Argentina's National Program for Control of Breast Cancer: Time 1, Patient Navigation, and Patient Cancer Education Experience

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Abstract

Argentina has the second highest mortality rate for breast cancer (BC) in South America. The age-standardized incidence of BC in Argentina is 73 per 100,000. Despite the availability of early detection services, 30% of BCs are diagnosed at advanced disease stages. The National Cancer Institute (NCI) of Argentina and the National Program for Control of Breast Cancer (NPCBC) focus on two main objectives: guaranteeing adequate and timely BC treatment and reducing BC mortality in Argentina. These objectives are addressed by maintaining three core concepts: quality control, disease monitoring, and wide coverage of available early detection and treatment services. The NPCBC is currently implementing the “Time 1 Survey Study.” Time 1 is defined as the time from the first appearance of BC signs or symptoms to the first consult within the public healthcare system. This timeframe is important in Argentina because it is outside of the health timeframes and data parameters monitored by the national cancer data registry system. The Time 1 Survey study has the potential to serve as an informational tool for BC patient navigation efforts in Argentina because it can be used to identify and characterize the barriers and delays that women face during Time 1. Lessons and experiences included in this study could be translated to other Latin American and middle-income countries for developing cancer control programs that can lead to improving treatment and reducing mortality through patient navigation and cancer education efforts for the public, health professionals, and patients.

Keywords Breast cancer · Time 1 · Patient navigation · Argentina · Latin America · Barriers · Cancer education

Overview

Breast Cancer in Argentina

Breast cancer (BC) is a global health problem. Among women in Latin America, the most common cancer is BC; with the highest rates of this disease found in South America [1]. Uruguay currently has the highest BC mortality rate in South America, while the mortality rate in Argentina comes at a close second. Argentina's BC mortality rate accounts for approximately 6380 deaths per year [2]. Furthermore, the age-standardized incidence of BC in Argentina is 73 per 100,000, which is the highest BC incidence in the South American continent [2]. In 2017, the province of San Luis had the highest BC mortality rate in Argentina, 23 per 100,000, while the capital city of Buenos Aires had a BC mortality rate of 19 per 100,000 [3, 4].

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Breast Cancer Services Provided by the National Cancer Institute of Argentina and the Argentinian Public Healthcare System

Argentina's current efforts to control and decrease BC mortality rates focus on early detection and provision of appropriate and timely treatment to individuals diagnosed with the disease [4]. The National Cancer Institute (NCI) of Argentina, a specialized department of the National Health Ministry, was established in 2010 to focus on cancer as an important public health problem in the country [5]. Following establishment of the NCI, the National Program for Control of Breast Cancer (NPCBC) was implemented in 2013 to reduce BC mortality rates. Since its establishment, the three core concepts of the NPCBC have included quality control, disease monitoring, and coverage of treatment and prevention services. Accordingly, the main objectives of the NCI of Argentina include guaranteeing adequate and timely cancer treatment and decreasing cancer mortality. In order to address BC, the NPCBC adheres to the Institute's objectives and its own three core concepts by providing information to the general public, training and certifying health professionals in BC early detection, maintaining BC data and monitoring BC trends within the national data registry system, offering data registry training and validation of data to other health and public health institutions, providing certification of breast imaging services, auditing for quality control of treatment protocols, and performing evaluation research focused on the implementation of public health programs and interventions [4–6].

The NPCBC in Argentina is considered to be effective because its core concepts and general makeup overlap with the breast healthcare guidelines for early detection, established by the Breast Health Global Initiative (BHGI) [7]. The current NPCBC team consists of individuals from various professions, including health and non-traditional health professionals such as sociologists and anthropologists, who are recommended by the BHGI for inclusion in public health programs, because of their expertise in community conversations and barrier identification [7].

At the national level, the Argentinian healthcare system provides free access to the services delineated by the BHGI at three distinct levels, defined as basic, limited, and enhanced services. Some of the services provided include cataloging of histories of BC symptoms, targeted educational information, physical examinations, diagnostic imaging, opportunistic screening through mammography, and biopsy [4, 7]. Specific to breast healthcare, the NPCBC recommends breast cancer screening through mammography, at least once every 2 years, for women of ages 50–69 (Argentina's target age group for preventive and screening efforts), who are asymptomatic and do

not have cancer antecedents [4]. Women under age 50 or over 69 years old are advised to discuss with their doctor in order to make a personalized decision as to whether to screen or not [4]. Screening through mammography of high-risk women under 50 years of age is also recommended [4]. The Argentinian public healthcare system covers the cost for screening through mammography and access to clinical breast exams for all women [4].

Despite the provision of preventive and early diagnostic services, about 30% of BC cases, detected in the Argentinian public healthcare system, are diagnosed at advanced stages of the disease [4]. According to Surveillance, Epidemiology, and End Results Program (SEER) data, about 30% of BC cases in the USA are also diagnosed at regional stages, meaning that the cancer has spread to the regional lymph nodes [8]. This trend of delayed diagnoses is of significant concern because the stage at which BC is diagnosed reflects the knowledge, attitudes, and practices of patients, healthcare providers, and underlying systemic characteristics of entire healthcare systems [9]. The knowledge, attitudes, and practices of the aforementioned parties come together to create barriers that hinder early detection and reduce access to appropriate healthcare services [4]. The stage of diagnosis is also an important predictor of the 5-year survival of women diagnosed with BC [4, 8, 9]. Patients diagnosed at advanced stages show not only lower survival rates but also require more aggressive treatments and surgeries [4, 9]. For this reason, research that characterizes the causes of late diagnosis needs to be prioritized and the National Cancer Institute of Argentina has assigned a high priority to completing this task.

Introduction to Time 1 and Time 1 in the Argentinian context

In an effort to address the aforementioned objectives and program specific core concepts, and in response to the results obtained from two previous Argentinian studies (described below), the NCI of Argentina expanded upon a survey that aimed to analyze the experiences that Argentinian women faced during Time 1 (T1). T1 is defined as the time from the first appearance of BC signs or symptoms to the first medical consult within the public healthcare system. This has been identified as the “patient delay” timeframe in other published cancer literature [9]. Patient delay and system delay are both factors leading to late diagnosis; yet research into these two timeframes is extremely limited [9]. The characterization of patient and system delay is important because presently, the delay of diagnosis is most often attributed to the patient's failure to present to the healthcare system within an optimal timespan [9]. In reality, the causes of diagnostic delay are complex and highly interrelated and cannot be clearly defined by this correlation. In this regard, more needs to be

done to adequately characterize the barriers that constitute and perpetuate patient delay or T1 delay and system delay, including the intersection of the two, and the resulting delay of diagnosis.

Argentina has identified patient delay and system delay as public health issues, both leading to diagnostic delays. In the case of BC in Argentina, T1 is of particular importance because it lies outside of the health timeframes and data parameters measured and monitored by the national cancer data registry system, known as SITAM (Sistema de Información de Tamizaje; English translation: Screening Information System).

The process to obtain a first consult often involved women seeking care through consultation with a breast health specialist, generalist, or a gynecologist at a public hospital, as this option is available for all those seeking breast healthcare in Argentina. Also in some instances, women sought consultation at an outpatient healthcare clinic. Women were then referred for diagnostic studies. In most hospitals or cancer centers, women did not have access to mammography and/or ultrasound services without a doctor's order. In a limited number of public healthcare settings, women may have a screening mammogram done without a medical referral. At these institutions, women show documentation to establish that they are within the 50–69 target age group for breast cancer screening. If documentation is not available, a data base search can also confirm the age of those women seeking screening. In addition, it was also not uncommon in the hospital setting for medical professionals not specializing in breast health to refer patients to a breast health specialist along with their order for a mammography or ultrasound screening, so as not to miss this window of opportunity. Thus, obtaining a first consult could happen through multiple means, depending on individual circumstances. This emphasizes the importance of characterizing the experiences of patient delay or Time 1 along with system delay. Both patient delay and system delay are depicted below in Fig. 1. The figure illustrates the areas in which patient delay and system delay possibly intersect. If this framework is used to analyze all cancer healthcare timeframes, the intersection point of patient delay and system delay can raise questions as to where barriers to timely cancer diagnosis and adequate cancer treatment exist and/or persist due to the lack of translational problem-solving efforts within healthcare and public health systems.

What Determined the Relevance of the T1 Timeframe in Argentina?

The relevance of the T1 timeframe in BC diagnosis and treatment delays was examined in two previous Argentinian studies [10–12]. The main objective of these studies was to evaluate the delays and barriers experienced during the first

medical consultation, diagnosis, and treatment of Argentinian women with BC.

The first retrospective study by Mignini et al. used quantitative and qualitative methods to characterize the delays and barriers present since the women's first contact with the healthcare system as well as those faced throughout their diagnosis and treatment [10]. This was analyzed by dividing women's trajectories within the healthcare system into four different timeframes.

The four timeframes were defined as follows: Time 1 (T1), the time from the first appearance of signs or symptoms to the date of the first consult, mammography and/or ultrasound [10]. Time 2 (T2), the time from the date of mammography and/or ultrasound until the date of biopsy which confirmed the diagnosis of BC [10]. Time 3 (T3), the time passed from the date of diagnosis to the start of treatment [10]. Time 4 (T4), the time elapsed between the start of treatment to the end of treatment [10]. Figure 2 is a visual representation of the aforementioned four timeframes. These timeframes represent the typical pathways that women with BC likely follow as they traverse through the healthcare system.

The results of the Mignini et al. study showed that participants experienced barriers at the intrapersonal level (personal beliefs), the interpersonal level (familial responsibilities and physician–patient communication), and at the institutional level (lack of registries, poor organization of services, and quality of medical attention received) [10, 11]. It was also found that most women experienced delays with BC services and treatments. These delays far surpassed the timelines deemed appropriate by several international screening guidelines [10, 11]. The aforementioned timeframes were defined using information from SITAM. The delays experienced during T1 could not be characterized using SITAM, because in this study, T1 encompassed the time from the first appearance of signs or symptoms to the date of the first mammography and/or ultrasound. As expected, this timeframe is outside of the parameters measured by SITAM and therefore, it was necessary to develop a tool that could accurately characterize the T1 timeframe. The results of the Mignini study also affirmed sociodemographic characteristics of the study participants. These include being of ages 51–60 years, having completed elementary school, being in a civil union or marriage, having 3 or more children, and not working outside of home [10, 11]. Most importantly, the results showed that the majority of women did not have health coverage despite universal healthcare services [10, 11]. These sociodemographic characteristics are important indicators of the barriers experienced by the participants and merit further characterization and analysis. Further qualitative analysis of participant interviews found that if the patients did not feel any symptoms, then they believed that it was not necessary to attend nor seek clinical breast

Fig. 1 Time delay in the breast cancer healthcare system. Figure 1 was modified from Harford JB., n.d. The Three Most Prominent Features of Breast Cancer in Africa: Late Diagnosis, Late Diagnosis, and Late Diagnosis [9] and was originally published by *Global Perspectives on Cancer* authored by Hansen et al., 2011 Time intervals from first symptom to treatment of cancer: a cohort study of 2,212 newly diagnosed cancer patients

exams and biennial mammography appointments [11]. This belief was further exacerbated by the fact that many women lived far away from their respective hospitals and clinics and could not afford the transportation fare to attend their appointments [11]. Participants also struggled with the fact that there were limited appointments available in the public sector, some then sought appointments in the private sector to not delay diagnosis, but this increased financial burdens

for the women interviewed [11]. Through the use of qualitative analysis, the results affirming the fact that patients faced barriers at every level of the socioecological model were only reinforced.

In response to the results obtained from the aforementioned study, a second investigation by Moreira et al. was developed and utilized the T1 survey as a data collection tool that could specifically characterize the barriers and other events experienced during Time 1 by women diagnosed with BC. The T1 Survey specifically inquired about women's motives for their first medical consult, the location of their consult, their healthcare coverage, and most importantly the barriers and delays that were present during the T1 timeframe, from the appearance of their first symptoms to their first medical appointment [12]. The results showed that participants did not seek medical care until a symptom arose, that they experienced delays of over a month in obtaining a medical consult, and that participants with only public medical coverage often sought care in private clinics [12]. This study was completed with a small sample of 44 women from one health institution, and the results merited continued investigation with a larger sample size [12].

Overall, both Argentinian investigations confirmed the need to pursue further research into the experiences faced by women from their first notice of the signs and symptoms of BC to their first medical consult within the public healthcare system or Time 1. This research must be continued in order to adequately identify the barriers and delays that women face and that keep them from seeking timely medical attention within the public healthcare system, as is provided by the Argentinian universal healthcare policies. By identifying and addressing these barriers and delays, it is hoped that early detection would improve and ultimately help to decrease the mortality rates of advanced stage BC in Argentina.

The 4 Timeframes

Fig. 2 The 4 timeframes pathway

As such, the Time 1 Survey study is currently being expanded to capture a more representative portion of the Argentinian population and to further describe the barriers and delays faced by women when accessing BC healthcare, specifically during the T1 timeframe, which is outside of the currently measurable parameters. Due to the nature of the questions posed by the T1 Survey and its projected future expansion at the national level, this survey can be used as a tool to guide present and future patient navigation strategies within the public, breast healthcare centers of Argentina.

Patient Navigation Overview

Patient navigation efforts began in 1999 after Dr. Harold Freeman established a patient navigation program in Harlem, New York [13]. Since the establishment of the Freeman patient navigation program, others have adopted similar strategies and have experienced successes in achieving timely diagnosis and treatment. These results indicate that patient navigation can be effective when attempting to improve cancer treatment initiation and adherence among underserved or otherwise disadvantaged groups [14]. This is a significant finding for Latin American populations considering that BC is the leading cause of cancer-related deaths in Latinas, which is thought to be due to late diagnosis [15].

Expansion of Patient Navigation in Argentina

The NCI of Argentina currently plays a key role in the expansion of patient navigation strategies within the country. The NCI provides guidelines for navigation training and makes the resources available to patient navigators [16]. In Argentina, patient navigators are integrated directly into the healthcare system and are tasked with three specific job functions: (1) identification of the population of women that should receive patient navigation using the national data registry system, SITAM; (2) completion of patient follow-up, including registration of all patients in the national data registry system; and (3) identification of barriers to timely and adequate diagnosis and treatment experienced by patients with symptoms of cancer or those with a confirmed diagnosis [16].

In 2015 and 2016, the provinces of Mendoza and Buenos Aires established patient navigation programs through the guidance of the NPCBC [17]. In 2018, the NPCBC published a programmatic document establishing their intention to expand patient navigation strategies within the Argentinian BC healthcare system. These programs along with other research completed in Argentina reported that it would be highly beneficial for these strategies to be expanded throughout the country.

The main objective of patient navigation within this sector is to resolve barriers that cause delays in care and that

in turn pose problems to timely and adequate diagnosis and treatment for BC [17]. The programmatic document published in 2019 states that patient navigators in the breast healthcare system will be tasked with identifying barriers inherent to the healthcare system and to specific situations faced by each woman. They will also educate and inform BC patients, will navigate women with BC through the four pathways of the breast healthcare system, will help to bridge gaps within the healthcare system, will optimize the time elapsed between detection of BC signs and symptoms, diagnosis, and treatment, will update and maintain information within the national data registry system, and ultimately will work towards achieving women's satisfaction with the BC healthcare system [17].

Due to increased interest in expanding patient navigation in Argentina, the Time 1 Survey Study is likely to serve as a tool that will identify points of importance during Time 1 and will help to formalize the core principles of patient navigation within the BC public healthcare sector, ideally optimizing timely care and decreasing BC mortality rates in Argentina.

T1 Survey Study Methodology

Study and Survey Design

The T1 Survey Study is a cross-sectional, retrospective study that utilizes a descriptive survey as the main data collection tool. The survey has been formulated to collect both quantitative and qualitative data of the experiences, barriers, and delays being faced by women from their first notice of the signs and symptoms of BC to their first medical consult within the public healthcare system, known as the Time 1 timeframe. A mixed methods survey tool is appropriate for research questions that require real-life contextual understanding of viewpoints of various perspectives and cultural influences [18]. Completion of the survey is completely voluntary; therefore, the final population of the study will be determined upon completion of the surveying period.

The survey was designed to be implemented by “data registers” of the National Cancer Institute who are specifically charged with inputting data into SITAM. The data that is registered into SITAM includes demographic profiles, dates of screening, mammography results, diagnoses, treatment types, and surgeries, among other factors. Currently, data registers have been faced with the challenge of identifying appropriate times in which to complete the T1 survey. The current appointment system and limited availability of appointments in the BC public healthcare system has made it difficult to locate participants during optimal times for survey completion.

Selection of the Sample

The sample for the T1 survey study is women diagnosed with BC from 01/01/2016 to 12/31/2017 by the public healthcare system, an addendum will be proposed to expand the sample size to include women who were diagnosed with BC between 01/01/2018 and 12/31/2019. The women that fit these criteria have been and will be identified through the screening data registry system of the National Cancer Institute, SITAM. These women are currently receiving BC treatment in one of the five hospitals located in the Argentinian provinces of Mendoza, Santa Fe, and Buenos Aires. The selection of participating provinces was based on several factors. First, a province was selected if they had a high number of breast cancer cases registered in SITAM. Hospitals were selected if they had personnel employed by the National Program for Control of Breast Cancer of the National Cancer Institute, as these individuals would act as study surveyors. Additionally, the availability and consistency of each hospital's research ethics committee were taken into consideration when choosing the final study sites. It is inferred that there were no major socioeconomic differences, such as income level, in the populations from the three provinces that have participated in the study because all participants only had public healthcare coverage. All participating hospitals were also public hospitals.

Training of Surveyors

Selected data registers have been working for the NCI for several years and have completed educational trainings on BC. Accordingly, the educational surveying training module centers around basic research and survey methodologies and best practices. The module was formulated based upon review of the published literature and coupled with expert-knowledge content contributed by experienced members of the NCI. Since the use of mixed methods research in healthcare is relatively new, the creation of collective training methods, for use by surveyors, to capture strengths and weaknesses that can be readily identified, has been deemed highly desirable [18]. Such an approach may enhance survey implementation and increase survey response rates [18, 19].

This online surveying training module is available through the NCI's "virtual campus." The virtual campus is an online platform that is frequently utilized by the NCI for various other online trainings, continuing education courses, and cancer awareness campaigns. Completion of the training module is a crucial step in study design and is projected to improve the implementation of the T1 survey in each of the participating hospitals.

Since the creation of the online training module, all participating NCI data registers have completed the training. After completion of online trainings, surveyors participated

in a one-on-one meeting scheduled through an online, screen-sharing system. The purpose of these meetings was to review the T1 survey at length and to address questions and concerns. Feedback from the surveyors stated that they experienced no difficulty with the training module and showed that they had an understanding of surveying best practices, likely due to their experience as NCI data registers. The surveyors showed knowledge of surveying best practices and the importance of mixed methods health research. By the end of the training module, they understood the layout and purpose of the survey after only one complete run. Most importantly, participants expressed understanding of how to successfully implement the survey in their respective hospitals. All T1 surveyors have access to the training module as a "refresher" tool that will allow them to recapitulate the information presented during training.

Present Status of T1 Survey Study

Initially, delays were experienced in the approval of the study protocols, followed by the provincial and hospital Institutional Review Boards (IRB) of three (out of five) hospitals who approved the study. As such, surveying will continue to take place in the three selected provinces. The first surveys were completed in 06/28/2019, 08/16/2019, and 11/26/2019 in Buenos Aires, Santa Fe, and Mendoza, respectively. Presently, 32 surveys have been conducted and during this initial surveying phase, it was found that it was difficult to locate the women who are part of the sample because most are not presenting for their follow-up appointments, or they present as "walk-in" appointments that do not require a previous appointment request. Therefore, it is difficult for the surveyors to make contact with the women from the sample set. This is relevant given that the survey was planned to be in-person and not by phone calls. We do not consider it to be appropriate to ask participants to come to the hospital specifically to be surveyed. Therefore, we must continue to wait for participants to schedule a follow-up appointment, a process that has been negatively impacted by the COVID-19 pandemic.

Surveying is ongoing but due to unexpected delays in hospital survey implementation and circumstances related to the COVID-19 pandemic, survey implementation has been paused at the present time. Through the pandemic, public healthcare services had to adapt to be able to care for patients affected or suspected of COVID-19. Emergency care services have continued to function in the vast majority of hospitals and many of the patients who are consulted with symptoms of suspected breast cancer still continue to be referred to specialists. However, an increase in Time 1 could be expected due to patient delays and the underlying

barriers and delays exacerbated by the pandemic. The survey study should be adapted to identify barriers and delays specific to the pandemic and compared to those that already existed but were heightened due to the current public health crisis.

After the end of surveying, data analysis will commence. All survey responses should be translated to identify common issues such as financial barriers and delays, possible familial and physician–patient communication barriers, healthcare system delays, and emotional barriers that Argentinian women may face during the Time 1 timeframe. These should also be categorized into intrapersonal, interpersonal, and institutional barrier levels. Common occurrences of the above-mentioned issues should be documented in order to identify important trends. Such trends can then be used as elements within the patient navigation strategy, and possibly identify unique factors that advance our current understanding of barriers to diagnosis and treatment. Of note, advanced patient navigation strategies, such as patient navigation partnered with T1 survey information, may reach women before they actually begin their care within the public healthcare system.

Future data analysis should utilize information obtained from SITAM at baseline. The baseline information will be compared with information available from the implementation of the program. The baseline and implementation data will be translated into geographic mapping to characterize regional variation in BC early detection, diagnosis, and treatment.

Conclusion

The importance of identifying barriers and delays present during Time 1 cannot be overstated. Such efforts can allow the NCI of Argentina to create a larger-scale patient navigation platform that may include national BC awareness campaigns, provision of BC education courses for the general public both in-person and online, informational events, mobilization of screening efforts, and teams of professionals that reach out to women at public locations. The ultimate goal is to reduce barriers and delays of Time 1 and to give women the tools and knowledge to seek timely and appropriate care. This same patient navigation strategy can continue to follow participating women as they navigate the complexities of the healthcare system in order to ensure timely diagnosis and timely and appropriate treatments as needed.

Lessons learned from this navigation experience and its possible effect on down-staging of BC and BC mortality rates, in specific regions in Argentina, can be disseminated into tailored patient, public, and professional cancer education interventions for the rest of Argentina and similar middle-income countries.

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Declarations

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