

AN ASSESSMENT OF THE BREAST CANCER SITUATION FROM SCREENING TO TREATMENT



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ABBREVIATIONS

ACS Agente Comunitário de Saúde (Community Health Agent)

ANS Agência Nacional de Saúde (National Health Agency) Centro Estadual de Oncologia (Oncology State Center) **CICAN**

CNES Cadastro Nacional de Serviços de Saúde (National Healthcare Services Registry)

CNS Conselho Nacional de Saúde (National Healthcare Board)

DATASUS Departamento de Informações do Sistema Único de Saúde (Unified Public Health

Information System Department)

EAB Equipe de Atenção Básica (Basic Attention Team)

ESF Equipe de Saúde da Família (Family Care Team)

GAMMA / Grupo de Apoio às Mulheres Mastectomizadas da Liga Bahiana de Combate ao Câncer **LBCC**

(Support Group for Mastectomized Women of Bahia League for Cancer Control)

HAM Hospital Aristides Maltez (Aristides Maltez Hospital)

IBGE Instituto Brasileiro de Geografia e Estatística (Geography and Statistics Brazilian Institute)

INCA Instituto Nacional do Câncer

MS Ministério da Saúde (Ministry of Health)

ONG Organização Não Governamental (Non-governmental Organization)

RCBP Registro de Câncer de Base Populacional (Population Based Cancer Registry)

RMS Região Metropolitana de Salvador (Salvador Metropolitan Region)

SESAB Secretaria da Saúde do Estado da Bahia (Bahia State Department of Health)

Sistema Único de Saúde (Unified Public Healthcare System) **SUS**

UBS Unidade Básica de Saúde (Basic Health Unit)







This research was carried out by Viva Maria, a non-governamental organization that works in Salvador, Brazil and its surrounding areas, in partnership with Susan G. Komen.

This health system assessment was elaborated and conducted by Viva Maria's multidisciplinary team including:

Director:

Maria do Carmo de Oliveira Lapa Monteiro (Executive Coordinator)

Research Team:

Lycia Tramujas Vasconcellos Neumann (Research Coordinator)

Vera Osório (Senior Researcher)

Vera Lídia de Oliveira (Epidemiologist)

Junior Researchers:

Camilla Costa Conceição Carlene Almeida Oliveira Elisângela Pires dos Santos Rosângela Oliveira

Administrative and Technical Support:

Sandra de Oliveira do Carmo Olga Xavier Almeida



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- · Maria de Fátima Pereira Volunteer Coordinator



Poderosas e Iluminadas NGO:

- · Bárbara Vita Dias dos Santos Secretary
- · Itana Marta de Oliveira Treasurer
- · Maria Vilma dos Santos Pereira President
- · Marilene Oliveira Costa Vice-president

SESAB - Bahia State Department of Health:

- · Claudia Rodrigues Almeida Director of Strategic Projects
- · Glayce Albgernaz Advisor at the Health Integral Attention Division
- · Liliane Mascarenhas Silveira Director of Care Management
- · Olga Cristina Lima Sampaio Gender and Life Cicle Care Coordinator
- · Paula França Rocha Director of Regulation
- · Rita de Cássia Velozo Women Health Coordinator
- · Solange Souza Santos Breast and Cervical Cancer Control Reference Program Coordinator

Candeias City Health Department:

- · Carla Maria Bugos de Oliveira Women's Reference Center Coordinator
- · Jaciara de Santana Macedo dos Santos Basic Attention Director
- · Lúbia da Cunha Moraes Macedo Subsecretary

Madre de Deus City Health Department:

- · André Santos Gomes Secretary's Advisor
- · Greice da Silva Gouveia Basic Attention Coordinator

Salvador City Health Department:

- · Ana Maria Guimarães Dortas Matos Regulation
- · Jorge Luiz Fortes de Magalhães Regulation
- · Joventina Julita Pontes de Azevedo Women's Health Staff
- · Marília Cardoso de Sant'Ana Regulation
- · Tarcisio Oliveira Silva- Basic Attention Coordinator

Simões Filho City Health Department:

- · Bárbara Duarte Women's Health Center Coordinator
- · Bárbara Rosário dos Santos Health Integral Assistance Coordinator
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- · Camila Santos Santana Basic Attention Director
- · Cauane Souza Rebouças Basic Attention Coordinator
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EXECUTIVE SUMMARY



This research study aimed to assess the breast cancer situation in Salvador and its Metropolitan Region, and the pathways public healthcare system patients had to go through, from screening to treatment. It was planned considering the *Linha de Cuidado do Câncer de Mama* (Ministry of Health's Breast Cancer Care Pathway) that is divided in 4 steps: Health Promotion/Prevention, Screening, Diagnosis and Treatment.

The information contained herein represents a comprehensive look at breast cancer care in the region resulting from a combination of mixed methods; data collected from key stakeholders including patients, survivors, community health agents, public health professionals and managers, and an evaluation of pre-existing informational resources, processes and barriers.

The Salvador Metropolitan Region (RMS) is comprised of 13 municipalities where about 2 million women live (645,000 of which are over the age of 40). In order to guarantee accurate representation of this population in the study, municipalities were divided into 3 Strata: Stratum 1 is the city of Salvador; Stratum 2 included cities with less than 50,000 residents; and Stratum 3, included those with over 50,000 people.



A total of 81 breast cancer patients under treatment in public health institutions were interviewed:

31 25 25 from Salvador from municipalities in Stratum 2 from municipalities in Stratum 3

An additional 34 health managers and professionals working in the breast cancer sector from 10 government institutions and social organizations were interviewed in six different cities. Finally, 4 focus groups were held: one with women under treatment, one with breast cancer survivors and two with community health agents - who are the link between communities and the public health system.

In Brazil, health is guaranteed in the Constitution as "a right of all and an obligation of the State". In general, healthcare programs and services are offered by a regional and hierarchical network that forms the Unified Health System (Sistema Único de Saúde - SUS). Primary access to public health services is made available to citizens through the Basic Health Units (Unidade Básica de Saúde - UBS) which provide primary care and are a gateway to SUS.

To guarantee the provision of integral healthcare service, the Federal Government, through the Ministry of Health, instituted several mechanisms, as Plans and Agreements, for better management of resources and partnership between federal, state and municipal governments.



The *Política Nacional de Prevenção e Controle do Câncer* (National Policy for Cancer Prevention and Control) was released in 2003 with goals and strategies to reduce incidence and mortality in the country. More recently, the establishment of the "60 Day Law" set parameters for the transition from breast cancer diagnosis to the beginning of treatment, mandating the initiation of treatment no later than 60 days after a confirmed diagnosis.

Breast cancer is the cancer with the highest incidence in Brazilian women, with a total of 57,120 new cases estimated in 2014. The city of Salvador presents an incidence rate of 63 per 100,000 women, which is higher than national average (56/100,000 women) and almost twice the state average (33/100,000 women in the state of Bahia). In women aged 40 to 49, breast cancer is the second most frequent cause of death and the first cause of hospitalization.

While mortality rate increased 32% in the country from 2003 to 2012, in Salvador it increased an astounding 54.6% in the same period – having a higher rate than the national average for the same period. And while breast cancer hospitalization admissions increased 28% in Brazil, from 2008 to 2012, in Salvador data shows a growth of 85.3% in the same period.

Public primary care coverage is greater in smaller cities, reaching 96.6% of the Mata de São João population, for example. In Salvador, its coverage extends to only 31.4% of the population with the majority of the city's residents relying on privatized healthcare plans and services.

Despite limited reliance on SUS by residents of the major city, oncology, mammography and biopsy services are centralized in Salvador. Access to these services is granted to smaller cities of the metropolitan area through formalized agreements and an established patient referral system.

There is an apparent lack of organized data and knowledge about the availability of mammograms and biopsies quoted under the formalized agreements with Salvador. City government officials and health system representatives expressed frustration regarding the difficulty to schedule such exams. As a result, some cities opt for paying for private services. However, in the majority of cases women are oriented to go straight to reference centers – Hospital Aristides Maltez (HAM) and the State Center for Oncology CICAN (Centro Estadual de Oncologia) – that attend the natural patient demand from SUS with limited daily availability.

Initiatives geared towards health promotion and early detection of breast cancer are either not well structured or simply do not exist in the majority of the communities. Consequently, women barely understand the risk and severity of the disease and are not aware of the importance of screening tests. Moreover, there appears to be a lack of active search



strategies targeting women in the priority age group for screening, which, according to the Ministry of Health, is from 50 to 69.

The Clinical Breast Exam (CBE) has not yet become standard practice in appointments at the basic health unit. Most of the time, the CBE is only done when a woman requests it to the doctor, and the process of scheduling a mammogram is even more convoluted. Results from our focus groups indicated that women spend on average about 36 hours in the process of going back and forth to request, schedule, complete the exam and then obtain the results. All procedures from first appointment to the analysis of the results by the doctor may take 3 or more months.

Aware of the difficulties and the waiting time to have a mammography test done at SUS, many women simply don't get screened until they notice something different or become aware that they are dealing with a symptom of breast cancer. At which time, some of them choose to seek affordable private healthcare services, often paying for tests sometimes with poor quality, with inconclusive results and that may need to be redone.

The alarming number of women who notice changes in their body related to signs of breast cancer is a direct indication that screening programs are not being carried out properly or having the expected results in terms of early detection. Out of 81 patients interviewed for this study, 58 suspected breast cancer through changes they noticed on their bodies (72%), in two cases it was a relative who noticed a change and in 21 cases it was detected by a health professional (26%).

Focus group participants also indicated a perception that younger women have been increasingly affected by the disease. In fact, of the patients interviewed, 53% were under 50 years old when diagnosed and among interviewed patients from Salvador, this group represents 61%.

Results also suggested that women who noticed a change in themselves sought screening services earlier when compared to those whose first sign was detected by a health professional. On average, 40% of these women sought health services within a week. Despite this information, comparative data on time of suspicion to diagnosis suggests that the transition time is lessened when a woman seeks regular health screening and the professional identifies risk signs.

Access to the biopsy as a diagnostic tool is described as the primary bottleneck in the healthcare system. Currently, the waiting list at SUS Regulatory Services in Salvador exceeds 500 people and about 100 women are on the waiting list for Hospital Aristides Maltez (HAM). The regulation of services is a mechanism by which SUS attempts to triage



access to specialized services by considering a patient's condition and level of need (whether emergency or elective). Similar to the Department of Health Planning in the U.S., SUS Regulatory Services seeks to control patient flow and tries to prevent bottlenecks in the system. Unfortunately, deficiencies in infrastructure and in the strategy for regulating services end up creating delays and extensive waiting lists. With the exception of the implementation of a new information system, not much is being done to optimize services and consequently reduce these delays.

Data collected from healthcare managers and patients show a concerning situation. It can take more than six months to complete the process of requesting a biopsy test and present the results to a doctor for evaluation. Worried or in pain, many women instead of relying on availability of services from SUS, choose the alternative of seeking paid services at a private clinic; a recourse that causes an undue financial burden, often leading women to borrow funds from family or friends, or worse, depend on credit cards or personal loans.

Aware of the weaknesses of the patient referral system, many women decide to "walk-in" to oncology reference centers in Salvador, and wait in line for the opportunity to get diagnostic screening. Health professionals are also aware of the challenges in obtaining timely appointments for services through the referral system and often advise their patients to walk-in at oncology reference centers. In order to get an appointment at HAM or CICAN, women must arrive at the hospital early in the morning and compete for one of the 60 vouchers available daily for walk-in services.

For both diagnostic screening and access to treatment, commuting represents one of the biggest challenges for women – especially for those from the RMS. Municipalities offer a shuttle bus service that has one daily fixed departure and arrival time. This service is offered to all patients, despite their disease or health condition. These buses tend to be so crowded that patients are advised not to take a companion with them. The government's benefit *Tratamento Fora de Domicílio* (Out of Home Treatment) states that transportation and meals are covered for patients and a companion, however, the program is not fully recognized and does not appear to be accessible to the population.

Without information on available resources and healthcare services, and a general lack of knowledge on their rights as citizens and SUS patients, women tend to accept, in a very resigned way, the poor quality of attendance and orientation, as well as long waiting lines and wait time in each of the steps along the patient care pathway. If better educated and empowered, women could demand health system improvements, potentially resulting in earlier diagnoses and a long-term overall reduction of breast cancer mortality.



The authors believe that when speaking of breast cancer in Salvador and RMS,

it is not the disease that kills, but the lack of organization in the public healthcare system.

To improve the scenario and conditions herein described, we believe four urgent issues must be addressed:

Priority 1 HEALTH EDUCATION IN COMMUNITIES

It is vital to improve women's knowledge about breast health, breast cancer risk reduction strategies, early detection, and breast self-awareness.

Priority 2 QUALIFICATION OF PRIMARY CARE HEALTH PROFESSIONALS AND MANAGERS

As primary care is the gateway for communities to access SUS, there is a need for better qualified professionals to assist women and guide those with questions, suspicion and diagnosis of breast cancer.

Priority 3 FLOW ORGANIZATION AND BETTER COMMUNICATION BETWEEN HEALTHCARE SERVICES

Improving the timeliness of a woman's access to breast cancer diagnosis and treatment relies on more regulation and referral system strengthening between Basic Attention Units and medium and high complexity healthcare services. It also depends on better communication between their managers and health professionals.

Priority 4 PROMOTION OF PATIENTS RIGHTS

Women and breast cancer patients must know their rights and find ways to guarantee them.







A

PUBLIC HEALTH POLICIES AND SYSTEM IN BRAZIL

In order to better understand the context for this study, it is important to recognize the main public health policies in Brazil; how services are organized; and the primary policies for health management and breast cancer control.

As presented in figure 1, health assistance in Brazil evolved along the years to the creation of a Unified Health System - SUS in 1988.

FIGURE 1. TIMELINE OF PUBLIC HEALTHCARE UP TO CURRENT CONSTITUTION.

1988	· Federative Republic of Brazil (1985 to present); 1988 Constitution. · Articles 196-200: "Health is a right of every citizen, and a duty of the State", created SUS.
1967	 Federative Republic of Brazil (military government: 1964 to 1985); 1967 Constitution Article 8 lists the responsibilities of the Federal government to establish health and education standards.
1946	 Republic of the United States of Brazil (1945 to 1964); Constitution (September 18, 1946) Article 5 lists the responsibilities of the Federal government to establish fundamental health standards.
1937	 Republic of the United States of Brazil (1889 to 1937); Constitution (November 10, 1937) Article 16 lists the responsibilities of the Federal government to establish fundamental health standards.
1934	· Republic of the United States of Brazil (1889 to 1937); Constitution (July 16, 1934) · Article 10 sets forth the obligations of the Union and States in public health assistance.
1891	· Republic of the United States of Brazil (1889 to 1937); Constitution (February 24, 1891) · Legislation did not include any health provisions.
1824	· Empire of Brazil (1822 to 1889); Constitution (March 25, 1824) · Legislation did not include any health provisions.

Source: Brazil Ministry of Health Online Public Health Library (2013)

SISTEMA ÚNICO DE SAÚDE (SUS), UNIFIED HEALTH SYSTEM

The health system in Brazil has public and private components that are interconnected and are divided in three subsectors: the public (SUS), in which services are financed and provided by the state; the private (for-profit and non-profit) that offers paid and unpaid services financed by public and private funds; and the private health insurance subsector, which offers different forms of health plans, varying insurance premiums, and tax subsidies¹.



Articles 196 and 198 of the Brazilian Federal Constitution of 1988 state that health is a "right of all and an obligation of the State". In response, the Unified Public Healthcare System - SUS, a nationally integrated system based on the concept of health as a citizen and human right and the principles of decentralization, integral attendance, community participation and social control was created². Through SUS, all initiatives and programs must be offered in an integral way and organized in a regional and hierarchical network.

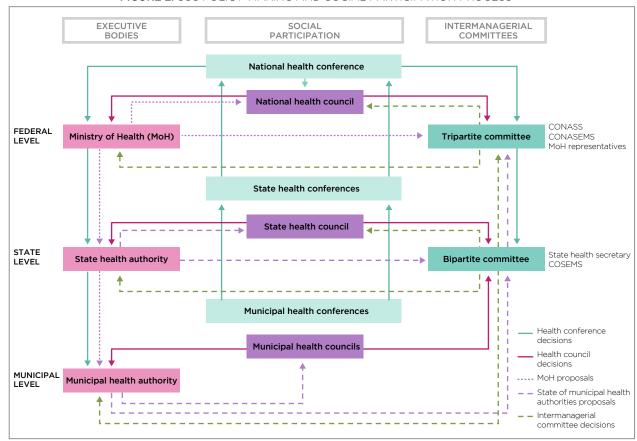


FIGURE 2. SUS POLICY-MAKING AND SOCIAL PARTICIPATION PROCESS

Source: (Paim et al., 2011)



Atenção Básica (Primary Care) is available to citizens throughout the country and its services are decentralized, providing ease of access to citizens and families right where they live. At the *Unidades Básicas de Saúde - UBS* (Basic Health Units) the population count on the support of the *Equipes de Saúde da Família - ESF* (Family Health Teams) and of *Equipes de Atenção Básica - EAB* (Basic Attention Teams). UBSs are considered the main point of entrance into the Unified Health System.



At the community level, primare care is responsible for the coordination and organization of the healthcare network; generating referrals and providing guidance to patients who require more specialized care. In this sense, it tracks users throughout the transition of care, even when special treatment or hospitalization is required. Primary care teams are also the principal connection between the community and the healthcare network, participating in policy development and helping define how community health needs should be prioritized³.

D HEALTH POLICY AND CITIZENSHIP

When SUS was created, citizen participation in Municipal and State Health councils was seen as an important strategy to promote health equity in the country by engaging citizens and the civil society in health policy planning and control processes.

During the 198ª Reunião Ordinária do Conselho Nacional de Saúde (198th National Health Council Meeting), on June 17th 2009, the Carta dos Direitos dos Usuários da Saúde (Letter of Rights for Users of the Health System) was approved, aiming to guarantee free universal and equal access to programs and services related to promotion, protection and recovery of health.

The document presents six basic principles of citizenship and is an important tool for users in understanding their rights and obligations when seeking private or public healthcare:

- 1 Every citizen has the right to access an ordely and organized health system.
- 2 Every citizen has the right to an appropriate and effective health treatment.
- **3** Every citizen has the right to humane treatment free from any discrimination.
- 4 Every citizen has the right to care that respects their person, their values and their rights.
- **5** Every citizen also has responsibilities to assure their treatment is managed properly.
- Every citizen is entitled to the commitment of health authorities to ensure that the principles above are met⁴.



Cases regularly presented by the media demonstrate that despite this commitment on the part of the government, Brazilian citizens still lack core knowledge about their rights when related to public or private healthcare services. Poor knowledge of health rights can be said to translate to more passive and resigned patient attitudes. Citizens in general wait very long periods of time to receive care. They accept the often poor quality of services and receive limited or no guidance at all from healthcare professionals and social workers.

NATIONAL POLICY FOR BREAST CANCER CONTROL AND PREVENTION

Published on the 16th of May of 2013, the Brazilian Ministry of Health instituted Ordinance number 874 which established a national policy for breast cancer control and prevention in the healthcare network within SUS for persons with chronic diseases.

The ordinance has as one of its objectives, the reduction of mortality and disability caused by the disease through health promotion, prevention, early detection and opportune screening, and also the possibility of reducing the incidence of some types of cancer. It also aims to contribute to improving patient's quality of life through actions of promotion, prevention, early detection, timely treatment and palliative care⁵.

For a health policy to be successful, sometimes it is necessary for specific legislation to be elaborated and approved, defining processes and procedures. A good example of this is the recent approval of Order 1,220 6 in 06/03/2014, commonly recognized in the field as the "60 day law" which establishes that:



Patients with malignant neoplasia have the right to initiate their first treatment through SUS no more than 60 days from the day when diagnosis was confirmed in the pathological report or even sooner according to needed therapeutics registered in the medical report⁷.







The methodology for this study was established considering:

- a set of predefined objectives;
- the characteristics of the Brazilian public health system;
- cultural aspects of the Northeast region where the state of Bahia is located as well as its capital, Salvador.

Figure 3 below describes the four phases of progression for the project as well as the objectives and methodologies utilized in each.

PHASE 1 PHASE 2 PHASE 3 PHASE 4 S W Describe the system Describe population and access to breast cancer breast cancer statistics ECTIV care in women of the of Salvador and each of Describe the barriers and RMS to understand the the twelve municipalities Describe the main services pathways that breast needs in the continuum of that form the and resources for breast cancer patients go breast cancer care Metropolitan Area, BJ cancer care available in the through from the first perceived by the main comparing them with studied area. symptoms or abnormal stakeholders. state and country screening tests until the indicators. end of treatment. Exploratory study through Exploratory study through A comprehensive research U semi-structured interviews semi-structured interviews on secondary data from 010 A descriptive study and focus groups and focus groups National Database on developed using Health Services secondary data from Individual interviews ETHOD DATASUS conducted government information conducted with breast Focus group sessions with aiming to describe the systems cancer patients and women in treatment, resources available for and reports. survivors, health survivors, and community breast cancer care in professionals, health health agents. region. managers, patient support Σ groups and organizations.

FIGURE 3. SUMMARY OF THE METHODOLOGY USED IN THIS STUDY.

As described earlier in this report, to represent the entire RMS, the cities considered in this study were grouped and categorized according to their population size (see Table 1):





TABLE 1. POPULATION OF SALVADOR METROPOLITAN REGION, BY STRATUM, GENDER AND TOTAL, 2012.

STRATUM	MUNICIPALITIES	MALE	FEMALE	TOTAL
1	Salvador	1,265,378	1,445,590	2,710,968
	Madre de Deus	8,765	9,418	18,183
	Itaparica	10,296	10,698	20,994
	Vera Cruz	19,311	19,437	38,748
2	Pojuca	16,584	17,522	34,106
	São Francisco do Conde	16,713	17,513	34,226
	Mata de São João	20,547	20,980	41,527
	São Sebastião do Passé	20,872	21,613	42,485
	Total of Stratum 2	113,088	117,181	230,269
	Dias d'Ávila	34,391	35,237	69,628
	Candeias	40,778	43,343	84,121
3	Camaçari	126,801	128,437	255,238
3	Lauro de Freitas	82,957	88,085	171,042
	Simões Filho	59,669	61,747	121,416
	Total of Stratum 3	344,596	356,849	701,445
	TOTAL	1,723,062	1,919,620	3,642,682

Source: IBGE / Datasus

In order to outline a socioeconomical and epidemiological profile of RMS, data was analyzed from the *Sistema de Informações sobre Mortalidade* (Mortality Information System) (SIM), *Sistema de Informação Hospitalar* (Hospital Information System) (SIH), and *Registro de Câncer de Base Populacional* (Population Based Cancer Registry).

Information on the services profile and resources availability for breast health was gathered primarily from a broad search on secondary data available at DATASUS (Public Healthcare Information System). With these pieces of information it was possible to describe and classify services provided to breast cancer patients in the region.

To understand the path taken by women, from the first sign to treatment, the challenges and barriers faced and its consequences in women's lives, an exploratory study was developed based on semi-structured interviews and focus groups to complement and validate the information collected.

The sample of women interviewed for this study was calculated using the StatCalc from Epi-Info software, based on values shown in chart 2. A prevalence of 50% and an expected accuracy of 80% were considered.



The use of these parameters is justified as it is an exploratory study in which results were validated in focus groups as described below.

TABLE 2. NUMBER OF WOMEN WHO ARE 40 YEARS AND OVER AND ESTIMATES OF BREAST CANCER CASES, BY MUNICIPALITY - SALVADOR METROPOLITAN REGION, 2012.

STRATUM	MUNICIPALITIES	NUMBER OF WOMEN AT 40 & OVER	ESTIMATED BREAST CANCER CASES*
1	Salvador	510,132	762
	Madre de Deus	2,916	5
	Itaparica	3.488	6
	Vera Cruz	6,372	10
2	Pojuca	5,049	9
	São Francisco do Conde	4,736	9
	Mata de São João	5,923	11
	São Sebastião do Passé	6,691	11
	Total of Stratum 2	35,175	61
	Dias d'Ávila	9,318	19
	Candeias	12,835	23
3	Camaçari	34,040	68
	Lauro de Freitas	26,384	46
	Simões Filho	16,416	33
	Total of Stratum 3	98,993	189
	TOTAL	644,300	1,012

Source: IBGE / Datasus, INCA

INTERVIEWS WITH CANCER PATIENTS UNDER TREATMENT

Individual interviews were conducted with 31 resident women of Salvador, 25 women from Stratum 2 and 25 women of Stratum 3 for a total of 81 breast cancer patients under treatment in the public healthcare system. All of the interviews were conducted by 4 trained interviewers (local residents) with previous experience in health surveys.

The questionnaire developed for this study includes questions about:

- socioeconomic status,
- healthcare routine before diagnosis,
- previous knowledge about the disease,
- journey from the first symptom to treatment (time to diagnosis, barriers and feelings).



 $^{^*}$ Calculated considering crude incidence rate per each 100,000 residents in Salvador in 2012 - 54.72/100,000 residents.

Interviews were captured as women entered or exited HAM, one of the main reference hospitals in the region. Other interviews were conducted by phone, using the snowball method to reach patients residing in the target areas for the study.

INTERVIEWS WITH HEALTH MANAGERS AND PROFESSIONALS

The primary institutions comprising the women's healthcare network in the RMS were notified of the study early on and a formal request for cooperation was issued. Through these initial contacts, key personnel within the healthcare system responsible for breast cancer control were selected and subsequently interviewed on policies and procedures related to breast cancer services.

To ensure a proper understanding of the differing realities and diverse representation of municipalities in the study, two cities from Stratum 2 (Madre de Deus and Vera Cruz) and two cities from Stratum 3 (Candeias and Simões Filho) were selected for interviews with local healthcare managers and professionals. These cities were selected based on population size and the distance from the capital where breast cancer diagnosis and treatment services are concentrated.

In the municipality of São Francisco do Conde an interview with a local patient support team was also conducted.

Based on the information collected, a script was developed to guide the interviews with health managers and professionals.

In sum, there were site visits made to:

6 municipalities: · Candeias

· Madre de Deus

· Salvador

· São Francisco do Conde

· Simões Filho

· Vera Cruz

institutions:

10 public health · 5 Municipal Health Departments: Salvador (Basic Attention and Regulation), Madre de Deus, Vera Cruz, Candeias and Simões Filho.

> · State Health Department: Regulation, Strategic Projects and Superintendency to Integral Health Attention.



- · 2 Patient Support Groups: Poderosas e Iluminadas (São Francisco do Conde) and Grupo GAMMA/LBCC (Support Group for Mastectomized Women).
- · 2 Hospitals: Hospital Aristides Maltez HAM and Centro Estadual de Oncologia CICAN.

A total of 34 managers and professionals:

that work with breast cancer were interviewed either individually or in groups.

3 FOCUS GROUPS

To validate collected information in the previous stages and to promote a contextualized discussion about the path of each woman from first sign or suspicion of breast cancer to medical follow-up and treatment, 4 focus groups were formed: 1 with survivors, 1 with women under treatment and two with community health agents from Salvador and the RMS.

Dynamics used in meetings resulted in boards created with facts and observations related to the main challenges, barriers and other situations faced by women along the breast cancer care path, which is divided in 4 steps: Health Promotion/Prevention, Suspicion, Diagnosis, Treatment and Survivorship.

In total there were 41 participants in the focus groups as below:

- 16 breast cancer survivors
- patients under treatment
- 1 co-survivor / patient relative (who asked to participate)
- community health agents (11 from Salvador, 4 from Candeias, 4 from Vera Cruz and 2 from Pojuca)

The biggest challenge faced in those focus groups was the participation of patients under treatment. In the day when two sessions were arranged with patients (one in the morning and another in the afternoon) the public transportation system went on strike and it also rained heavily. So, only three patients and one relative participated in the morning. Consequently, we decided to reschedule the afternoon group, but no one showed up then.





Afterwards, phone contact was made with some of the patients that had confirmed attendance but didn't show up. They justified their absence for different reasons: one was involved in surgery preparations, the other had changes on her radiotheraphy agenda, the other was having difficulty with the side effects of chemotheraphy, another had a cold and one had last minute personal arrangements.

Considering that there was an abundance of data collected with patients during individual interviews, the absence of these individuals in the focus group did not hinder our ability to generate the final results of the study.

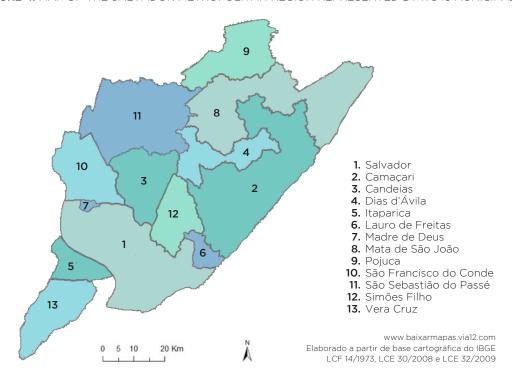






A BREAST CANCER EPIDEMIOLOGICAL PROFILE

FIGURE 4. MAP OF THE SALVADOR METROPOLITAN REGION REPRESENTED BY ITS 13 MUNICIPALITIES.



A1. BREAST CANCER INCIDENCE

The country of Brazil has 19 Population-based Cancer Registries (RCBP) that have been active since the end of 1990. The RCBPs collect data of new cancer cases in a continuous and systematic way, estimate cancer incidence, and supply information about cancer occurrence and the epidemiological profile of different neoplasias in communities.

Salvador's RCBP was founded in 1996 and data collection initiated in 1997. Originally managed by the Bahian League for Cancer Control, a sector of HAM, the RCBP in Salvador is now under the responsibility of the State Health Department.

A total of 45 sources feed information into the RCBP including: one specialized hospital, one university hospital, 14 general hospitals, 28 histopathology labs, 3 hematology centers, 4 oncology clinics, 4 radiotherapy centers and 4 chemotheraphy centers⁸.



Breast cancer is the cancer with the highest incidence in women all over the world, both in developed countries as in developing ones. In 2014, 57,120 new breast cancer cases were expected to be diagnosed in Brazil, with an estimated risk rate of 56.09 cases per each 100,000 women.

For Salvador, in that same year, 980 new cases of breast cancer were estimated, with a higher risk rate than the national one (63.00/100,000 women), as explained below:

TABLE 3. ESTIMATED NUMBER OF NEW BREAST CANCER CASES IN 2014 AND CRUDE INCIDENCE RATE - BRAZIL, NORTHEAST REGION, BAHIA AND SALVADOR.

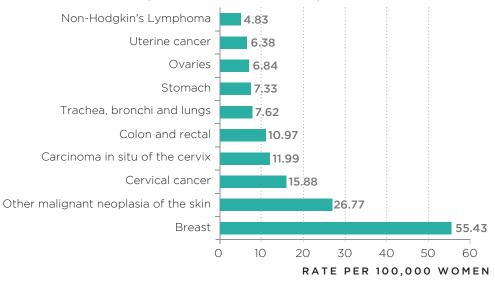
REGION	NUMBER OF NEW CASES	CRUDE RATE /100,000 WOMEN
Brazil	57,120	56.09
Northeast	10,490	36.74
Bahia	2,560	33.00
Salvador	980	63.00

Source: MS/INCA Estimativa 2014

Apart from non-melanoma skin tumors, breast cancer is the most frequent type of cancer in women in four of the five Brazilian regions: Southeast, South, Central-West and Northeast. In the North region it is the second most frequent.

In Salvador, it is also the most frequent neoplasia among women and the incidence rate is twice as high as the second most frequent neoplasia for this gender.

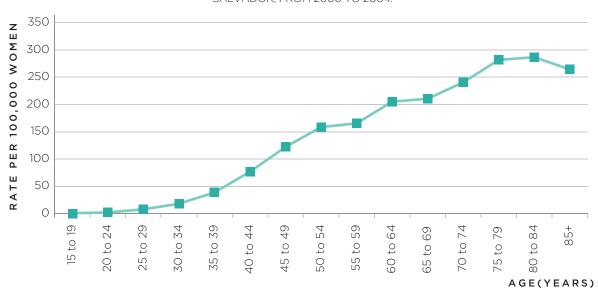
GRAPH 1. INCIDENCE RATE OF THE 10 MOST FREQUENT PRIMARY TUMORS THAT AFFECT WOMEN,BY AGE GROUPS - SALVADOR, FROM 2000 TO 20049.



Source: MS/INCA Estimativa 2014



Age is a key risk factor to breast cancer. Graph 2 provides a breakdown of breast cancer incidence rates according to age groups in Salvador.



GRAPH 2. BREAST CANCER INCIDENCE RATES ACCORDING TO AGE GROUPS
- SALVADOR, FROM 2000 TO 2004.

Source: MS/INCA Estimativa 2014

A2. MORTALITY

Death data obtained from the Sistema de Informação sobre Mortalidade (Mortality Information System) (SIM), available in the Departamento de Informações do Sistema Único de Saúde (SUS Information Department) - Ministry of Health (DATASUS-MS) shows that in Brazil, breast cancer was in the seventh place among specific death causes in the



female population in 2012 reaching 13.7 deaths per 100,000 women. However, when evaluating the age-relative rate, it is the second specific cause of death between women aged 40 to 49 years and the fourth in the 30 to 39 and 50 to 59 age groups (Table 2 and Chart 3).



TABLE 4. SPECIFIC CAUSES OF DEATH IN WOMEN - BRAZIL, 2012.

SPECIFIC CAUSES OF DEATH	#	%
Heart attack	34,602	6.8
Pneumonia by microorganism	28,116	5.5
Diabetes mellitus	27,577	5.4
Brain stroke	21,170	4.2
Chronic lung diseases	14,172	2.8
Heart failure	13,870	2.7
Breast malignant neoplasia	13,591	2.7
Others	356,661	69.9
TOTAL	509,885	100.0

Source: DATASUS

 TABLE 5. SPECIFIC CAUSES OF DEATH IN WOMEN BY AGE GROUP - BRAZIL, 2012.

AGE RANKING	30 TO 39	40 TO 49	50 TO 59
1 st	Viral infections (7.8%)	Cerebrovascular disease (8.4%)	Heart ischemia disease (9.3%)
2 nd	Transpor accident (7.4%)	Breast neoplasia (7.2%)	Cerebrovascular disease (8.8%)
3 rd	Aggression (6.2%)		Diabetes (6.2%)
4 th	Breast neoplasia (5.1%)		Breast neoplasia (6.2%)

Source: DATASUS

Breast Cancer Mortality in Brazil:

- In the state of Bahia, breast cancer was the 11th cause of death among women in 2012, which represents 2.1% of total deaths for this gender.
- In Salvador, breast neoplasia represented the 8th cause of death in 2012, which means an overall 3.8% of total deaths.



- In municipalities with less than 50,000 residents (i.e. Stratum 2), breast neoplasia represents 1.3% of deaths, reaching the 17th position in the specific death causes ranking.
- In the cities with more than 50,000 residents (i.e. Stratum 3) breast neoplasia represents 3.0% of total deaths and the 7th most frequent death cause.

TABLE 6. BREAST NEOPLASIA RANKING AND PERCENTAGE AS CAUSE OF DEATH IN WOMEN - BRAZIL, BAHIA, SALVADOR, STRATA 2 AND 3, 2012.

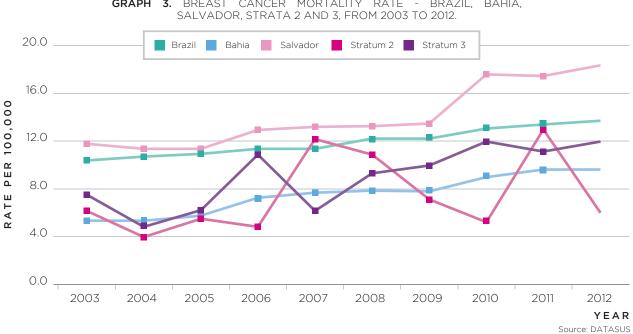
	BRAZIL	ВАНІА	SALVADOR	STRATUM 2	STRATUM 3
RANKING	7 th	11 th	8 th	17 th	7 th
PERCENTAGE %	2.7%	2.1%	3.8%	1.3%	3.0%

Source: DATASUS

Although breast cancer is known to be treatable when diagnosed at earlier stages, mortality rates continue to rise in all of the regions considered. It is suggested that there is a potential correlation between the continued increase and high rates of advanced-stage diagnoses in the country. As shown in Graph 3:

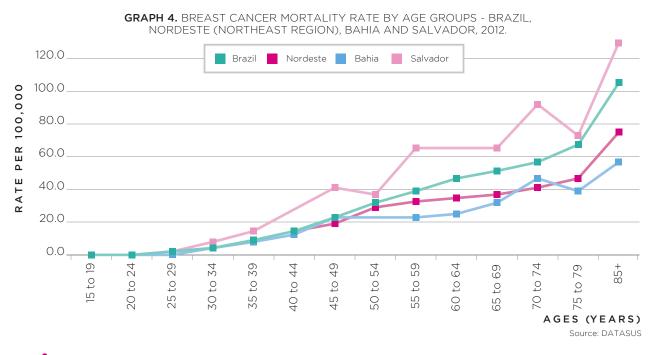
- breast cancer mortality rates have risen 32% in the past decade from 10.4 per 100,000 women in 2003 and 13.7 per 100,000 in 2012.
- In Bahia specifically, albeit below the national average, an increase in breast cancer mortality rates from 5.4 to 9.7 per 100,000 women for the same time period is noteworthy; particularly considering that 15% of deaths in the region are not tracked correctly, which may contribute to underreporting of breast cancer deaths.
- Narrowing further down to Salvador, the statistics show that when conducting this same analysis, the resulting outcome is an increase of 54.6% in breast cancer mortality from 11.9 per 100,000 women in 2003 to 18.4 per 100,000 women in 2012. Salvador has always historically assumed higher values than the national average.
- Despite irregular trends observed in data of Strata 2 and 3, it is possible to notice this indicator increasing in these areas as well.





GRAPH 3. BREAST CANCER MORTALITY RATE - BRAZIL, BAHIA,

As shown below, Graph 4 shows breast cancer mortality rates by age groups. In Salvador, breast cancer mortality rates are higher than the national average.





A3. HOSPITAL MORBIDITY

To assess mortality rates for patients actively receiving services in the hospital, morbity rates were analysed through hospitalization monitoring data given by the *Sistema de Informações Hospitalares* (Hospitalization Information System) (SIH-SUS). SIH-SUS combines data from all SUS hospital applications and excludes data related to private insurance or negotiated insurance plans.

After pregnancy, childbirth and puerperium, malignant neoplasias represent the 7th cause of hospitalization or 8.1% of total hospitalizations in Brazil. For women in particular, this represents 9.9% of hospital admissions and is the 5th cause of hospitalization.

Neoplasia hospitalization is more frequent in women from age 30 to 59 as it is in one of the three most frequent causes of hospitalization. Also, it is worth noting that in the group aged 40 to 49, it is the number one cause of hospitalization (Table 7). The same can be seen in other regions analyzed (Bahia, Salvador, Strata 2 and 3):

TABLE 7. NEOPLASIAS CLASSIFICATION AS CAUSES OF HOSPITALIZATION IN WOMEN BY AGE GROUP - BRAZIL, BAHIA, SALVADOR, STRATA 2 AND 3, 2014.

AGE RANKING	30 TO 39	40 TO 49	50 TO 59
Brazil	3 rd	1 st	2 nd
Bahia	2 nd	1 st	3 rd
Salvador	1 st	1 st	2 nd
Stratum 2	1st	1st	2 nd
Stratum 3	1st	1st	1st

Source: DATASUS

Among malignant neoplasias, breast cancer is the number one cause of hospitalization in women (Table 8).

TABLE 8. SPECIFIC CAUSES OF HOSPITALIZATION FOR MALIGNANT NEOPLASIAS IN WOMEN - BRAZIL, BAHIA, SALVADOR, STRATA 2 AND 3, 2014.

LOCATION	BRAZIL	ВАНІА	SALVADOR	STRATUM 2	STRATUM 3
1 st	Breast neoplasia				
	(12.9%)	(10.2%)	(14.5%)	(12.7%)	(15.9%)

Source: DATASUS



Breast cancer hospitalization rate analysis shows significant increases over the past 5 years in the regions analyzed, as shown in Graph 5:

- From 2008 to 2012 breast cancer hospitalization rates increased 28.0% in Brazil, an increase of 38.5 to 49.3 per 100,000 residents in 2012.
- In the state of Bahia we also noticed an important increment in the rate: from 27.6 to 44.0 per 100,000 residents. However, along the 5-year period, the rate of hospitalization for the state remained under the national average.
- An 85.3% increase in hospitalizations from breast cancer in Salvador was observed. The rate of 51.7 per 100,000 in 2008 exhibited a drastic increase to 95.9 per 100,000; a rate higher than the all-time national average for the period.
- Municipalities in Strata 2 and 3 also experienced an increasing trend.



GRAPH 5. BREAST CANCER HOSPITAL ADMISSION RATE - BRAZIL, BAHIA,

PUBLIC BREAST HEALTHCARE NETWORK

Epidemiologic data showed the burden of the disease in the local population. While mortality rates for breast cancer are decreasing in many countries, they are still on an ascending trend in Brazil and, more specifically, in the RMS.



Analysis of the available resources for early detection and secondary prevention, diagnosis and treatment in the region helps to better understand some of the causes for such high incidence, morbidity and mortality rates.

B1. PRIMARY CARE

Primary care services are delivered through the Basic Health Units (*Unidades Básica de Saúde - UBS*). While UBS structures may vary per location, each unit is strategically located in communities near highly populated areas and is responsible for offering a variety of health services including: oral care, children's health, women's health (pre-natal, mammography), men's health and elderly care.

Analysis of SUS access in the 12 municipalities considered in the study revealed a variation of 31.4% in Salvador to 96.6% in Mata de São João. It is noticeable that, in general, the proportional access reduces as city population rises. Better access to SUS health services are seen in cities with up to 50,000 residents (Stratum 2). Salvador has the lowest basic coverage when compared with the other municipalities.

TABLE 9. ACCESS TO BASIC HEALTH BY MUNICIPALITY - 2015.

STRATUM	MUNICIPALITY	POPULATION	BASIC HEALTH ACCESS
1	Salvador	2,710,968	31.4
	Madre de Deus	18,183	94.4
	Itaparica	20,994	94.0
	Vera Cruz	38,748	87.0
2	Pojuca	34,106	94.1
	São Francisco do Conde	34,226	81.8
	Mata de São João	41,527	96.6
	São Sebastião do Passé	42,485	86.5
	Average of Stratum 2		90.6
•••••	D:!/Á.:: -	CO COO	F7.0
	Dias d'Ávila	69,628	57.2
	Candeias	84,121	58.4
3	Camaçari	255,238	64.5
	Lauro de Freitas	171,042	69.5
	Simões Filho	121,416	61,0
	Average of Stratum 3		62.1

Source: DATASUS



B2. ONCOLOGY CARE SERVICES

There were a total of 28 oncology care service centers according to Cadastro Nacional de Serviços de Saúde - CNES (National Healthcare Registry) in December 2014, most of them were located in Salvador (85.7%) and 50% of them are private services.

TABLE 10. TOTAL NUMBER AND TYPE OF ONCOLOGY CARE SERVICES OFFERED BY MUNICIPALITY - DECEMBER, 2014.

	NUMBER	ТҮРЕ
SALVADOR		
	10	Private services
	4	Managed by Government
	11	Non-for-profit services
LAURO DE FREIRAS		
	3	Private services
CAMAÇARI		
	1	Private services

Source: CNES

Five of the listed services offer breast health and are reference centers for the population of the state of Bahia. Three of them are managed by government and two are private companies. Most breast cancer patients go to HAM, CICAN or Irmã Dulce Hospital.

TABLE 11. INSTITUTIONS PROVIDING ONCOLOGY CARE SERVICES IN SALVADOR MUNICIPALITY, BY CATEGORY - DECEMBER, 2014.

INSTITUTION	ADMINISTRATIVE SPHERE	ТҮРЕ
SALVADOR		
CICAN - Oncology State Center	STATE	Managed by Government
Roberto Santos General Hospital	STATE	Managed by Government
Prof. Edgard Santos University Hospital	FEDERAL	Managed by Government
Aristides Maltez Hospital	PRIVATE	Nonprofit
Sto Antônio / Irmã Dulce Hospital	PRIVATE	Nonprofit

Source: CNES



B3. MAMMOGRAPHY

In the coverage area of the municipalities under study, there are a total of 130 mammography devices in use, of which 58 located at public health centers (considering associated ones or governmental). The majority (47 devices) are concentrated in the State capital, Salvador.

TABLE 12. NUMBER OF MAMMOGRAPHY DEVICES, TOTAL AND AT SUS, BY MUNICIPALITIES AND CATEGORIES - DECEMBER, 2014.

	TOTAL		AT S	sus
EXISTEN		IN USE	EXISTENT	IN USE
SALVADOR	115	110	52	47
Madre de Deus	0	0	0	0
Itaparica	0	Ο	0	0
Vera Cruz	0	0	0	0
Pojuca	1	1	1	1
São Francisco do Conde	0	Ο	0	0
Mata de São João	1	1	1	1
São Sebastião do Passé	1	1	1	1
TOTAL OF STRATUM 2	3	3	3	3
Camaçari	7	7	3	3
Candeias	3	3	1	1
Dias D'Ávila	Ο	Ο	0	0
Lauro de Freitas	8	7	4	4
Simões Filho	0	Ο	0	0
TOTAL OF STRATUM 3	18	17	8	8
TOTAL	136	130	63	58

Source: DATASUS/CNES

Ordinance 1.101 from the Ministry of Health instituted June 12th, 2002, established a parameter of one mammography device per each 240,000 residents. INCA suggests that each device should perform about 6,758 exams each year.



Considering these guidelines and the estimated number of women ages 50 to 69 dependent on SUS, the suggested availability of devices is greater than what is needed for the population. Even considering that mammography centers in the capital attend to a bigger, more populous area, the supply is still greater than the demand.

TABLE 13. DEMAND FOR MAMMOGRAPHY DEVICES AND MAMMOGRAMS BY MUNICIPALITY WITHIN THE STRATA - 2014.

STRATUM	MUNICIPALITIES	MAMMOGRAPHY DEVICES		MAMMOGRAPHY EXAMS	
STRATUM	MONICIPALITIES	NEEDED	EXISTENT AT SUS	NEEDED	EXISTENT AT SUS
1	SALVADOR	11.3	47	81.682	317.626
	Madre de Deus	0.1	-	489	0
	Itaparica	0.1	_	769	0
	Vera Cruz	0.2	- -	1,429	Ο
2	Pojuca	0.1	1	906	6,758
2	São Francisco do Conde	0.1		908	Ο
	Mata de São João	0.2	1	1,182	6,758
	São Sebastião do Passé	0.2	1	1,340	6,758
	TOTAL OF STRATUM 2	1	3	7,023	20,274
	Camaçari	0.3	-	1,712	0
	Candeias	0.4	1	2,589	6,758
3	Dias D'Ávila	1.1	3	6,056	20,274
	Lauro de Freitas	0.7	4	3,742	27,032
	Simões Filho	0.5	- -	3,268	0
	TOTAL OF STRATUM 3	2.9	8	17,367	54,064
	TOTAL	15.2	58	106,072	391,964

Source: MS/ANS/CNES

The Brazilian Ministry of Health recommends that every woman, ages 50 to 69, have a mammogram at least once every two years. The estimated mammography coverage for this population, excluding those covered by private health insurance, may be observed in graphs 6, 7 and 8.

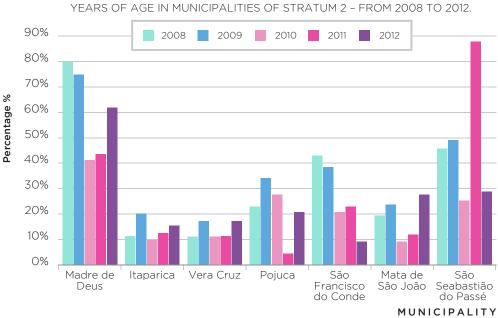


Among studied regions, Salvador has the highest coverage with a noticeable decreasing slope. In 2012 coverage was about 50% in the city. Lowest coverage rates are observed in the set of municipalities with fewer number of residents (Stratum 2).

GRAPH 6. MAMMOGRAPHY COVERAGE AMONG WOMEN FROM 50 TO 69

YEARS OF AGE PER STRATUM - FROM 2008 TO 2012. 90% 2008 2009 2010 2011 2012 80% 70% Percentage % 60% 50% 40% 30% 20% 10% 0% Salvador Stratum2 Stratum3 STRATUM

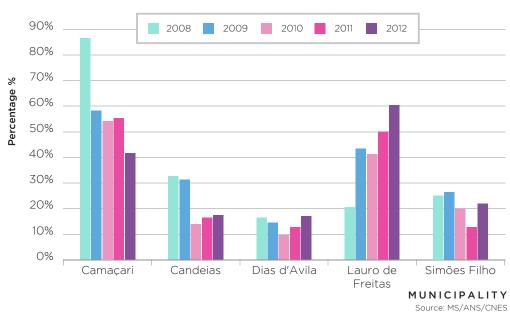
Source: MS/ANS/CNES



GRAPH 7. MAMMOGRAPHY COVERAGE AMONG WOMEN FROM 50 TO 69

Source: MS/ANS/CNES





GRAPH 8. ACCESS TO MAMMOGRAPHY AMONG WOMEN FROM 50 TO 69 YEARS OF AGE IN MUNICIPALITIES OF STRATUM 3 - FROM 2008 TO 2012.

B4. BIOPSIES

Similar to mammography, biopsy services are also concentrated in the capital and are guided by the *PPI - Programação Pactuada e Integrada* (Integrated Services Plan), a set of guidelines that establish the responsibilities of each city or municipality to offer healthcare services based on level of utilization.



As seen in table 14, Salvador is the city that receives more referred patients from the cities studied. A total of six cities refer patients to the capital for diagnostic tests: Dias D'Avila, Itaparica, Lauro de Freitas, São Francisco de Conde, São Sebastião do Passé and Simões Filho.

The other six municipalities offer services such as biopsy¹⁰ that can be done locally: Camaçari, Candeias, Madre de Deus, Mata de São João, Pojuca and Salvador. São Francisco do Conde has an agreement with a service provider located in Madre de Deus city to offer these services.



TABLE 14. INTEGRATED SERVICES PLAN - *PROGRAMAÇÃO PACTUADA E INTEGRADA (PPI)* - OF BIOPSY - MUNICIPALITIES OF SALVADOR METROPOLITAN REGION, 2010.

PPI - 2010					
BIOPSY TESTS	OFFERS BIOPSY SERVICES		REFERRALS TO OTHER CITIES		
BIOPSY TESTS	LOCALLY	# OF TESTS/YEAR	MUNICIPALITY	# OF TESTS/YEAR	
Camaçari	Yes	146	No	-	
Candeias	Yes	56	No	-	
Dias D'Avila	Yes	20	Salvador	19	
Itaparica	No	-	Salvador	14	
Lauro de Freitas	No	-	Salvador	106	
Madre de Deus	Yes	11	No	-	
Mata de São João	Yes	27	No	-	
Pojuca	Yes	22	No	-	
São Francisco do Conde	No	_	Madre de Deus	12	
Suo i runeisco do conac	110		Salvador	10	
São Sebastião do Passé	No	-	Salvador	96	
Simões Filho	No	-	Salvador	79	
Vera Cruz	No	-	No	25	
Salvador	Yes	2,386	No	P	

Source: SESAB

CINTERVIEW

Through interviews with health managers and professionals it became clear that information from different divisions (Surveillance, Basic Attention Units, Regulatory Services, Women's Health, Family Health Strategy, Information Systems) were not, in general, organized, updated, available or systematized.

Out of all visited cities, Candeias was the only team that presented data on estimated new breast cancer cases per year. In the other cities, the policies and program planning processes did not seem to consider this data context and previous history of services performed.



Medium and high complexity services concentration in Salvador demands effective and necessary regulation of patient referrals from the metropolitan region to the capital. However, it was clear that managers and health professionals from Strata 2 and 3 were not familiar with the policy detailing the number of mammograms and biopsies to which they had access through their agreement with the Salvador City Health Department. Not even the health planning professionals in regulatory services had accurate information about how many exams they could perform per year or historical records of the number of exams done to date.

Health institutions, such as HAM and CICAN, attempt to meet the natural demand for sevices despite limited appointments each day. People from all over the state rely on these institutions to receive care, not only those from the metropolitan region; many of which are oriented by the Basic Attention professionals to seek assistance in Salvador on their own and to not wait for a formal referral from regulatory services. They are informed to bypass the system and go on a walk-in basis to get care in a more timely manner.

In an effort to improve the regulatory process, Salvador City Health Department recently created the VIDA system, where cities that have an agreement with the capital can schedule exams electronically. However, other cities describe the system as difficult to access and operate. In order to avoid the "patient-flow agreement" some cities prefer to use their own financial resources to contract out services from private providers (e.g. private clinics).

C1. CHALLENGES RELAYED IN THE INTERVIEWS

a. Mammography challenges

Concentrated in Salvador, mammography devices have a low rate of utilization. The two devices installed in HAM, for example, conducted approximately 6,600 tests in 2014, representing a mere 50% of available capacity.

When questioned about alternatives to expand the network of health services and offer exams in other neighborhoods throughout Salvador, the Health Department professionals explained that exams done by service providers that have formal agreements with SUS are often done in poor quality.

Currently, there isn't a way for the health professionals to demand or ensure higher quality control. According to them, the reimbursement rates through SUS are extremely low.



Many of the private service providers prefer to offer exams directly to women who pay out of pocket. For example, the provider reimbursement from SUS for a mammogram is R\$25.00 (US\$8.93), when compared to a direct fee payable by the patient of R\$65.00 (US\$23.21).

In the municipalities of the metropolitan region, interviews revealed that the challenge of expanding this service is even higher as it is difficult to find skilled professionals and materials supply is short. Consequently, inappropriate techniques are applied, such as reusing the same plate to do multiple images or positioning the patient in the wrong way, which complicates the doctor's analysis.

The interviews showed that, in general, most municipalities perform mammography screening for women ages 35 and above. While they are registering a high number of tests performed, priority age groups (from 50 to 69 according to the Ministry of Health) are not actually receiving good coverage.

Absenteeism is also a problem. According to the State Health Department, about 20% to 30% of women who schedule an exam, don't show up.

HAM is a well-recognized hospital in the region and offers a program called Peito Amigo (Friendly Breast) in which women over age 40 can schedule their mammogram by phone. If the exam results come back with abnormalities, the woman is then routed to an appointment with a specialist. Considering the difficulties in scheduling an appointment, most clinicians refer women to HAM where they can wait in line without an appointment and be seen on a first-come first-serve basis. This includes women from cities where a pre-existing formal agreement is in place that makes the city responsible for delivering services to their residents. On average, it can take from 10 – 30 days from the appointment date when the patient is seen to the time they receive results.

b. Biopsy challenges

Biopsies are recognized throughout the healthcare system as the cause of system bottleneck. Women who follow the established pathway to request this service encounter a complicated and time-consuming process that can take up to six months or more (Figure 7 on page 68).

One of the factors contributing to these delays is the low number of service providers registered with the Salvador City Health Department.

There are a total of six providers. Similar to when seeking mammograms, women find themselves seeking care at HAM to bypass the long waits instead of following the systematic route.

If the patient is diagnosed with cancer, the treatment can be continued in the same hospital. The wait time for women registered at HAM is 45 days.

Limitation in the number of specialists to analyze exam results was also noted as a point of concern. Many clinicians within SUS are not fully trained to screen and diagnose breast cancer and end up sending benign cancer cases to biopsy further burdening the system.

c. Challenges in access to treatment



FEAR

According to interviewed health professionals, some women, afraid of undergoing treatment and of its potential consequences, hide their biopsy results and decide not to seek further healthcare support.



LIMITATIONS IN TREATMENT LOCATIONS

As mentioned earlier in this report, the treatment pathways in Salvador are limited to two institutions, HAM and CICAN. Patients can schedule appointments or stand in line on a first-come first-serve basis.

At HAM, upon consultation with a specialist, patients wait for an average of three weeks to have the surgery performed. However, if there is a higher risk or comorbidities, waiting can be longer due to intensive care unit availability (there is only one bed for breast cancer).

At CICAN, there is an internal flow management system called Data Oportuna (Opportunistic date) - DO, that prioritizes confirmed cancer cases. However, as CICAN does not provide radiotheraphy and only performs low or medium complexity surgeries, more complex cases are sent to HAM. Interview responses suggested that chemotherapy was readily accessible. At CICAN for example, patients may initiate treatment in as little as 48 hours.



TRANSPORTATION AND LIMITED RESOURCES

In interviews and focus groups, patients mentioned that commuting or transportation is the main source of difficulty, especially for those under radiotheraphy treatment since they have to go to treatment daily and do not have sufficient time to recover from the discomfort, waiting and oftentimes hunger.



Health professionals mentioned attrition as a challenge for effective treatment. CICAN has created a follow-up program (Programa de Seguimento) in which they contact patients to find out why they didn't show up and then try to reschedule the appointment. The results of the program have showed that 10% of patients with confirmed diagnoses (including breast cancer) miss their treatment sessions. The main reasons presented by patients have been regarding money shortage, hospitalization, complications or the lack of companionship, especially for elderly people. In some cases the patients are succumbed by the disease during the course of treatment.

Overall, the approval of the 60-day law has increased demand for the expansion of treatment sevices by the city of Salvador and other cities throughout the State. In Salvador, the Department of Regulation for the city appointed an Oncology Committee to oversee the application of the law.

Some have noted the impact of influential figures from the community in access to treatment. The support of a local physician or politician advocating on a patient's behalf can open doors where they might otherwise be closed.

Despite these pronounced barriers in access to treatment, city officials interviewed did not mention a patient waiting list. The Department of Regulation also did not confirm the difficulties in access to treatment.

THE JOURNEY, BARRIERS AND CHALLENGES FACED BY BREAST CANCER PATIENTS

This summary of the paths and difficulties faced by breast cancer patients is a comprehensive analysis of the data collected from the interviews with patients, health managers and professionals, and also the focus groups.

Interviews were held in the period from December 1st, 2014 through February 12th, 2015. Of a total of 87 surveys, four were rejected as they didn't fit the research criteria. Additionally, two women denied participation. In total, there were 81 valid interviews conducted.

In each Stratum, the number of interviews was one unit greater than the necessary sample and all cities were represented (Table 15).



TABLE 15. NUMBER OF INTERVIEWS BY STRATUM AND HOMETOWN.

STRATUM	HOMETOWN	SAMPLE	# INTERVIEWS
1	SALVADOR	30	31
	Madre de Deus		2
	Itaparica		3
	Vera Cruz		6
2	Pojuca		5
	São Francisco do Conde		6
	Mata de São João		1
	São Sebastião do Passé		2
	TOTAL OF STRATUM 2	24	25
	Dias d'Ávila		1
	Candeias		2
3	Camaçari		8
	Lauro de Freitas		8
	Simões Filho		6
	TOTAL OF STRATUM 3	24	25
	TOTAL	78	81

a. Interviewed patients profile



Women aged 29 to 83 were interviewed for this study; with the majority of the interviewees within the age group of 40 to 59 years old (65.4%).



Other factors such as schooling, income and marital status were also considered.



50% of the participants completed elementary school, or at least 8 years of studies



Only 5% had partial or complete undergradutate degree



Also, about 60% of women had an income of up to one minimum wage (Graph 9)



44% received some kind of government financial support like "Bolsa Família" or

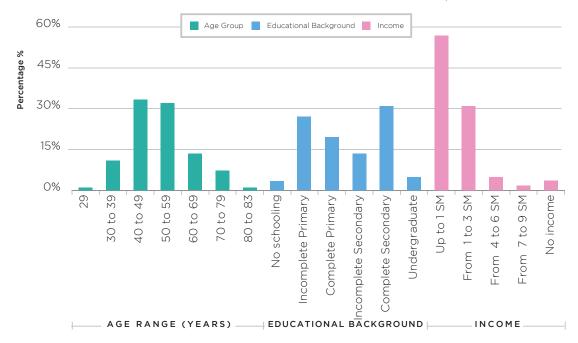


"Auxílio Doença"

Approximately 44% were married or lived with their partners in stable relationships 90% of them had children and 88% self-identified themselves as pardo or black.







GRAPH 9. DISTRIBUTION OF WOMEN INTERVIEWED ACCORDING TO AGE GROUP, EDUCATION AND INCOME.

 $Obs.: SM\ means\ Sal\'{a}rio\ M\'{i}nimo\ (Minimum\ Wage)\ and\ currently\ is\ an\ amount\ of\ R\$788.00\ (or\ US\$281.43).$

The data collected was organized according to the Breast Cancer Care way that "aims to provide integral, humanized and qualified healthcare to women in order to promote breast cancer prevention, early detection and timely and appropriate treatment".

By triangulating methods and sources of information, it was possible to identify 5 critical issues that contribute negatively to high breast cancer incidence and mortality rates in the region (Figure 5).

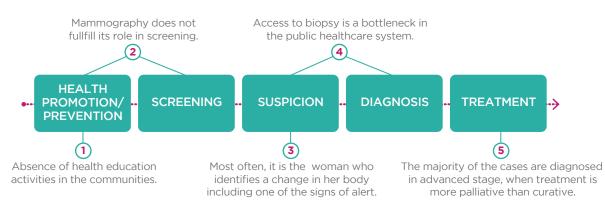


FIGURE 5. BREAST CANCER CRITICAL ISSUES IN SALVADOR METROPOLITAN REGION.



b. Health promotion and prevention

Defined as "actions performed towards social determinants of the health-disease process and that promote quality of life", actions of promotion and prevention are fundamental to population life improvement and disease control.

When talking about breast cancer, these actions aim to raise the population's awareness and to control modifiable risk factors, such as obesity after menopause, sedentarism, excessive alcohol consumption and hormone replacement therapy. They also offer appropriate and timely communication on non modifiable risk factors like: hereditary factors and the ones associated with a woman's reproductive cycle.

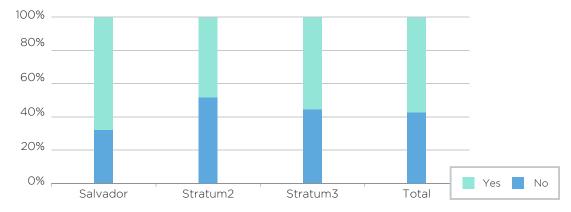
It is also important at this stage to spread information about the importance of getting regular screening tests and to pay attention to abnormal signs or symptoms.

However, even though the Ministry of Health suggests that "actions of promotion are performed in basic attention units as it is closer to women's daily life and follows them along the years" (Source: MS, 2013, pg.17), this study demonstrates that health education activities in communities are still constrained.

When interviewed patients were asked if they had received information about breast cancer and preventative actions to take before being diagnosed, 58% said they had not received any guidance (Graph 10). For the ones who said yes, only half had received information from a health professional. This proportion is bigger in smaller cities as reflected in Stratum 2 (Graph 11).

GRAPH 10. PERCENTAGE DISTRIBUTION OF INTERVIEWED WOMEN ACCORDING TO INFORMATION RECEIVED BEFORE DIAGNOSIS. PER STRATUM TOTAL.

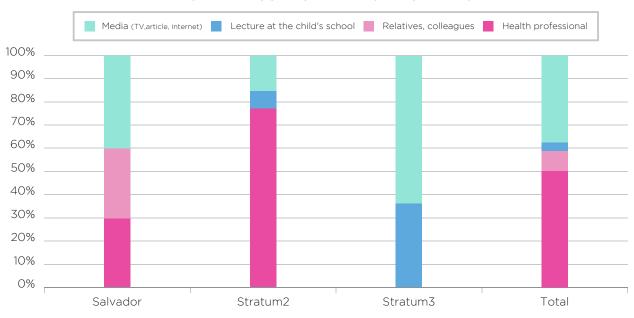






GRAPH 11. PERCENTAGE DISTRIBUTION OF THE WAY INFORMATION WAS RECEIVED, PER STRATUM AND TOTAL.

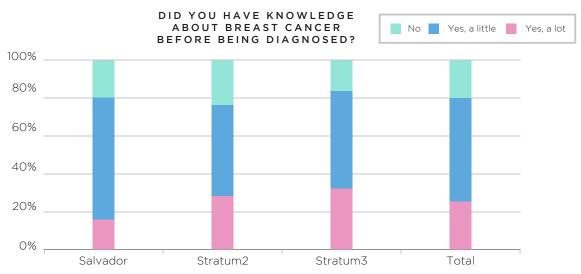




Obs: Data from those 34 women who said had received some information before diagnosis.

Furthermore, 55% of women said they had little understanding of the disease before diagnosis (Graph 12). News or TV programs were cited as the main source of information. Health education activities had a greater impact in smaller cities (Graph 13).

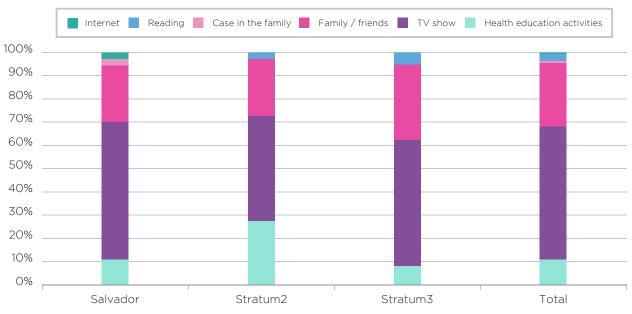
GRAPH 12. PERCENTAGE DISTRIBUTION OF INTERVIEWED WOMEN ACCORDING TO THEIR PREVIOUS LEVEL OF KNOWLEDGE ON BREAST CANCER, PER STRATUM AND TOTAL.





GRAPH 13. PERCENTAGE DISTRIBUTION FOR RATES ACCORDING TO THE MEDIA COMMUNICATION, PER STRATUM AND TOTAL.

HOW DID YOU LEARN ABOUT BREAST CANCER?



Obs: Data from those 65 women who said they had some level of previous knowledge about breast cancer.

One of the most significant factors for breast cancer prevention is the understanding of the importance of getting screened.

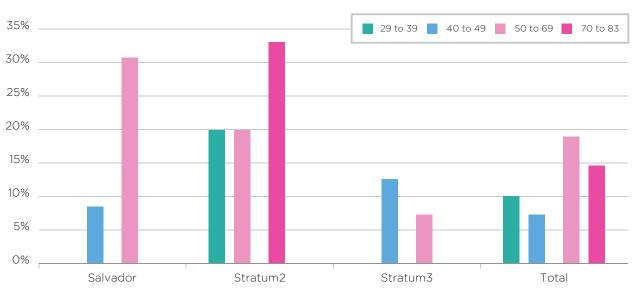
Even though the Brazilian Ministry of Health recommends that every woman at age of 50 to 69 gets a mammogram at least once every two years, only 19% of the interviewed patients from this age group were contacted by basic attention professionals to do so.

In Salvador, despite commentary from interviewed health professionals and managers indicating that women at the "mandatory age group" receive special guidance to get screened, only 30% of interviewed patients confirmed that they had been contacted by the health team to schedule and complete the exam (Graph 14). It is important to note that according to interviewees, this type of contact only happens when the quota for exams is not being reached.









During visits to multiple City Health Departments and Basic Health Units it was observed that when there are education activities of promotion and prevention, they occur inside the health center and thus have a limited scope as it only reaches people who seek the health system. There is no active community outreach program that recruits women in other public services or in the community itself to participate in educational health activities; particularly women in distant areas or those who are more skeptical about healthcare.

When debating this topic during the focus groups the idea that women often don't care for their health was reinforced. Some of the common excuses are that they "have more important things to do" or "because they need to take care of the home, husband and kids". It was also clear that socioeconomic disparities reflect both on their healthcare knowledge and in their access to the health services.

Community health agents showed great concern for women in rural areas. They indicated that barriers for these women included the distance to the healthcare units, their religious and cultural beliefs, for example, feeling ashamed to talk about the subject and ignoring their risk. These difficulties make these women much harder to reach.



c. Screening

There is a clear conflict between the recommendations from the Brazilian Ministry of Health explained on page 54 and Law 11.664 (instituted in 2008) which states that every woman has the right to get a mammogram after the age of 40 years old. The National Cancer Institute (INCA) states that "although it has raised some deviations in terms of interpretation, the text [from the mentioned law] doesn't change screening recommendations regarding the age group for healthy women: 50 to 69 years old"¹².

According to INCA, the most effective ways to detect breast cancer early are mammograms and clinical breast exam that all women over 40 should get once a year.

Nevertheless, in interviews with patients over 40, 55% of them mentioned that they had never received a clinical breast exam or had only been examined sometimes (Graph 15). Of the 44 women who had received a CBE at least once, the exam was done by a doctor 90% of the time.

MINISTRY OF HEALTH GUIDELINES FOR BREAST CANCER EARLY DETECTION & PREVENTION

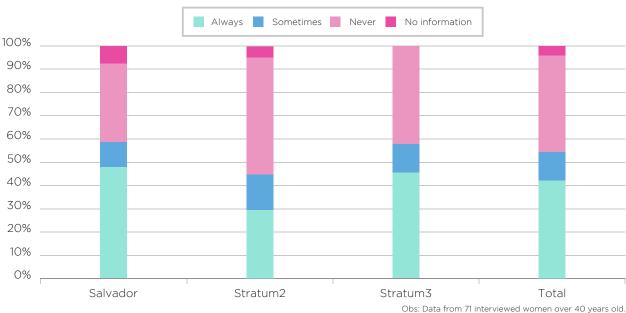
- ✓ Strengthen and expand access to information on breast cancer prevention. Emphasize that body weight management, limiting alcohol ingestion, nursing and exercising are preventive measures for the disease.
- ✓ Warn doctors and the population about the risks of hormone reposition therapy.
- Strengthen and expand access to information about breast cancer early detection to all women and emphasize the early warning signs and symptoms of breast cancer.
- Quickly diagnose breast cancer indicative wounds and refer them as priorities to special treatment.
- Organize screening for women from 50 to 69 years old in areas where high incidence rate justifies this initiative.

Source: MS, 2013, pg.27



GRAPH 15. PERCENTAGE DISTRIBUTION OF INTERVIEWED WOMEN ACCORDING TO THE FREQUENCY OF THE CLINICAL BREAST EXAM, PER STRATUM AND TOTAL.

DID YOU RECEIVE A CLINCIAL BREAST EXAM DURING YOUR MEDICAL APPOINTMENT?



Obs. Data from 71 interviewed women over 40 years old

Health professionals interviewed stated that the clinical breast examination (CBE) is a practice still to be integrated in the Basic Attention Units and, when performed, it is usually done by a nurse in the moment of the cytopathologic exam or if the patient demands. The authors of this report also find it important to note that the realization of the clinical breast exam is not part of the standard nursing training curriculum in Brazil and rather only offered as a specialization course outside of the degree program in most public universities.

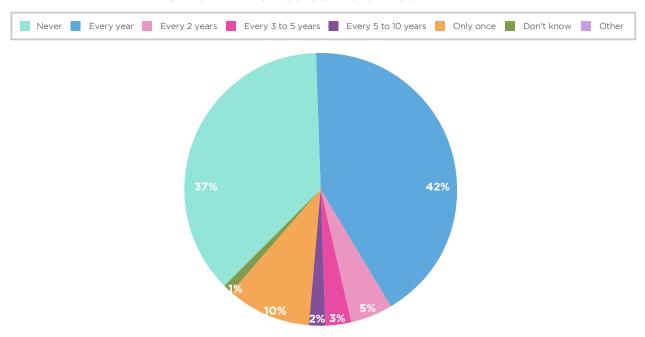


From all the interviewed women, 47% had never had a mammogram or had it only once. Out of those, 44% were over the age of 50 and should have been getting screened at least once every two years (Graphs 16 and 18). Of those that were used to getting screened regularly, none would do it in a Basic Attention Unit near their home, which confirms the challenge of commuting, and suggests, from the authors' understanding that the mammography devices in the nearest health units are perhaps not functional, of poor quality, and that the process is too burdensome. Most of them, 55%, were examined in a hospital and 25% in a service facility affiliated with SUS (Graph 17).



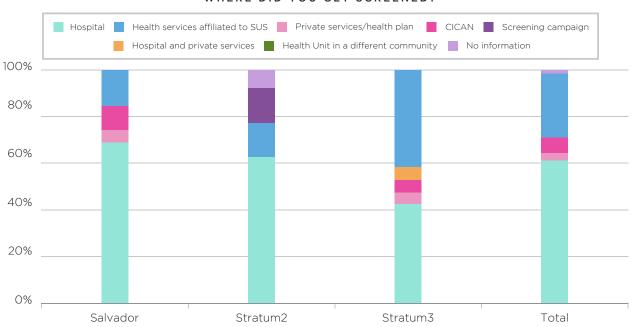
GRAPH 16. PERCENTAGE DISTRIBUTION OF INTERVIEWED WOMEN ACCORDING TO FREQUENCY OF MAMMOGRAPHY EXAM COMPLETION AND PER STRATUM.

HOW OFTEN DO YOU USE TO GET SCREENED?



GRAPH 17. PERCENTAGE DISTRIBUTION OF WHERE WOMEN GET SCREENED, PER STRATUM AND TOTAL.

WHERE DID YOU GET SCREENED?

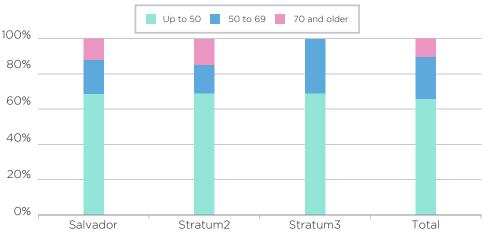


Obs: Data from 51 women who had received mammography test at least once.



GRAPH 18. PERCENTAGE DISTRIBUTION OF INTERVIEWED WOMEN WITH LOW MAMMOGRAPHY FREQUENCY RATE, BY AGE GROUP, PER STRATUM AND TOTAL.

WOMEN WHO WERE NEVER SCREENED OR SCREENED JUST ONCE



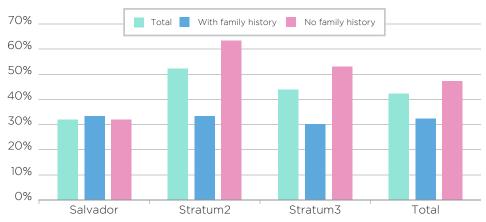
Obs: Data from those 38 women who stated had never had a mammography exam before or had it only once in their lifetime.

Although the Ministry of Health proposes that women with a familial cancer history must be referred to the doctor beginning at 35 years of age, none of the responses throughout this study seemed to validate this statement. There is no evidence to suggest that women in this high risk group received any type of personalized guidance that was different from the other women when it came to screening.

In Salvador, access to prevention and orientation services was the same in both groups. In other strata, women with no family history said they had better access to information than the ones with a family history of cancer (Graph 19).

GRAPH 19. PERCENTAGE DISTRIBUTION OF INTERVIEWED WOMEN ACCORDING TO THE GUIDANCE RECEIVED, BY FAMILY HISTORY OF BREAST CANCER, PER STRATUM AND TOTAL.







Even though some community agents related that women felt afraid and resistant to get a mammogram and 13 interviewed women blamed lack of information and interest as primary reasons for not getting examined. This research demonstrates that there are significant barriers to effective screening including: the functionality and organization of the healthcare system and the time consuming process from being examined to presenting the results to a doctor.

As indicated in Table 12, 47 of the 58 mammography devices in use at SUS in the Salvador Metropolitan Region are in Salvador city. Due to this disproportionate allocation of equipment most women from cities throughout the metropolitan region must commute to the capital in order to get screened and later retrieve the results.

Since the primary entrance to SUS is through the UBS, women need to have an appointment with a general practitioner there in order to receive a referral for mammography. They then must take the referral to a designated location to schedule a date for the exam. Later they have to come back to the same place to get the appointment proof voucher, just so they are informed about the date and time when they can obtain their mammogram.

Considering the amount of time spent in line waiting to complete each of these steps, it is appropriate to suggest that women may need to spend 36 hours from beginning to finish in the process to get a mammogram and the results. Then, repeat it once every two years. The estimation is that the time between the first and last doctor appointment is at least three months (Figure 4).

FIGURE 6. JOURNEY OF WOMEN RESIDENTS IN SALVADOR METROPOLITAN REGION TO RECEIVE A SCREENING MAMMOGRAM¹³.



GO 3 TIMES SPEND ABOUT 12 HOURS.

- 1. Set a medical appointment
- 2. Appointment with a general practitioner
- 7. Take the result of the mammography



GO TWICE SPEND ABOUT 6 HOURS

3. Take the exam requirement term

4. Get the appointment proof voucher

MUNICIPAL HEALTH ··· DEPARTMENT - REGULATION

GO TWICE SPEND ABOUT 16 HOURS

- 5. Do the exam (it might take longer than a month)
- 6. Get the mammography results

(it takes at least 15 days) PUBLIC OR ASSOCIATE **HEALTH SERVICES**

- THE JOURNEY: It might take about 36 hours, 5 half-days or 2 full days and a cost equal to R\$100,00 (US\$35.71) or more for transport and food.
 - · Time spent between the first medical appointment, getting the results and presenting them to a doctor might be over 3 months.



As the established pathways require women to go back and forth to get a referral, make the appointment, get the exam done and so on, apart from money and time spent, many women simply choose not to get screened or look for private healthcare services outside of the SUS system where they would generally be covered at 100%.

Private services, which sometimes don't even follow minimum quality control regulations, offer exams in crowded places (bus stations, as an example) and are a lower cost, faster and easier alternative.

The quantity and distribution of mammography devices as shown in Table 12 demonstrates that there are enough devices in the region to meet 3.7 times the demand of exams for women aged 50 to 69 and who depend on the public healthcare system. Furthermore, data shows that the equipment is under utilized and that there is an urgent need to reorganize and simplify the patient flows in order to expand coverage (see graphs 6, 7 and 8) and improve the effectiveness of screening exams.

In interviews and focus groups it also became clear that the capability of basic attention health professionals to provide guidance and follow up and navigate target residents to mammography is limited.

On one side, community agents do not know the quantity and profile of women at the target age for screening, and on the other it has been hard for the Family Health Teams to develop strategies to expand coverage. All in all, there is a great dependence on mammography campaigns to accomplish annual mammography tests targets.

Interview responses show that even though campaigns help to fulfill the objective of expanding screening access, there is a great obstacle that accompanies these activites; which is to locate the patients that were found to have abnormal results for follow-up after the campaign is over. These events attract people from different communities, and often their personal information is not properly registered as the number of women attending these types of events is fairly high, As a result, many women are lost and possibly never receive their results.

There are also serious problems related to the quality of the mammograms, which has led the Ministry of Health to launch, in 2013, the National Program on Quality Mammography (Plano Nacional de Qualidade da Mamografia – PNQM) that aims to guarantee high quality imaging with low dosages of radiation. The government's goal is to include all mammography services in the program.



It is not easy to get it done.
Sometimes appointments are
not available. There is a
specific day to schedule the
exam. People don't have
money. Many work days are
lost in this process.
They just give up.

Quote from a Community Health Agent
about reasons why women don't get screended.

That is why women don't get mammography tests: it hurts; husband does not allow them to do it; they tried to schedule the exam but couldn't do it and didn't try it again; they are afraid or they don't have anyone to show the results to.

Quote from a Community Health Agent about the results of a survey done with women from a low income neighborhood.

d. Breast cancer suspicion

In the results of the field research with breast cancer patients under treatment, it was detected that out of the 81 interviewed women, 58 of them identified a sign of alert or symptom on their body. Self-exploration or touching of their bodies was the main form of identification reported, in 56 out of 60 stories told.

In most cases the first sign was a lump, hard knot or thickening inside the breast (58%) and in only 38% of the cases there were more than just one sign (Graphs 20 and 21).

WHO IDENTIFIED THE FIRST SIGN OR SYMPTOM?

Other Health professional Herself

Herself

Own

Salvador Stratum2 Stratum3 Total

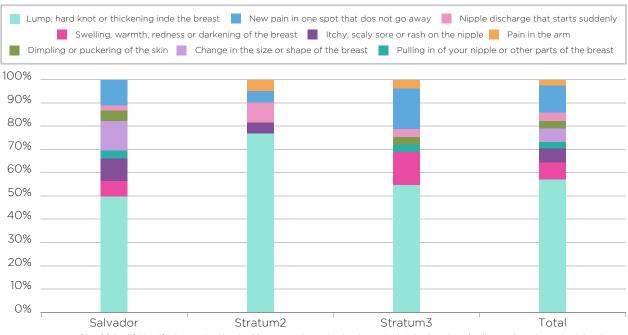
GRAPH 20. PERCENTAGE DISTRIBUTION OF INTERVIEWED WOMEN ACCORDING TO WHO NOTICED A SIGN OF ALERT OR SYMPTOM, PER STRATUM AND TOTAL.

Obs: Other: in one case who found out was the daughter and in the other, the husband.



GRAPH 21. PERCENTAGE DISTRIBUTION OF THE FIRST SYMPTOM OR SIGN, PER STRATUM AND TOTAL.

WHAT WAS THE SIGN THAT MADE YOU SUSPICIOUS THAT SOMETHING WAS WRONG?

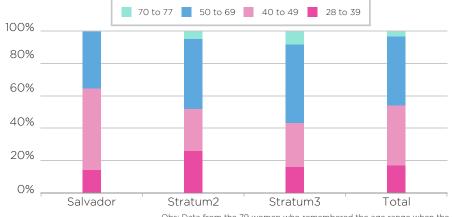


Obs: Of the 96 identified signs cited by the 60 women who noticed a change in their body or by a family member who noticed the change.

Only two interviewed women didn't remember the date when the first sign was found. Among those who remembered it, 40.7% were between 50 and 69 years of age and would be considered in the target population for screening. It is important to call attention to the 53% of women who identified first simptoms when they were under 50 (in Salvador this percentage was 64%) (Graph 22).

GRAPH 22. PERCENTAGE DISTRIBUTION OF INTERVIEWED PATIENTS BY AGE GROUP WHEN FIRST SIGN WAS FOUND, PER STRATUM AND TOTAL.

WHAT WAS YOUR AGE WHEN THE FIRST SIGN OR SYMPTOM WAS FOUND?



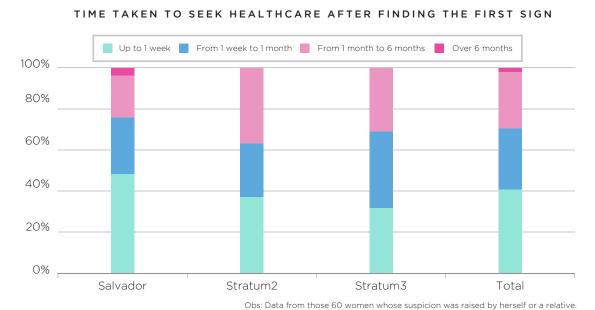
Obs: Data from the 79 women who remembered the age range when the first sign was found.



The participants of the focus groups also brought up their perception about how younger women are being diagnosed with breast cancer recently and stated that this would be a good reason for the government to expand screening to other age groups.

Among those women who noticed a change in their bodies (or their daughter or husband), only 40% sought health services within a week's time (Graph 23).

GRAPH 23. PERCENTAGE DISTRIBUTION OF INTERVIEWED PATIENTS ACCORDING TO TIME SPENT BETWEEN SUSPICION OF BREAST CANCER AND SEEKING THE OPINION OF A HEALTHCARE PROVIDER, PER STRATUM AND TOTAL.



Among 34 women that waited longer than a week to seek medical advice after finding out the first sign, 33 of them addressed the reason. Some presented personal barriers, such as lack of knowledge about the disease, its severity, signs and symptoms, as well as financial problems.

Others described challenges to access healthcare or the quality of services received, citing the time taken to set an appointment and wrong diagnosis given by doctors.

Finally, some women brought issues related to the challenge of seeking healthcare while maintaining their work life. This shows employers lack of awareness about the severity of the disease (Table 7).



 TABLE 16. BARRIERS MENTIONED BY WOMEN AS REASONS FOR NOT SEEKING HEALTHCARE IMMEDIATELY WHEN THEY NOTICED THE FIRST SIGN.

TYPE OF BARRIERS	INTERVIEWERS' NOTES
PERSONAL ISSUES	"SHE DIDN'T THINK IT WAS SOMETHING SERIOUS" "SHE THOUGHT IT WAS NOTHING SERIOUS" "SHE HAD TO RAISE MONEY" "BECAUSE SHE DIDN'T TAKE IT SERIOUSLY" "FINANCIAL SITUATION" "SHE WAS SUSPICIOUS BUT SHE THOUGHT IT WAS NOTHING SERIOUS" "SHE THOUGHT IT WAS A NORMAL LUMP IN HER BREAST, WHEN IT DIDN'T DISAPPEAR SHE SOUGHT FOR A DOCTOR" "SHE DIDN'T GIVE IT MUCH THOUGHT" "HER MOTHER WAS SICK AND WHEN SHE GOT BETTER SHE WENT LOOK FOR HER HEALTH" "SHE ACKNOWLEDGES THAT SHE WAS NEGLECTFUL. SHE NOTICED THINGS AND DIDN'T WORRY' "INITIALLY SHE THOUGHT SHE HAD GOT HURT WITH HER BRA" "SHE THOUGHT IT WAS NOTHING SERIOUS, AS THE PAIN CONTINUES SHE SOUGHT HEALTHCARE" "HER NEGLECTFULNESS, BECAUSE SHE GOT SCREENED EVERY YEAR AND THE DOCTOR SAID THAT THERE WAS NOTHING ABNORMAL" "FEAR" "SHE WAITED FOR THE COMMUNITY HEALTH AGENT'S HOME VISIT, AS SHE CAME OFTEN"
SYSTEM ISSUES	"BECAUSE SHE HAD TO GET AN APPOINTMENT CARD. SHE CONSIDERS THAT IT WAS FAST BECAUSE SHE KNEW SOMEONE THERE" "SHE SOUGHT HEALTHCARE SERVICES ON THE NEXT DAY, BUT COULD ONLY GET A DOCTOR APPOINTMENT 2 MONTHS LATER" "DIFFICULTY TO SCHEDULE AN APPOINTMENT AT SUS" "SHE WENT TO MANY DOCTORS WHO AFFIRMED THAT IT WAS NOTHING SERIOUS" "SHE USED TO WORK AT THE PUBLIC HEALHCARE AND SHE GOT (THE APPOINTMENT) THROUGH THE INFLUENCE OF PERSONAL NETWORK" "SHE USED TO WORK IN A HEALTH UNIT, TALKED TO THE DOCTOR WHO REQUEST THE EXAM" "DIFICCULTY TO SET AN APPOINTMENT; DELAY AT SUS" "SOUGHT IT MANY TIMES AND THEY SAID THAT IT WAS NOTHING SERIOUS" "TIME TAKEN TO SEEK THE NEAREST HEALTH UNIT AND CICAN" "SHE GOT AN APPOINTMENT (8 DAYS) BUT THE DOCTOR DIDN'T SHOW UP" "DELAY TO SET AN APPOINTMENT"
SOCIAL	"SHE WAS WORKING AT THAT TIME AND HAD TO QUIT GOING TO THE DOCTOR" "SHE WAS WORKING HARD AND IT WAS VERY HARD TO SET AN APPOINTMENT" "SHE WAS WORKING HARD" "SHE WAS WORKING IN EVERY DAYS THAT THE DOCTOR WAS AT THE HEALTH UNIT, SO SHE WAITED TO SET THE APPOINTMENT"



During the focus groups sessions these same barriers were described by participants. Many said they could only schedule the appointment with the help of someone in the health service or a politician.

The delay to access public health services led women to seek private healthcare, sometimes having to raise money with friends and family to be able to afford paying for exams and doctor appointments.



Many of the stories reflected disdainful behaviors by the doctors about the women's requests. They shared situations in which they had to grab the doctor's hand and make him feel the lump to so that he would refer for a diagnostic exam.

Participants told personal cases where the patient had a breast cancer case in the family and even so doctors said things like "you are imagining a lump", "this fluid is colostrum as you didn't nurse correctly", "it is nothing".

Finally, issues were raised regarding the poor quality of mammography which prevents early detection and a precise diagnosis. All of these issues have increased disbelief on early and timely diagnosis through mammography, both in women as in community health agents.

e. Breast cancer suspicion

In order to understand the journey from suspicion to breast cancer diagnosis the same questions were asked to women who noticed a change in their body and to those whose suspicion was raised by the doctor.

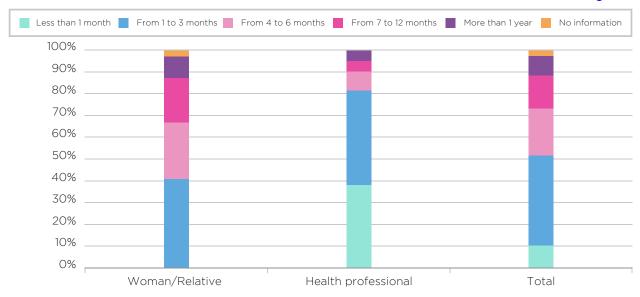
The process from suspicion to diagnosis went faster in cases in which a health professional noted the change (Graph 24), but it unfortunately happened to only 26% of interviewed patients. In patient and survivor focus groups the only cases whose suspicion came from the doctors were the ones of patients who were being followed up for breast dysplasia treatment.





GRAPH 24. PERCENTAGE DISTRIBUTION OF PATIENTS ACCORDING TO THE PERIOD OF TIME BETWEEN SUSPICION AND FIRST DIAGNOSIS, PER WHO IDENTIFIED THE FIRST SIGN AND TOTAL.

TIME PERIOD BETWEEN SUSPICION AND DIAGNOSIS BY FIRST SIGN IDENTIFIER



The concentration of biopsy services in Salvador and in a few cities of the metropolitan region constitutes a challenge for women. Among the interviewed from Strata 2 and 3, around 86% had the diagnostic exam done in Salvador (Graph 25). Around 83% did the exam in hospitals or reference healthcare centers (Graph 26), being that CICAN is the main reference center mentioned (stated per 28 out of 30 who went to reference centers).

GRAPH 25. PERCENTAGE DISTRIBUTION OF PATIENTS BY THE CITY WHERE DIAGNOSIS EXAM WAS TAKEN, PER STRATUM AND TOTAL.

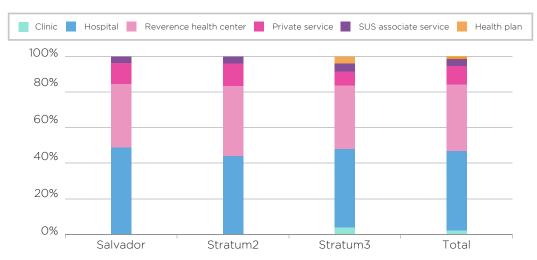
Salvador Camaçari Vera Cruz São Francisco do Conde Simões Filho

Solvador Stratum2 Stratum3 Total



GRAPH 26. PERCENTAGE DISTRIBUTION OF PATIENTS BY HEALTHCARE SERVICE WHERE DIAGNOSIS EXAM WAS TAKEN, PER STRATUM AND TOTAL.

CATEGORY OF HEALTH SERVICE WHERE DIAGNOSTIC EXAM WAS CONDUCTED



For women residents of one of the municipalities from the RMS, in order to get a biopsy it is necessary that a doctor requests the exam. Then, the patient has to go to scheduling for them to check the referral, authorize and schedule the test (which requires women to go back and forth three separate times). It is also necessary to go to the center twice, first to get tested and later on to get the results. Finally, the patient goes back to the Basic Health Unit to schedule and have an appointment with a specialist for results analysis and referral. All in all, this process takes at least six months (Figure 5).

FIGURE 7. JOURNEY OF WOMEN RESIDENTS IN SALVADOR METROPOLITAN REGION TO HAVE A BIOPSY TEST TAKEN14.



In general, at the **RMS** municipalities the time spent between checking the exam request at regulation and having the final medical appointment to show the results is of 6 months or more.

GO TWICE SPEND ABOUT 8 HOURS

- 1. Take the exam request at Regulation to check, authorize and schedule the exam
- 2. Get the appointment proof voucher
- 5. Schedule appointment with a specialist



MUNICIPAL HEALTH ... DEPARTMENT - REGULATION

GO TWICE SPEND ABOUT 16 HOURS ..

3. Get tested (it might take longer than 1 month)

4. Get the test results (it takes at least 15 days) PUBLIC OR ASSOCIATE

···> HEALTH SERVICES

GO TWICE

6. Have appointment with a specialist for results, SPEND ABOUT 16 HOURS .. analysis and referral. PUBLIC OR ASSOCIA HEALTH SERVICES

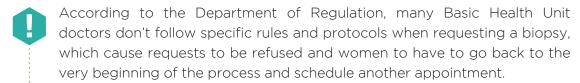
PUBLIC OR ASSOCIATE

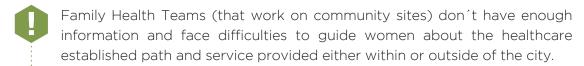
THE JOURNEY: It might take about 40 hours, 6 half-days or 3 full days and a cost equal to R\$160,00 (US\$57.14) or more for transport and food.

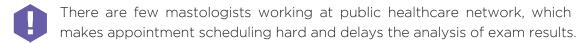


This delay could be a result of different factors as described both by patients and health managers:









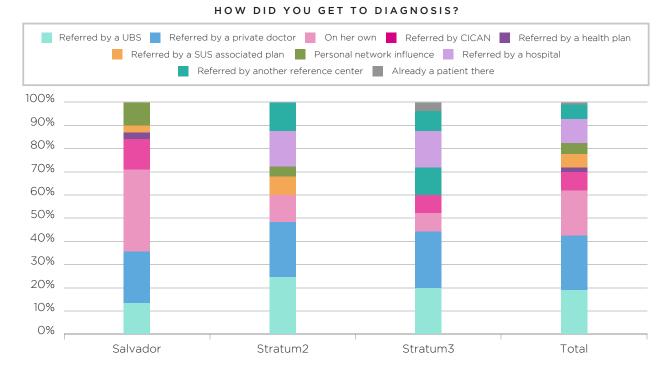
These difficulties faced by women, combined with weakness (from pain and other symptoms) make them choose a private healthcare service thus paying for the test and all combined costs: transportation, meals and doctors appointments.

Biopsy exam prices varies from R\$600 to R\$800 (US\$214.28 to US\$285.71), and women sometimes only find out at the end of the process that the price didn't include a medical summary (which costs around R\$50 or US\$17.86 extra). Also, the private exam may not be accepted by the public healthcare center in which they seek treatment.

The lack of adherence to systematic protocols is a serious issue. Particularly as interviewees have related that when health professionals identify a suspicious sign, they inform women to look for a reference center (such as CICAN or HAM) or a private healthcare service instead of following the protocols set by the regulatory department. The authors of this report believe that this creates an unecessary burden on the woman by making her believe that it is her responsibility to make every effort to obtain the necessary diagnostic tests and subsequent treatment of her cancer.

Interview data confirmed the fact presented above by demonstrating that out of 81 patients, only 18% got to the diagnosis test referred by a Basic Health Unit. Other 23% were referred from a private doctor, 20% got there on their own and 5% because they had personal acquaintances at the institution (Graph 27).





GRAPH 27. PERCENTAGE DISTRIBUTION OF PATIENTS PER HOW THEY GOT TO DIAGNOSIS, PER STRATUM AND TOTAL.

When seeking services at one of the reference oncology care centers (CICAN and HAM) without a referral, women must obtain an attendance voucher and wait.. To do so, women arrive early in the morning (around 5 AM) in hopes to receive one of only 60 vouchers handed out daily. Many leave their homes when it is still dark and face the risk of violence.

Do you want me to tell you how it works? The woman leaves her house at the crack of dawn, afraid of street violence, takes the bus crying and gets to CICAN to wait for hours in line for an appointment and exam request term. There she meets many women under treatment and gets even more scared.



Quote of a Community Health Agent about what happens when a woman finds the first sign and goes on her own to get diagnosed.

f. Access to treatment and follow-up

All 81 interviewed patients were under breast cancer treatment in Salvador, 92% in the hospital. Most of them were referred by the system itself and 50% by reference centers. However, 15% were referred by a private doctor; a percentage that comes up to 20% in smaller cities, reinforcing the idea that women seek private healthcare service in order to obtain a quicker diagnosis (Graph 28).



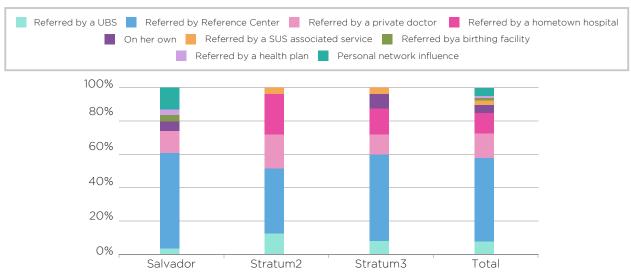
For 80% of patients that get here all we can offer is a palliative healthcare. In only 20% of cases we can really treat cancer.



Quote of the director of a reference center in Salvador.

GRAPH 28. PERCENTAGE DISTRIBUTION OF PATIENTS ACCORDING TO HOW THEY GOT TO TREATMENT, PER STRATUM AND TOTAL.

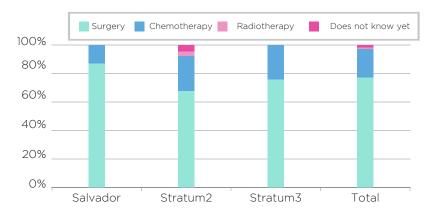
HOW DID YOU GET TO TREATMENT?



Of the 81 interviewed patients, 72 were not under their first treatment. For most of them (78%) surgery had been the first one (Graph 29).

GRAPH 29. PERCENTAGE DISTRIBUTION OF PATIENTS BY FIRST TREATMENT, PER STRATUM AND TOTAL.

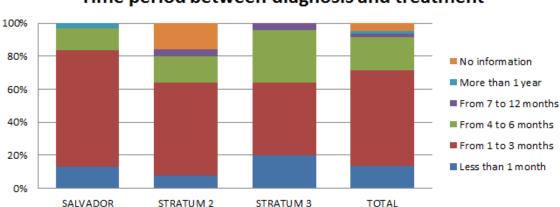
WHAT WAS YOUR FIRST TREATMENT FOR BREAST CANCER?



When asked about when they started their first treatment only one patient did not have an answer. By analyzing the beginning dates of diagnosis and treatment, it is possible to verify that for 36% of them this time period was over 60 days. In Stratum 3, this percentage rises to 44% (Graph 30).



GRAPH 30. PERCENTAGE DISTRIBUTION OF PATIENTS ACCORDING TO THE PERIOD OF TIME BETWEEN DIAGNOSIS AND TREATMENT, PER STRATUM AND TOTAL.



Time period between diagnosis and treatment

This indicator is relevant as it ensures the importance of Law 12.732, from November 2012 as known as "60 Day Law" already discussed in the section about the National Policy for Breast Cancer Control and Prevention.

When analyzing the reasons why interviewed patients took longer than 60 days to start their treatment, it was noticeable that the challenges were primarily when it came to taking the required exams and getting the results, and scheduling the treatment, as many of the places available were hard to find (Table 17).

TABLE 17. REASONS MENTIONED BY WOMEN FOR STARTING TREATMENT OVER 60 DAYS AFTER DIAGNOSIS.

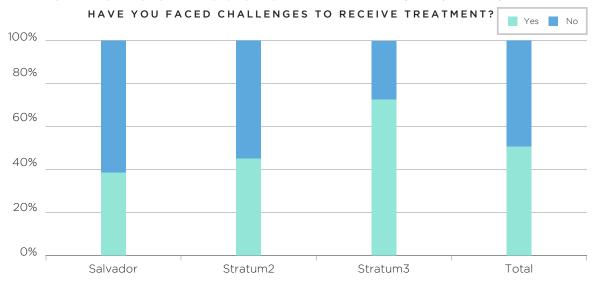
REASONS	INTERVIEWERS' NOTES
WAITING FOR EXAMS, RESULTS AND SCHEDULING	"SHE WAS WAITING FOR THE RESULTS OF EXAMS" "WAITING FOR EXAMS RESULTS" "IT TOOK LONG TO GET THE RESULT OF THE EXAMS" "SHE HAD TO TAKE PRE-SURGERY EXAMS AND THE RESULT OF ONE OF THEM TOOK LONG TO BE RELEASED" "WAITING FOR THE RESULT OF SOME OF THE EXAMS AND FOR SCHEDULING THE SURGERY" "BECAUSE OF THE RESULTS OF EXAMS THAT WEREN'T DONE THROUGH SUS" "THE SURGERY WAS SCHEDULED BEFORE HAVING THE RESULT OF BIOPSY" "SHE HAD TO TAKE OTHER EXAMS AND WAIT FOR SURGERY TO BE SCHEDULED" "IT WAS THE TIME REQUIRED TO HAVE SOME EXAMS TAKEN AND THE HOSPITAL CARD MADE" "TIME NEEDED TO TAKE OTHER EXAMS AND WAIT FOR THEIR RESULTS"



	"I SHOULD HAVE DONE IT IN SEPTEMBER 2014, BUT SOME EXAMS WERE MISSING AND TOOK LONG. SURGERY HAD TO BE RESCHEDULED. AT THAT DAY HOSPITAL WAS OUT OF POWER AND THE SURGERY WAS RESCHEDULED AGAIN" "SHE WAS WAITING FOR SOME EXAMS AND IT WAS ALSO THE TIME NEEDED TO SCHEDULE THE SURGERY" "BECAUSE OF SCHEDULING AND OTHER EXAMS. SHE SAID THAT THEY EVEN ANTICIPATED, THAT IT WAS FAST" "WAITING FOR RESULT OF SOME EXAMS" "BECAUSE SHE HAD TO REDO ALL THE EXAMS"
NO VACANCIES AVAILABLE	"WAITING FOR VACANCY AVAILABILITY" "NO AVAILABILITY FOR SURGERY" "EVERYTIME SHE TRIED TO SCHEDULE IT THERE WERE NO APPOINTMENTS AVAILABLE" "SHE COULDN'T SCHEDULE SURGERY ON THE DAYS REQUIRED" "IT TOOK HER LONG TO SET A MEDICAL APPOINTMENT AND THEN TO HAVE AVAILABILITY FOR SURGERY" "THERE WAS NO VACANCY AVAILABILITY AT THE HOSPITAL" "NO VACANCY AVAILABILITY"
OTHER	"MONEY TOO SHORT TO PAY THE EXAMS" "FIRST TRY OF DIAGNOSIS DID NOT WORK OUT AND SHE HAD TO GO TO SURGERY" "IT TOOK HER LONG BECAUSE SHE WENT THROUGH MANY DOCTORS THAT REFFERRED HER TO OTHERS INSTEAD OF REFERRING HER STRAIGHT TO ARISTIDES MALTEZ HOSPITAL"

When questioned if they had faced difficulties to have the treatment performed, 49% said yes (Graph 31).

GRAPH 31. PERCENTAGE DISTRIBUTION OF PATIENTS ACCORDING TO WHETHER THEY DID OR DID NOT FACE CHALLENGES TO RECEIVE TREATMENT PER STRATUM AND TOTAL.





Among difficulties described, half were related to commuting, 10% to lack of family and friends support and 4% regarding not having a place to stay. These issues were also addressed in the focus groups where it was concluded that commuting was hard especially from metropolitan region municipalities to the capital:



- **Transportation** offered by the Municipal Governments has an established schedule. Most of the time it leaves the city at 5AM and comes back from Salvador by 12PM. If women miss it they have to go on their own.
- Vehicles carry all kinds of patients to Salvador and are overcrowded. Thus, women are oriented not to take a companion with them.
- Rural district patients must go on their own up to the "road" (highway where the government bus passes by). It forces them to walk there most of the time and in some cases leave home by 3 a.m.

All these issues should be minimized by Out-of-the-Home Treatment¹⁵ benefit (TFD), which gives transportation and money support to meals and accomodation for patients under tratment who live at least 50km far away from the healthcare center, along with their companion.

However, during manager interviews and focus groups with community health agents it was clear that TFD is not completely known, requesting it is confusing and it ends up not benefiting most of patients. It was heard that in one of the cities TFD is not paid after every trip, but after a period of time, and only if the patient insists.

Other important challenges for patients' adherence to treatment identified were:

- The necessity of going to Salvador once a month only to take the medication (in the case of oral antineoplastic or adjuvant treatment) and wait long hours in lines.
- It takes too long to have additional medical exams taken. Therefore, to avoid having another commuting session or missing an appointment already scheduled, patients prefer paying for private services.
- The lack of support or the fear of missing family and husband support, sometimes make women hide their problems and feelings.



- Since transportation places are limited and there are limited funds to pay for a private service, many women choose not to take a companion with them.
- Low self esteem, especially when their hair falls, makes women want to hide at home.
- Faith sometimes is a barrier, as women give up treatment believing they are already cured.
- Radiotherapy's weariness comes from having to go to Salvador everyday.

Professionals at CICAN stated that around 10% of patients with a confirmed diagnosis (including breast cancer) don't start the treatment or quit in the middle of it.

Although, the Ministry of Health's directives determine that after getting a confirmation result Basic Attention Units must follow this patient up, refer her to a healthcare center to complete diagnosis and start the treatment. During this process it is essential to assess the patient and her understanding about the disease, encourage her to adhere to the treatment¹⁶.



It is noticeable that patients are not followed up systematically by the Basic Health Units.

Although data collected shows challenges faced by women in their pathways since suspicion, 57% of interviewed patients said that they had not faced problems or difficulties in the healthcare services they had attended to. This percentage is even higher in smaller cities, reaching 72% (Graph 32).

When justifying this answer those women who denied having faced challenges stated:







RECOMMENDATIONS



Results of this assessment show a serious situation for breast cancer in Salvador and its metropolitan region. Besides identifying important reasons why this disease is not controlled and has high mortality and incidence rates, the data collected also pointed to critical issues along the breast cancer continuum of care.

A lot must be done to improve this situation; increase political and social commitment to it and guarantee a less painful future for patients and their families. Four target priorities must be addressed to improve this situation. They are:

Priority 1

HEALTH EDUCATION IN COMMUNITIES

It is vital to improve women's knowledge about breast health, breast cancer risk reduction strategies, early detection, and breast self-awareness.

By not valuing their own health and assuming a great number of functions and daily activities, women do not prioritize their personal healthcare. Myths and beliefs also contribute to their not wanting to discuss breast cancer nor comprehend its severity.

Due to a lack of knowledge, many women neglect their medical exams, fear their results, and do not immediately seek for help when they notice changes in their breasts. It is important that, from cooperation between government and non-for-profit organizations, a community health education program be created with a particular methodology, focusing on contents that increase women's awareness and empowerment for better breast care.

RECOMMENDED INITIATIVES:

- Creating an effective community health education program.
- Strengthening non-for profit organizations and social groups that support women.

Priority 2

QUALIFICATION OF PRIMARY CARE HEALTH PROFESSIONALS AND MANAGERS

As primary care is the gateway for communities to access SUS, there is a need for better qualified professionals to assist women and guide those with questions, suspicion and diagnosis of breast cancer.

Working directly in communities, Basic Attention teams are formed by doctors, nurses, dentists, community health agents and other professionals and are normally the first and



main contact of residents to the public healthcare system.

It is under Basic Attention responsibilities to promote health promotion actions and contribute to organizing the flow in order to ease access to timely and effective diagnosis and diseases treatment.

When talking about breast cancer, it is essential that the whole Basic Attention team fully understands the disease, its signs and symptoms, to adequately respond to the needs of women that arrive with questions or suspicions instead of disqualifying her comments as discovered in this study.

It is also important that they are knowledgeable about available resources in the city for breast health, and the agreements established with other municipalities that may facilitate and/or expedite the referral of women and potentially make it easier to offer them proper and comprehensive guidance.

Apart from all of this, it is fundamental that they are aware of the relevance of screening exams, especially when considering that many of the women in the target age groups are not being reached. It is also important that the CBE is adopted and implemented as an important screening tool and essential part of the doctor visit.

By doing all of this, early diagnosis rate can be improved, reducing mortality by breast cancer in the region in the long term.

RECOMMENDED INITIATIVES:



Creating a capacity building program on breast cancer for Basic Health Attention teams.

Priority 3 FLOW ORGANIZATION AND BETTER COMMUNICATION BETWEEN HEALTHCARE SERVICES

Improving the timeliness of a woman's access to breast cancer diagnosis and treatment relies on more regulation and referral system strengthening between Basic Attention Units and medium and high complexity healthcare services. It also depends on a better communication between their managers and health professionals.

Currently, from the point of breast cancer suspicion forward, a woman begins an arduous journey throughout the healthcare system facing poorly qualified health professionals, unmatched pieces of information, long lines and a lot of waiting time.

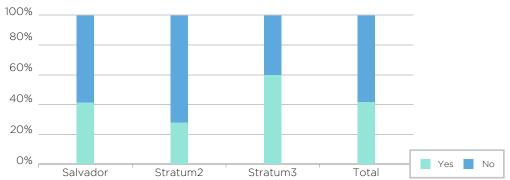


The responsibility to have the exam done quickly suddenly becomes a burden on the woman's shoulders as she is oriented to seek assistance from the reference centers in the capital city on her own and with no financial or emotional support offered by SUS.

In order to avoid this time consuming back and forth and six-month wait or even more to get diagnosed, women, who many times can't afford it, choose a private healthcare service to alleviate their worries and/or confirm their fears.

GRAPH 32. PERCENTAGE DISTRIBUTION OF PATIENTS WHO FACED DIFFICULTIES AT HEALTHCARE CENTERS, PER STRATUM AND TOTAL.

HAVE YOU FACED DIFFICULTIES OR PROBLEMS IN THE SERVICES YOU ATTENDED SO FAR?



The lack of a clear mapped out flow of referrals and requests allows for political influence during screening campaigns (for example, the exchange of votes for an exam) and preferred attendance to the ones who know someone "from the inside" the system.

Having no clear information or control over the quota for biopsies agreed to with the Salvador City Health Department, municipalities face challenges to schedule the exam and the general perception is that "there are no biopsies at SUS".

As treatment starts, women residents in the Metropolitan Region need to go often to Salvador facing many commuting challenges as government transportation has limited places, scheduled departure times and lack of access for people at rural areas.

This whole situation gets even more serious for those with low income and level of schooling as they find it hard to understand their situation and cannot afford paying for the exams or transportation. They count on contributions from family and friends or get indebted.

It is essential to increase the awareness of the Health Secretaries and managers regarding the seriousness and magnitude of breast cancer issues and the importance of putting into practice programs and policies for breast health.



With better communication and cooperation between professional teams of all components of the healthcare system (departments, hospitals, basic health units, regulation and client support services) action plans could be jointly created, reviewing protocols and practices that could reduce the amount of time women spend waiting in lines.

RECOMMENDED INITIATIVES:

- Review of breast care protocols and organization of patient flow.
- Restructuring of mammography device placement throughout the region.
- Include ultrasound devices in public healthcare network to complete diagnosis.
- ✓ Include mastologists in public healthcare network to streamline diagnosis and provide treatment referral.
- ✓ Monitoring of breast care public policies, programs and services and evaluation of results.
- Implement a follow up program at Basic Attention Units including all women since first sign or symptom.

Priority 4 PROMOTION OF PATIENTS RIGHTS

Women and breast cancer patients must know their rights and find ways to guarantee them.

Despite the barriers and challenges faced by women along the entire journey, it became clear that they have little or no knowledge about their rights and, consequently, adopt a resigned behavior. Furthermore, they lack support from social groups and institutions that could help them to better understand their situation as patients and guide them on how to better advocate for their rights.

RECOMMENDED INITIATIVES:

- Creating an education program in patient rights that promotes women and patients empowerment.
- ✓ Strengthening nonprofit organizations and social groups that support women.
- Social control of breast care programs and policies implementation and results.





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- ⁵Brasil. Instituto Nacional do Câncer. Nova Política Nacional para a Prevenção e Controle do Câncer é divulgada pelo MS. INCA website. Disponível em
- http://www.inca.gov.br/wps/wcm/connect/agencianoticias/site/home/noticias/2013/nova_politica_nacional_prevencao_controle_cancer_divulgada_pelo_ms
- ⁶ Published on June 3rd, 2014, Order 1.220 changes article 3rd of Order 876/GM/MS, from May 16th, 2013 which analyses the application of Law 12.732, from November 22nd, 2012 in which is stated the first treatment for patients with proved malignant neoplasia in SUS.
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- ⁹Translator's note: Linfoma Não Hodgkin (Non-Hodgkin Lymphoma NHL); Corpo Uterino e Útero (Uterine), Ovário (Ovarian); Estômago (Stomach); Traqueia, brônquios e pulmões (Trachea, brochi and lungs); Cólon e reto (Colorectal); Colo de Útero (Cervical cancer); Pele (Skin); Mama (Breast).
- ¹⁰ The way PPI document is provided it is not possible to know if healthcare is offered by SUS or by and associate.
- ¹¹ Brasil. Ministério da Saúde. Secretaria de Atenção à Saúde. Departamento de Atenção Básica. Controle dos cânceres do colo do útero e da mama. Ministério da Saúde, Secretaria de Atenção à Saúde, Departamento de Atenção Básica. 2. ed. Brasília: Editora do Ministério da Saúde, 2013, pp.26.
- ¹² Brasil. Instituto Nacional do Câncer. Nova Política Nacional para a Prevenção e Controle do Câncer é divulgada pelo MS. INCA website. Disponível em
- $http://www.inca.gov.br/wps/wcm/connect/agencianoticias/site/home/noticias/2013/nova_politica_nacional_prevencao_controle_cancer_divulgada_pelo_ms$
- ¹³ Conversion rate considered: US\$1 = R\$2;80.
- ¹⁴ Conversion rate adopted: US\$1 = R\$2,80.



¹⁵ Out of Home Treatment (TFD) is a government benefit that aims to guarantee SUS users commuting when treatment must be taken out of their hometowns or treatment offered in the hometown is run out, as long as there is potential for partial or complete cure. It was designed for patients who need medical assistance of high or medium elective complexity. Out of 12 Salvador Metropolitan Region municipalities, 8 are 50km or farther away from Salvador, which is a requirement for TFD to be offered to resident patients who are eligible to it (SESAB, 2010). The cities are: Camaçari, Candeias, Dias D'Ávila, Madre de Deus, Mata de São João, Pojuca, São Francisco do Conde and São Sebastião do Passé.

¹⁶ Brasil. Ministério da Saúde. Secretaria de Atenção à Saúde. Departamento de Atenção Básica. Controle dos cânceres do colo do útero e da mama. Ministério da Saúde, Secretaria de Atenção à Saúde, Departamento de Atenção Básica. - 2. ed. - Brasília: Editora do Ministério da Saúde, 2013, pp.18.

