ORIGINAL ARTICLE

Women screened for breast cancer: follow-up through Health Information Systems, Brazil, 2010-2012*

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Abstract

Objective: to describe the two-years follow-up of women with screening mammography showing lesions suspected or highly suspected of malignancy in the city of Rio de Janeiro, Brazil. **Methods**: this was a descriptive study of the care line using Health Information Systems (SIS) data on women who underwent screening mammography in the Brazilian National Health System (SUS) in the second half of 2010. **Results**: of the 206 women studied, 13.1% had their mammograms requested by Primary Health Centers; during follow-up 102 (49.5%) were identified on at least one SIS; of these, 12 had biopsy information, all of which was positive for breast cancer; 93 had treatment, one of whom had benign disease; 12 died from breast cancer; the proportion of women identified as having treatment was higher among those with suspected high malignancy and palpable lesions ($p<0.01$). **Conclusion**: information on the breast cancer care line was partially recovered through SIS records.

Keywords: Health Information Systems; Systems Integration; Breast Neoplasms; Continuity of Patient Care; Unified Health System; Epidemiology, Descriptive.

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Introduction

In Brazil, breast cancer is the most common type of cancer among women. Nationwide, 57,960 new cases were estimated in 2016.[1] This incidence, although lower than high-income countries, when contrasted with the mortality rate, suggests an unfavorable scenario in Brazil, since the mortality/incidence ratio is greater[2] and the difference between the incidence and mortality rates is lower, in comparison with high-income countries.[3] In 2014, breast cancer accounted for the highest cancer mortality rate in women taking the world population of women: 13.03 per 100,000 women.[4]

This scenario demonstrates the need to improve early detection and screening actions and to evaluate the continuity of diagnostic investigation and treatment.[5-7] Even so, a fall in breast cancer mortality can be seen in the Brazilian state capital cities, except for the Northern region;[8] whilst mortality is increase outside of these capital cities [9] possibly due to the difficulties in accessing diagnosis and treatment.

> *The reduction of inequalities in access to care and diagnostic and therapeutic methods can reduce breast cancer mortality.*

Mammography is the recommended technique for breast cancer screening, owing to its ability to detect non-palpable lesions and enable a reduction in mortality due to cancer.[10] This reduction in mortality can be attributed to advances in treatment, in addition to the detection of cases in the initial stages as a result of early diagnosis,[7,11] whereby it is fundamental to ensure access to diagnostic confirmation and treatment.[12] It is also necessary to ensure frequency and coverage of the target population equal to or greater than 70%, in order for there to be a reduction in mortality.[13]

In 2013, the current Brazilian Policy on Cancer Prevention and Control was published, namely Ordinance MS/GM No. 874, dated 05/16/13.[14] It reiterates screening and the guarantee of diagnostic confirmation as guidelines and principles related to cancer prevention. A fragmented system, with access and quality of care problems, leads to delays in diagnosis and starting treatment and, consequently, women entering the system at more advanced stages of the disease, thus making screening less effective.[15]

An analysis of population-based cancer records showed that 25% of breast cancer cases had a gap of more than three months between diagnosis and the start of treatment.[16] Another study, using the Hospital Cancer Registry, showed that in specialized hospitals the mean times between diagnosis and the first consultation (35 days) and between the first consultation and the start of treatment (22 days) were higher for women with prior breast cancer diagnosis than for those who arrived at these hospitals with no diagnosis (13 days and 28 days, respectively).

Late investigation of suspected breast lesions is identified as one of the factors related to the advanced stage.[18,19] However, difficulty of access to health services seems to be the most expressive component in this scenario.[7] Studies involving women with breast cancer, using health information systems, have served to identify and evaluate critical points in the health care network of the Brazilian National Health System (SUS).[20,21]

The reduction of inequalities in access to care and diagnostic and therapeutic methods can reduce breast cancer mortality. The concentration of services and human resources in urban areas is pointed out as one of the barriers to be overcome with regard to access to care,[22] indicating that the organization of the health care network remains as a challenge.

The objective of this study was to describe the two-year follow-up of women with screening mammography showing lesions suspected or highly suspected of malignancy in the city of Rio de Janeiro, Brazil, through follow-up using administrative and mortality databases.

Methods

A cohort was built to describe the follow up of women residing in the city of Rio de Janeiro who underwent screening mammography for breast cancer in the second half of 2010 via the Brazilian National Health System (SUS).

Women eligible for the study were those with BI-RADS® 4 (suspected malignancy) or 5 (highly suspected malignancy) mammogram results in one of their breasts,[23] registered on the Breast Cancer Information System (SISMAMA).

Data from a previous study were used[24] in which the RecLink program had been used to carry out probabilistic linkage between the data evaluated. The fields selected for pairing were 'name', 'mother's name' and 'date of birth'. Following the parameters proposed in the program manual. A manual review of all pairs formed with scores >0 was performed.

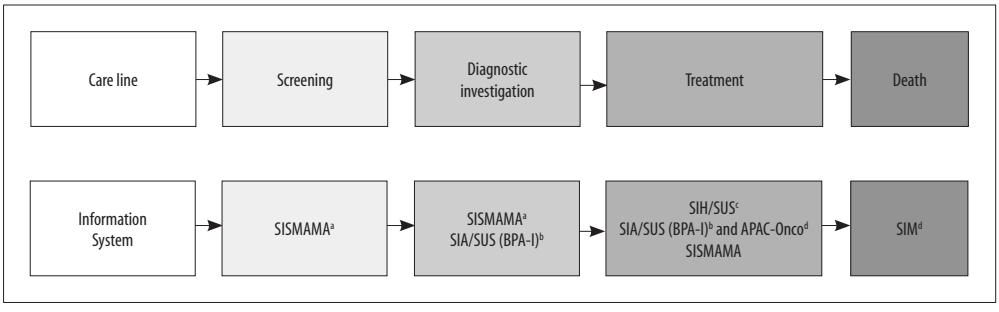
Follow-up was based on the breast cancer care line over two years and examined diagnostic investigation, treatment and death (Figure 1). The diagnostic investigation information consisted of procedures for breast biopsy retrieved from the SISMAMA histopathological module and from the Individualized Outpatient Production Bulletin (BPA-I) held on the SUS Outpatient Information System (SIA/SUS). In situations with more than one diagnostic test, the date of first diagnosis of breast cancer was considered. Surgical specimen was not included as a diagnostic investigation because it was considered to be an offshoot of the treatment stage.

Information about treatment (surgery, chemotherapy, radiotherapy, and hormone therapy) was retrieved from the SUS Hospital Information System (SIH/SUS), the High Complexity Oncology Procedures Authorizations (APAC-Onco) and surgical specimen histopathology retrieved from SISMAMA or BPA-I. In situations with information held on more than one database, the oldest date of treatment was considered, even if the date of hospital admission was available on the SIH/SUS system. Underlying causes of death were obtained from the National Mortality Information System (SIM).

Prevalent cases were excluded, i.e. women who presented the breast cancer (C50) or breast neoplasm of uncertain behavior (D48.6), or breast cancer treatment on a date prior to the mammography used for inclusion in the study. Nineteen such cases were found in the APAC-Onco records and eight cases in the histopathology examination records (SISMAMA or SIA/SUS).

The characteristics of the women included in the study, expressed in proportional values, were also assessed. The clinical characteristics evaluated were: mammography result (BI-RADS® 4 or 5), lesion type (palpable nodule [>20mm]; non-palpable nodule [up to 20mm] or no nodule) and prior clinical examination of the breasts (yes; no). The health care characteristics evaluated were the type of service requesting examination (Primary Health Centers [PHC], secondary service, general hospital or specialized hospital for cancer treatment) and the program area (PA) of the services requesting and performing mammography. The type service making the request was classified as per the description held on the National Database of Health Care Facilities (CNES). The socioeconomic characteristics evaluated were age group (in years: <40; 40-49; 50-69; 70 or more) and education level (illiterate, incomplete or complete elementary education; incomplete or complete higher education). The proportion of women identified and not identified during follow-up were also calculated.

The Pearson Qui-squared test, with or without Yates continuity correction, or the Fisher exact test,[25] as indicated, were used to compare the proportions of these characteristics in order to check for the existence of a statistically significant difference ($p<0.05$) between them.



a) SISMAMA: Breast Cancer Information System.
b) SIA/SUS (BPA-I): Brazilian National Health System Outpatient Information System (Individualized Outpatient Production Bulletin).
c) SIH/SUS: Brazilian National Unified Health System Hospital Information System.
d) APAC-Onco: High Complexity Procedure Authorization - Oncology.
d) SIM: Mortality Information System.

Figure 1 – Breast cancer care line and respective Health Information Systems

The study was approved by the Research Ethics Committee of the Institute of Social Medicine of the State University of Rio de Janeiro (Report No. 1,105,945, 05/25/2015), the Research Ethics Committee of the city of Rio de Janeiro (Report No. 1,162.544, 20/07/2015) and the Research Ethics Committee of the the National Cancer Institute José Alencar Gomes da Silva (Report No. 1,139.738, 07/06/2015).

Results

233 women with screening mammography showing lesions suspected or highly suspected of malignancy were eligible. 27 prevalent cases were excluded. Table 1 presents the characteristics of the 206 women studied, 54.9% of whom were aged 50-69 years. Only 13.1% of mammographies were requested by PHC and 85.4% of women reported having had their breasts examined previously. Services falling into Program Area 2.2, requested and performed 45.6% and 76.2% of mammographies, respectively. The education level variable field was frequently not filled in: 4.4%.

One hundred and two women (49.5%) were identified in at least one of the databases analyzed (Figure 2). Of these, 12 (11.8%) had histopathology biopsy examinations, 10 (83.3%) of whom had diagnosis on the SISMAMA database while the remainder had diagnosis on BPA-I; all 12 had positive malignancy results. 11 (91.7%) were identified as being in treatment, with four having data on SIH/SUS and seven having data on APAC-Onco. Only one died due to breast cancer.

Of the 194 women without biopsy information in the databases examined, 82 (42.3%) were identified as being in treatment. Information on 43 (52.4%) of these women was held on APAC-Onco database, 38 (46.3%) on the SIH/SUS database - one of them identified as a benign case following breast surgery as per International Statistical Classification of Diseases and Related Health Problems (ICD) - and one had information held on BPA-I. Among the 81 women identified as having treatment for breast cancer, seven (8.6%) died owing to this neoplasia. Only six women had information held both on SIH/SUS and on histopathological examination (surgical specimen) records; of these, four had exam completion date one day after hospital admission data, one after two days and one after five days. Among the 38 women who were identified as having breast cancer surgery, 28 (73.7%) were also identified as having chemotherapy, radiotherapy or hormone therapy at a later date (Figure 2).

Of the 112 women who were not identified as having diagnostic investigation or treatment, four (3.6%) died from breast cancer. Four deaths due to other causes were also identified: one from unspecified septicemia, one from finger and feet cellulitis, one from congestive heart failure and one from ill-defined/unspecified causes of mortality. No information was found for any of these deaths regarding an associated cause capable of indicating a possible relationship with breast cancer (Figure 2).

The proportion of women identified in the databases analyzed as being in treatment was greater among those with mammogram BI-RADS® 5 ($p<0.001$), palpable lesions ($p<0.001$), and those aged 50 or more (although with borderline statistical significance: $p=0.062$), when compared to those who were not identified as being in treatment (Table 2).

Discussion

The majority of mammograms was performed in the target age group recommended by the Brazilian Ministry of Health for breast cancer screening.[10] However, a high proportion of these exams was performed outside the target population, what contributes to the low coverage of exams of the target population, as pointed out in other studies.[12,26,27] Furthermore, 13.1% of women had their mammograms requested by PHC. This aspect needs to be studied in greater depth, considering that the Primary Care is responsible for organizing the line of care.[28]

The low level of information on histopathology examinations found in this study suggests difficulty in accessing diagnostic confirmation in SUS,[18,29] reiterating the possibility of conducting the examination outside of the System network, and even outside the city of Rio de Janeiro. Only 45.1% of women were identified as having surgery, chemotherapy, radiotherapy or hormone therapy in the information systems used. As mammography detects suspected cases and few records of diagnostic confirmation were found, it cannot be stated that women having no biopsy information could be undetected cases in this study. However, 42.2% (82/194) of women with no biopsy information were in treatment. This fact reinforces the possibility of having diagnostic tests done at private health services.

Table 1 – Characteristics of women with screening mammography showing suspected or highly suspected malignancy (n=206), women screened by the Brazilian National Health System, municipality of Rio de Janeiro, second semester of 2010

Characteristics	n	%
Age group (in years)		
<40	9	4.4
40-49	45	21.8
50-59	64	31.1
60-69	49	23.8
70-79	27	13.1
≥80	12	5.8
Type of mammography requesting unit		
Specialist hospital	91	44.2
General hospital	18	8.7
Secondary service	70	34.0
Primary health center	27	13.1
Previous clinical breast examination		
No	30	14.6
Yes	176	85.4
BI-RADS mammography® category		
4	162	78.6
5	44	21.4
Lesion type		
Non-palpable	171	83.0
Palpable	35	17.0
Mammography request Programmatic Area		
1.0	72	35.0
2.1	2	1.0
2.2	94	45.6
3.1	9	4.3
3.2	7	3.4
3.3	6	2.9
4.0	1	0.5
5.1	5	2.4
5.2	7	3.4
5.3	2	1.0
Outside the municipality	1	0.5
Mammography request Programmatic Area		
2.2	157	76.2
2.3	28	13.6
3.2	5	2.4
4.0	14	6.8
Outside the municipality/State	2	1.0
Education level		
No information	197	95.6
Illiterate	1	0.5
Incomplete elementary school	2	0.9
Complete elementary school	3	1.5
Complete higher education	3	1.5

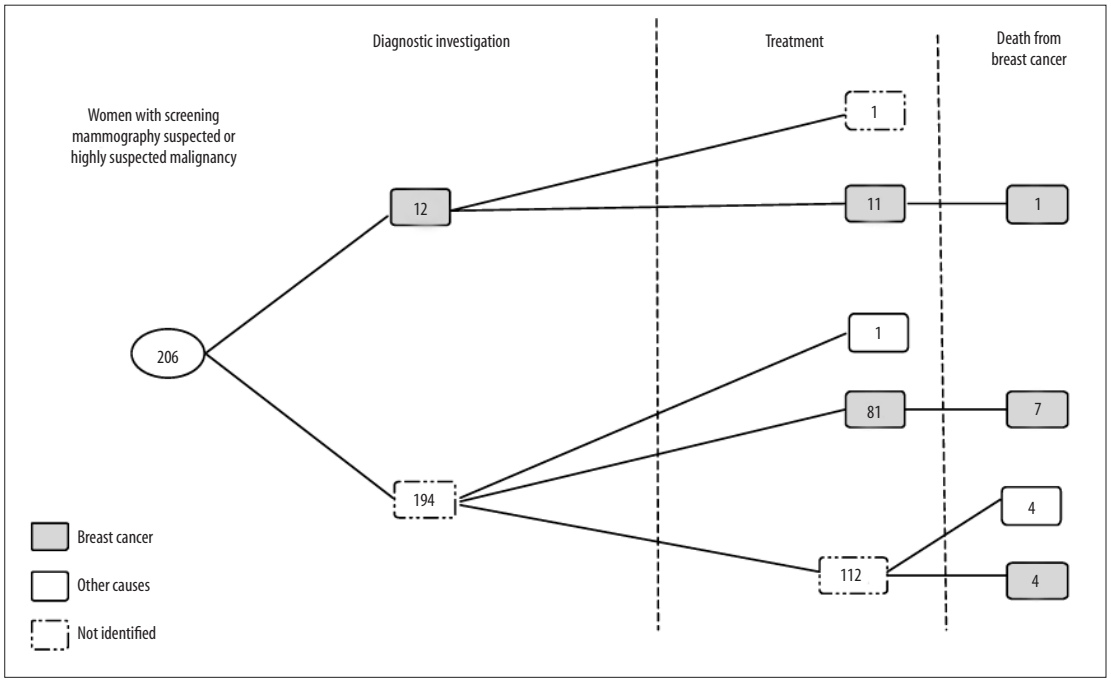


Figure 2 – Identification of eligible women at the stages of diagnostic investigation, treatment and death, municipality of Rio de Janeiro, 2010-2012

The fact that there were 27 prevalent cases which were excluded from the study suggests that the screening mammographies requested for them may refer to follow-up examinations of women with previous history of breast cancer. Once they have been treated, they should have follow-up but SISMAMA is not able to differentiate between screening mammography performed on asymptomatic women with standard risk and screening mammography performed on women already treated for breast cancer. The web version of SISMAMA, known as the Cancer Information System (SISCAN), which is currently being deployed, has been improved and enables differentiation between types of screening mammography.[30]

The presence of palpable nodules in the group of 206 women included in the study also indicates possible problems in the classification of type of mammography requested which should be registered as diagnostic mammography. The presence of palpable nodules in screening mammography was also identified in a previous study and was found to account for 11.4% for Brazil as a whole.[26] This proportion is lower than that identified in the present study. Our study was restricted to mammography which revealed suspected and highly suspected malignancy. This fact may explain, in part, the higher proportion of palpable nodules found.

In relation to the programmatic areas (PA), there were more PAs requesting the examination than PAs performing it. This indicates that the supply of this service is concentrated in certain areas. Despite PA 1.0 having requested 35% of mammograms, none was carried out in this area. However, PA 2.2 requested 45.6% of mammograms and was found to be a center where these exams are conducted (76.2%).

The use of the admission date recorded on SIH/SUS as a proxy for the surgery date appears to be a good strategy for estimating the surgical treatment date: for those cases which also had information on histopathology exams on surgical specimens, the interval between the admission date and the date on which this procedure was carried out was less than a week. When women had records on both SISMAMA and BPA-I for histopathology exams on surgical specimens, for the purposes of this study the date of surgery was taken to be the admission date recorded on SIH/SUS and not the date of the histopathology exams recorded on SISMAMA or BPA-I. In spite of the date of the histopathology exam on surgical specimens corresponding in fact to the date of treatment, the date of the histopathology exam was only found in six cases. Using this date could also lead to an undesirable

Table 2 – Characteristics of women identified and not identified as being in treatment, using Health Information Systems data, municipality of Rio de Janeiro, 2010-2012

Characteristics	Identified as being in treatment (n=93)		Not identified as being in treatment (n=113)		P -value p[a]
	n	%	n	%	
Age group (in years)					0.062
<50	18	19.4	36	31.9	
≥50	75	80.6	77	68.1	
BI-RADS category® [b]					<0.001
BI-RADS® 4	62	66.7	100	88.5	
BI-RADS® 5	31	33.3	13	11.5	
Lesion type					<0.001
Non-palpable	67	72.0	104	92.0	
Palpable	26	28.0	9	8.0	
Mammography request Programmatic Area					0.380
1	27	29.0	45	39.8	
2	49	52.7	47	41.6	
3	10	10.8	12	10.6	
4	1	1.1	–	–	
5	6	6.4	8	7.1	
Outside the municipality	–	–	1	0.9	
Mammography request Programmatic Area					0.339
2	82	88.2	103	91.1	
3	2	2.1	3	2.7	
4	9	9.7	5	4.4	
Outside the municipality/State	–	–	2	1.8	
Type of mammography requesting unit					0.274
Specialist hospital	46	49.5	45	39.8	
General hospital	10	10.8	8	7.1	
Secondary service	26	27.9	44	38.9	
Primary health center	11	11.8	16	14.2	
Previous clinical breasts examination					0.679
No	12	12.9	18	15.9	
Yes	81	87.1	95	84.1	

a) P-value: Pearson Qui-squared test, with or without Yates continuity correction or Fisher's exact test; categories with zero values were excluded.
b) BI-RADS: Breast Imaging-Reporting and Data System - classification of findings of radiological images, proposed by American College of Radiology and adapted to the Breast Cancer Information System (SISMAMA).

variation, since the SIH/SUS dates would be used for 36 of the surgeries. In addition, the admission date was found to be was a good estimator of the surgery date.

An important limitation of this study is the quality of data available in the information systems, which implies that some women can not be identifyied on the databases analyzed. In addition, some women may not have been found on the APAC-Onco database owing to the fact that they were treated for metastatic cancer and the criterion used to separate the records on that database took into account only cases registered for breast cancer treatment procedures.[24]

There is also the possibility that the treatment have been performed outside the municipality or in private health services. Four deaths caused by breast cancer were identified among women not found as being treated. Another limitation to be considered is the possibility of some women with breast cancer remained in the referral database, despite the exclusion criteria, because although they were submitted to surgery no biopsy information was avalilable and it was not possible to assess whether they had been previousily diagnosed for breast cancer among referral mammograms. In addition,

information on previous mammography showing alterations was not used as a selection criterion that could refine the referral database by excluding these cases. The absence of records on the SIH/SUS database for August 2011[24] may also have contributed to loss of information, in case some of histopathology exams have not been included.

The study showed that it is possible to retrieve information about the breast cancer care line from the records held on health information systems, albeit partially. The strategy used meant that some women were located but showed, in particular, the difficulty in obtaining information on diagnostic confirmation. This indicates the need to improve the organization of the breast cancer health care network. The classification of the type of establishment - Primary Health Centers, secondary service, general hospital or specialized hospital - enabled an assessment of the profile of health care services requesting the exams needed.

Authors' contributions

Tomazelli JG contributed to the conception and design of the study, data analysis and interpretation and writing the first version of the manuscript. Girianelli VR and Azevedo e Silva G contributed to data analysis and interpretation and critical review of the manuscript. All the authors have approved the final version and declared themselves to be responsible for all aspects of the study, ensuring its accuracy and integrity.

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