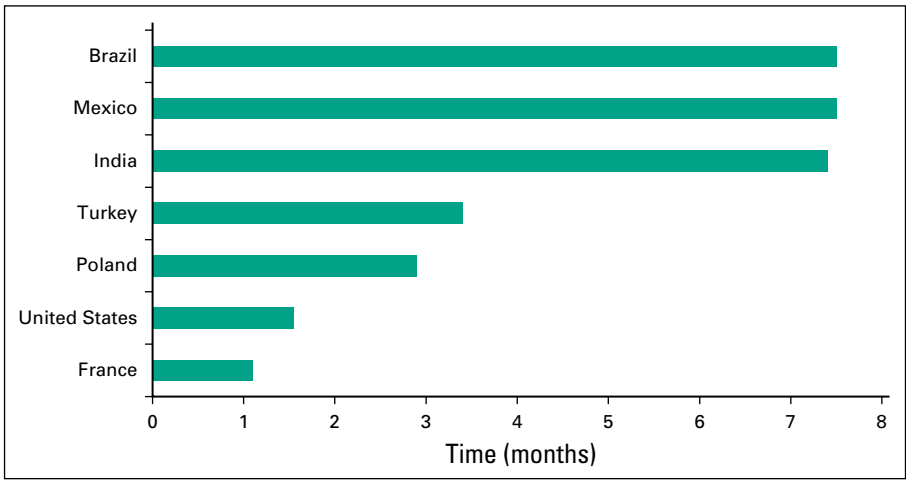

Fig 1. Median interval between problem identification (through symptom discovery or abnormal screening) and treatment start for patients with breast cancer. Data adapted.[10]

and advanced stages at diagnosis).[16-19] The negative impact of delays on the prognosis of patients with cancer within the public sector is so relevant that the Brazilian Ministry of Health enacted the aforementioned Law of 60 Days.[6] Although this law is an important and well-intentioned effort to begin to reduce health system delays, surveillance of its implementation has been deficient.

To monitor the law's application, the Ministry of Health in Brazil created the cancer database SISCAN. However, a survey of representatives from 59 public health institutions throughout Brazil showed that SISCAN is being used in only one quarter of Brazilian municipalities and that only approximately 1% of all patients with cancer had been registered in the system as of July 2014, almost 2 years after the announcement of the law.[7] In addition, a 2015 study that collected data from 239 hospitals throughout Brazil showed that approximately 40% of patients with breast cancer failed to initiate treatment within the mandated 60-day period.[13] This statistic varies widely by region, with the state of Rio de Janeiro reporting more than 70% of women failing to initiate treatment within the 60-day mandate.[7]

POTENTIAL ROLE OF PN IN BRAZIL

PN is designed to address health disparities and alleviate institutional, socioeconomic, and personal barriers to timely cancer care. Patient navigators are trained health care workers who facilitate a patient's passage through the health care system by providing services such as scheduling diagnostic and follow-up appointments, facilitating health system referrals, and coordinating communication between patients and health care professionals.[8,21]

First pioneered in New York City's Harlem district in the 1990s, PN was designed to improve timely access to cancer care among African American, Hispanic, and poor patients with low educational levels. The program achieved impressive results, improving the 5-year survival rate for breast cancer from 39% to 70% in the target population.[22] Subsequent studies have proven that PN can improve times to diagnostic resolution[21,23,24] and treatment,[25] reduce loss to follow-up rates[26-29] and health disparities,[30,31] and improve patient education.[26] For instance, in one study, PN programs reduced no-show rates for cancer follow-up screening by providing targeted education to patients.[26] In another study, patients receiving PN were more likely to attend all regular medical visits compared with those who did not receive PN[27] and had significantly shorter times to screening and diagnostic resolution.[23] Additionally, PN results in significantly lower rates of missed appointments, shorter follow-up times, and a decrease in the severity of cervical abnormalities,[28] as well as increased screening rates and improved equity in vulnerable patients.[30] Finally, studies have also shown a decrease in time to diagnosis for women navigated because of an abnormal Papanicolaou test[21] and shorter times from an abnormal cancer screen to a definitive diagnosis for underserved patients with breast and cervical cancer.[24]

Despite the great success of PN among underserved populations in the United States, PN has not been widely studied in LMICs. Patients in LMICs face structural barriers that are similar to those faced by underserved patients in the United States. In LMICs, urban poor, rural, remote, and indigenous populations often cannot access timely cancer care because of lack of awareness, complex and fragmented health care systems, low socioeconomic status, cultural barriers, and limited funding and human resources in public

institutions.[3] PN has already proven to be a valuable tool for tackling these barriers in the United States, and it could potentially be tailored and implemented to do the same in LMICs.

An ongoing study by our group, the Global Cancer Institute, in the Mexico City metropolitan area aims to establish proof of implementation of PN for patients with cancer within the public health system in Mexico. Mexico City is a large metropolis with a fragmented health care system, which makes referrals between centers complex. As a result of this fragmentation, patients often experience long health system delays, with one study finding the median interval from breast cancer identification to start of treatment to be 7 months.[11] In our study, a navigator is located at a secondary-level hospital and navigates patients with a suspected or confirmed diagnosis of cancer through the health care system, helping the patients to arrive at a tertiary care center for appropriate diagnosis and treatment. Results and lessons from this study in Mexico City will help us understand the feasibility and acceptability of PN in Latin America and guide the creation and adaptation of future PN sites throughout the region.

We previously proposed an action agenda aimed at successfully implementing PN in LMICs in general,[8] and this same agenda could be applied in the Brazilian context to guide implementation of PN in the country:

1. Target gaps in infrastructure. The timely initiation of treatment after a diagnosis of cancer is a major gap in cancer care delivery in Brazil. The Ministry of Health has already acknowledged this issue by passing the Law of 60 Days, but the impact of the law has been low. The aforementioned survey of 59 Brazilian public health institutions revealed that nearly half of all responders cited difficulties in the referral and follow-up of patients within the public health system.[7] Local PN programs should be designed to target delays in the health system interval of breast cancer care and promote total adherence to the Law of 60 Days.
2. Use a customizable protocol and training program. By using a template protocol designed in accordance with PN studies in the United States and implemented in our Mexico City site, the Brazilian PN program could be customized to address gaps in diagnosis and treatment pathways for public patients in Brazil. As one responder to the Brazilian survey stated: "One law does not alter the care and treatment of cancer; (the law's implementation) requires training, resources, and knowledge of the reality of each location."[7] We have also designed a customizable training program aimed at providing local navigators and health care workers with knowledge of both the general principles of PN and site-specific issues. Both the protocol and the training program include tools to collect data specific to the study's goals.
3. Engage policymakers. Because one of the goals of proof-of-implementation PN programs is to influence health care authorities and hospital administrators to integrate PN into the existing health system infrastructure, policymakers are engaged in our PN programs during the planning and implementation phases. This is essential, because PN should not be seen as an additional expense for health care systems, but as an opportunity for the reallocation of funds, focusing on use of scarce resources in prevention and early treatment, rather than late-stage disease. Within the Brazilian context, PN could represent an opportunity to implement the existing legislation appropriately, and as such, it would have a great potential for integration into the federal, state, and local health systems.

Implementing a breast cancer PN program in Brazil, which would reflect the lessons learned in studies from the United States and in our pilot project in Mexico City, has great potential to alleviate the barriers faced by patients in the public sector. By promoting adherence to the Law of 60 Days, PN could shorten the time to the start of cancer treatment, reduce loss to follow-up, and improve the outcomes of women with breast cancer in Brazil.

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Alexandra Bukowski
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Jessica St. Louis
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Eduardo Paulino
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Angelica Nogueira-Rodrigues
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Paul E. Goss
No relationship to disclose

Affiliations

Alexandra Bukowski, **Jessica St. Louis**, and **Paul E. Goss**, Avon International Breast Cancer Research Program, Massachusetts General Hospital; **Alexandra Bukowski**, **Sandra Gioia**, **Yanin Chavarri-Guerra**, **Enrique Soto-Perez-de-Celis**, **Jessica St. Louis**, **Eduardo Paulino**, **Angelica Nogueira-Rodrigues**, and **Paul E. Goss**, The Global Cancer Institute, Boston, MA; **Sandra Gioia** and **Eduardo Paulino**, Instituto Nacional de Câncer José Alencar Gomes da Silva; Rio de Janeiro; **Angelica Nogueira-Rodrigues**, Federal University of Minas Gerais, Belo Horizonte, Brazil; and **Yanin Chavarri-Guerra** and **Enrique Soto-Perez-de-Celis**, Instituto Nacional de Ciencias Médicas y Nutrición Salvador Zubirán, Mexico City, Mexico.

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REFERENCES

1. WHO: Global status report on noncommunicable diseases 2010. http://apps.who.int/iris/bitstream/10665/44579/1/9789240686458_eng.pdf
2. Ferlay J, Soerjomataram I, Ervik M, et al: GLOBOCAN 2012 v1.0, Cancer Incidence and Mortality Worldwide: IARC CancerBase No. 11. http://globocan.iarc.fr
3. Goss PE, Lee BL, Badovinac-Crnjevic T, et al: Planning cancer control in Latin America and the Caribbean. Lancet Oncol 14:391-436, 2013
4. Instituto Nacional de Câncer (Brasil): Estatísticas do câncer: Mortalidade. http://www1.inca.gov.br/vigilancia/mortalidade.asp
5. Instituto Nacional de Câncer (Brasil): Estimativa 2016: Incidência de câncer no Brasil. http://www.inca.gov.br/estimativa/2016/sintese-de-resultados-comentarios.asp
6. Presidência da República: Lei No. 12.732, de 22 de Novembro de 2012. http://www.planalto.gov.br/ccivil_03/_ato2011-2014/2012/lei/l12732.htm
7. Federação Brasileira de Instituições Filantrópicas de Apoio à Saúde da Mama: Pesquisa: A implementação da Lei dos 60 dias. http://www.femama.org.br/novo/arquivos/audiencia_publica_pesquisa_60_dias.pdf
8. Bukowski A, Chávarri-Guerra Y, Goss PE: The potential role of patient navigation in low- and middle-income countries for patients with cancer. JAMA Oncol 2:994-995, 2016
9. Richards MA, Westcombe AM, Love SB, et al: Influence of delay on survival in patients with breast cancer: A systematic review. Lancet 353:1119-1126, 1999
10. Unger-Saldaña K: Challenges to the early diagnosis and treatment of breast cancer in developing countries. World J Clin Oncol 5:465-477, 2014
11. Unger-Saldaña K, Miranda A, Zarco-Espinosa G, et al: Health system delay and its effect on clinical stage of breast cancer: Multicenter study. Cancer 121:2198-2206, 2015
12. Rezende MC, Koch HA, Figueiredo Jde A, et al: Factors leading to delay in obtaining definitive diagnosis of suspicious lesions for breast cancer in a dedicated health unit in Rio de Janeiro [in Portuguese]. Rev Bras Ginecol Obstet 31:75-81, 2009

13. Medeiros GC, Bergmann A, Aguiar SS, et al: Determinants of the time between breast cancer diagnosis and initiation of treatment in Brazilian women [in Portuguese]. Cad Saude Publica 31: 1269-1282, 2015
14. Barros AF, Uemura G, de Macedo JL: Interval for access to treatment for breast cancer in the Federal District, Brazil [in Portuguese]. Rev Bras Ginecol Obstet 35:458-463, 2013
15. Anderson BO, Yip CH, Smith RA, et al: Guideline implementation for breast healthcare in low-income and middle-income countries: Overview of the Breast Health Global Initiative Global Summit 2007. Cancer 113:2221-2243, 2008 (suppl 8)
16. Liedke PE, Finkelstein DM, Szymonifka J, et al: Outcomes of breast cancer in Brazil related to health care coverage: A retrospective cohort study. Cancer Epidemiol Biomarkers Prev 23: 126-133, 2014
17. Guerra MR, Silva GA, Nogueira MC, et al: Breast cancer survival and health iniquities. Cad Saude Publica 31:1673-1684, 2015
18. Soares PB, Quirino Filho S, de Souza WP, et al: Characteristics of women with breast cancer seen at reference services in the North of Minas Gerais. Rev Bras Epidemiol 15:595-604, 2012
19. Balabram D, Turra CM, Gobbi H: Survival of patients with operable breast cancer (stages I-III) at a Brazilian public hospital: A closer look into cause-specific mortality. BMC Cancer 13:434, 2013
20. Lee BL, Liedke PE, Barrios CH, et al: Breast cancer in Brazil: Present status and future goals. Lancet Oncol 13:e95-e102, 2012
21. Battaglia TA, Bak SM, Heeren T, et al: Boston Patient Navigation Research Program: The impact of navigation on time to diagnostic resolution after abnormal cancer screening. Cancer Epidemiol Biomarkers Prev 21:1645-1654, 2012
22. Freeman HP: Patient navigation: A community-centered approach to reducing cancer mortality. J Cancer Educ 21:S11-S14, 2006 (suppl 1)
23. Raich PC, Whitley EM, Thorland W, et al: Patient navigation improves cancer diagnostic resolution: An individually randomized clinical trial in an underserved population. Cancer Epidemiol Biomarkers Prev 21:1629-1638, 2012
24. Markossian TW, Darnell JS, Calhoun EA: Follow-up and timeliness after an abnormal cancer screening among underserved, urban women in a patient navigation program. Cancer Epidemiol Biomarkers Prev 21:1691-1700, 2012
25. Freund KM, Battaglia TA, Calhoun E, et al: Impact of patient navigation on timely cancer care: The Patient Navigation Research Program. J Natl Cancer Inst 106:dju115, 2014
26. Luckett R, Pena N, Vitonis A, et al: Effect of patient navigator program on no-show rates at an academic referral colposcopy clinic. J Womens Health (Larchmt) 24:608-615, 2015
27. Jabson JM: Treatment summaries, follow-up care instructions, and patient navigation: Could they be combined to improve cancer survivor's receipt of follow-up care? J Cancer Surviv 9:692-698, 2015
28. Percac-Lima S, Benner CS, Lui R, et al: The impact of a culturally tailored patient navigator program on cervical cancer prevention in Latina women. J Womens Health (Larchmt) 22:426-431, 2013
29. Percac-Lima S, Cronin PR, Ryan DP, et al: Patient navigation based on predictive modeling decreases no-show rates in cancer care. Cancer 121:1662-1670, 2015
30. Percac-Lima S, López L, Ashburner JM, et al: The longitudinal impact of patient navigation on equity in colorectal cancer screening in a large primary care network. Cancer 120:2025-2031, 2014
31. Percac-Lima S, Ashburner JM, Bond B, et al: Decreasing disparities in breast cancer screening in refugee women using culturally tailored patient navigation. J Gen Intern Med 28:1463-1468, 2013