



#### **ORIGINAL ARTICLE**

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## CERVICAL CANCER DIAGNOSTIC JOURNEY: COMPARISON BETWEEN THE BRAZILIAN PUBLIC AND SUPPLEMENTARY SYSTEMS

# JORNADA DIAGNÓSTICA DO CÂNCER DO COLO UTERINO: COMPARAÇÃO ENTRE OS SISTEMAS PÚBLICO E SUPLEMENTAR BRASILEIROS

### TRAYECTORIA DIAGNÓSTICA DEL CÁNCER CERVICOUTERINO: COMPARACIÓN ENTRE LOS SISTEMAS PÚBLICO Y SUPLEMENTARIO BRASILEÑO

Lívia Loamí Ruyz Jorge Paula<sup>1</sup>, Mateus Frederico Paula<sup>2</sup>, Levon Badiglian-Filho<sup>3</sup>

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#### **ABSTRACT**

**Objective:** Compare the diagnostic journey until access to treatment for women with cervical cancer who used the Unified Health System (SUS) and the Supplementary Health System (SSS). **Method:** Comparative and quantitative study carried out in two Brazilian cancer centers with 391 women >18 years old, with up to 18 months of treatment. Demographic, clinical and journey data were analyzed with descriptive statistics, Mann-Whitney test and proposed linear and logistic regression models. **Results:** The majority of women in the SUS had low education and advanced stages (p <0.05); longer duration of the total diagnostic journey (p <0.0001), between the first symptoms and the biopsy (p <0.0001) and between the biopsy and the first consultation with the specialist (p = 0.003).**Conclusions:** Women who used the SUS had a longer diagnostic journey to access treatment than those who used the SSS, in all its stages, converging in higher proportions of tumors with advanced stage.

**Descriptors:** Uterine Cervical Neoplasms, Diagnosis, Public Health, Early Detection of Cancer, Barriers to Access of Health Services.

<sup>&</sup>lt;sup>1</sup> RN. Post-doctorate in Health Economics from the School of Economics, Administration and Accounting at USP-RP. PhD in Oncology from the AC Camargo Cancer Center hospital. Master of Science from the Department of Maternal and Child Nursing and Public Health at the Ribeirão Preto School of Nursing - USP. Specialist in Family Health from UNIARA. https://orcid.org/0000-0003-2270-604X

<sup>&</sup>lt;sup>2</sup> Specialist. Pharmacist. Innovation Project Coordinator. Barretos Cancer Hospital. Barretos Cancer Hospital. https://orcid.org/0000-0003-1363-8962

<sup>&</sup>lt;sup>3</sup> Doctor. Physician. Surgeon in the Department of Gynecological Oncology at the AC Camargo Cancer Center. AC Camargo Cancer Center. https://orcid.org/0000-0001-8741-166X

#### **RESUMO**

**Objetivo:** Comparar a jornada diagnóstica até o acesso ao tratamento de mulheres com câncer do colo do útero que utilizaram o Sistema Único de Saúde (SUS) e o Sistema de Saúde Suplementar (SSS). **Métodos:** Estudo comparativo e quantitativo realizado em dois centros oncológicos brasileiros com 391 mulheres >18 anos, com até 18 meses de tratamento. Dados demográficos, clínicos e da jornada foram analisados com estatística descritiva, teste Mann-Whitney e proposto modelos de regressão linear e logística. **Resultados:** A maioria das mulheres do SUS tinham baixa escolaridade e estadiamentos avançados (p <0,05); maior tempo da jornada diagnóstica total (p <0,0001), entre os primeiros sintomas até a biópsia (p <0,0001) e entre a biópsia e a primeira consulta com o especialista (p = 0,003). **Conclusões:** As mulheres que utilizaram o SUS tiveram jornada diagnóstica mais longa até o acesso ao tratamento do que as que utilizaram o SSS, em todas as suas etapas, convergindo em maiores proporções de tumores com estadiamento avançado.

**Descritores:** Neoplasias do Colo do Útero, Diagnóstico, Saúde Pública, Barreiras ao Acesso aos Cuidados de Saúde, Detecção Precoce de Câncer

#### **RESUMEN**

**Objetivo**: Comparar el recorrido diagnóstico hasta el acceso al tratamiento de mujeres con cáncer de cuello uterino que utilizaban el Sistema Único de Salud (SUS) y el Sistema Suplementario de Salud (SSS). **Método:** Estudio comparativo y cuantitativo realizado en dos centros oncológicos brasileños con 391 mujeres >18 años, con hasta 18 meses de tratamiento. Se analizaron datos demográficos, clínicos y de trayectoria con estadística descriptiva, Mann-Whitney y propuestas de modelos de regresión lineal y logística. **Resultados:** La mayoría de las mujeres del SUS tenían baja escolaridad y etapa avanzada (p <0,05); mayor duración del recorrido diagnóstico total (p <0,0001), entre los primeros síntomas y la biopsia (p <0,0001) y entre la biopsia y la primera consulta con el especialista (p = 0,003).**Conclusiones:** Las mujeres que utilizaron el SUS tuvieron un recorrido diagnóstico más largo para acceder al tratamiento que aquellas que utilizaron el SSS, en todos sus estadios,convergiendo en mayor proporción de tumores con estadio avanzado.

**Descriptores:** Neoplasias Del Cuello Uterino, Diagnóstico, Salud Pública, Detección Precoz De Cáncer, Barreras de Acceso a los Servicios de Salud.

#### INTRODUCTION

Cervical cancer is the second most common type of neoplasia and the second leading cause of cancer death in women worldwide, with nine out of ten deaths occurring in less developed regions.<sup>1</sup> In Brazil, it is the third most common type of cancer in women, with 17,010 new cases expected for each year of the 2023-2025 triennium.<sup>2</sup>

Preventative exams, such as the Pap smear, can easily identify cellular changes

caused by HPV and most of these cases are successfully treated. However, the cervical cancer screening rate in Brazil was below 50% in 2019. In 2020, when the COVID-19 pandemic began in the country, this rate fell to less than 30%.<sup>3</sup>

Currently, Brazil's health system is made up of the public network (Unified Health System – SUS), which serves around 75.5% of the population; and private services, paid for by health insurance

companies, used by around a quarter of Brazilians.<sup>4</sup>

Users of public health services have reported difficulties in early diagnosis of cervical cancer, such as geographic accessibility, low resolution of services, delay in diagnosis and unavailability of material and human resources for treatment. Embarrassment, fear of pain and lack of time are also barriers reported by these women, leading to a possible diagnosis of advanced disease.<sup>5–7</sup>

Delays in cancer diagnosis and treatment are a problem observed in health systems worldwide. This limited access to timely and appropriate treatment is among the conditions that result in poor prognosis and increased mortality.<sup>8,9</sup>

Recently, studies investigating the diagnostic journey of these women have been conducted in several countries, such as Morocco<sup>9</sup>, Zambia<sup>8</sup> and Colombia<sup>10</sup>, with similar results: barriers to access to due diagnosis and treatment to socioeconomic and cultural factors, and structural conditions of the country. In Brazil, the studies conducted focused on describing the diagnostic journey in public health, but there is limited data on the differences in the diagnostic journey carried out in the Unified Health System (SUS) and the Supplementary Health System (SSS).

Thus, the objective of this study was to compare the diagnostic journey to access

to treatment of women with cervical cancer who used the Unified Health System (SUS) and the Supplementary Health System (SSS). Our hypothesis is that the journey of women who use the SUS is longer than that of SSS users.

#### **METHOD**

This is a cross-sectional, quantitative study conducted at two cancer treatment centers in the state of São Paulo between December 2016 and September 2018. The study included women over 18 years of age who were diagnosed with cervical cancer in the SUS or SSS, and had been undergoing treatment for up to 18 months. Patients who were receiving palliative care or who underwent cancer screening tests at one of the study sites were excluded, as they had screening, with organized patient recruitment and monitoring during the period of the study, which is not consistent with the reality of the SUS or SSS.

Eligible patients were identified from the electronic medical records of the Gynecology Oncology Departments of both institutions. The consent process and the application of the questionnaire were carried out by telephone and the Informed Consent Form was sent by email or post, as proposed by Paula.<sup>10</sup> This entire process took, on average, 25 minutes.

A multiple-choice questionnaire was developed by the researchers with variables

to characterize the participants' sociodemographic characteristics (including the health system of care, age, education, occupation, menarche, age at first sexual intercourse, and smoking history), clinical characteristics (such as histological type and tumor staging, history of cervical cancer screening), and diagnostic itinerary (date of examinations, biopsies, and consultations). A delay in diagnostic investigation was considered when the time between the first symptoms and the first consultation with a physician was greater than or equal to 90 days<sup>13</sup>, and a diagnostic delay when the time between the first symptoms and the first consultation with gynecological the oncologist was greater than or equal to 135 days.7,14

A pilot study was conducted in December 2016, involving 36 women users of the SUS and SSS, in order to evaluate the behavior of the data collection instrument, observing the order and understanding of the questions and terms at that time. The sample size was then calculated based on the difference in the time of the diagnostic itinerary in this pilot, based on a significance of 5% and a test power of 80%. Considering the number of women treated in each care system with this diagnosis both institutions, the allocation of these patients was made in a ratio of 2:1 (two patients in the SUS for one in the SSS). Thus, the

sample consisted of 264 patients from the SUS and 132 from the SSS.

Collected data were entered into Research Electronic Data Capture (REDCap).<sup>15</sup> Continuous variables were reported as mean, median, and standard deviation, and the Mann-Whitney test was used for between-group analysis. Categorical variables were presented as counts and/or proportions (%) and compared using the Chi-square test or Fisher's exact test, as appropriate.

A logistic regression model was proposed to evaluate factors associated with the risk of delayed diagnosis, considering the total time of the diagnostic itinerary as the outcome, categorized as delay if the time was greater than or equal to 135 days. We also proposed a linear regression model to evaluate the impact of each variable on the total time of the diagnostic itinerary. The variables that showed an association with a significance level of 20% in the univariate analysis were included in the multivariate models investigate independent associations with a significance level of 5%.

Statistics were performed using IBM SPSS Statistics for Windows, version 21.0. The level of statistical significance was considered as p < 0.05. The study was approved by the Research Ethics Committee of the Barretos Cancer Hospital (1491/2017) and the AC Camargo Cancer Center (46225115.8.0000.5432). All procedures

involving human participants followed the recommendations of Resolution 466/2012 of the National Health Council.

#### RESULTS

Characteristics of participants

A total of 424 eligible women were identified. Of these, 396 were included in the study and 28 refused. The main reasons for not participating were that they did not want to participate (42.0%), did not have time to answer the questionnaire (42.0%), or their spouses did not want them to participate (16.0%).

The characteristics of the patients were illustrated in Table 1. There were no significant differences in age, menarche, smoking history or work status at diagnosis between the groups of patients who used the SUS or the SSS.

**Table 1.** Sociodemographic and clinical characteristics of women with cervical cancer (n=396). Barretos, 2023.

Variables	SUS <sup>a</sup> (	n=264)	SSSb	(n=132)	p
Age in years					0.19
Median	46	5.0	4	42.0	
Mean (SD <sup>c</sup> )	47.0	(13.5)	4	45.1	
Min-Max	22.0 -	- 84.0	23.0	0 - 82.0	
Menarche					0.17
Median		3.0		13.0	
Mean (SD <sup>c</sup> )		(2.00)		0(2.0)	
Min-Max	10.0 -	-20.0	9.0	-16.0	
Coitarca					< 0.0001
Median		7.0		18.0	
Mean (SD°)	17.0 (3.0)		18.0 (4.0)		
Min-Max	11.0 -	- 30.0	14.(	0 - 37.0	
	n	%	n	%	
E duration					< 0.0001
Education Illiterate/Elementary School	132	50.2	16	12.1	
High School	92	34.6	31	23.5	
Higher education	40	15.2	73	55.3	
No response	0	0	12	9.1	
Total	264	100.0	132	100.0	
Smoking	201	100.0	132	100.0	0.65
Yes	46	17.4	23	17.5	0.00
No	218	82.6	96	72.7	
No response	0	0	13	9.8	
Total	264	100.0	132	100.0	
Work					0.12
Employee	143	54.4	81	61.4	0.12
Unemployed	84	31.5	30	22.8	
Retired/housewife	37	14.1	12	9.1	
No response	0	0	9	6.7	
Total	264	100.0	132	100.0	
Histological type of tumor	400				0.001
Squamous cell	188	71.3	70	53.1	
Adenocarcinoma	55	20.8	48	36.3	
Others	9	3.4	2	1.5	
No response	12	4.5	12	9.1	
Total	264	100.0	132	100.0	< 0.0001
Staging I	48	10 1	12	22.6	< 0.0001
I II	48 85	18.1 32.2	43 41	32.6 31.1	
III	83 72	27.3	20	15.1	
111	1 4	21.3	20	13.1	

IV	43	16.3	10	7.6	
No response	16	6.1	18	13.6	
Total	264	100.0	132	100.0	
Habit of performing Pap smear					0.16
Up to 1 year	119	45.1	74	56.1	
Every 2 years	28	10.6	10	7.6	
Did not perform regularly	97	36.7	31	23.4	
Do not remember / never did it	20	7.6	3	2.3	
No response	0	0	14	10.6	
Total	264	100.0	132	100.0	
Reasons for non-compliance					0.64
No commitment to health ("I was	40	15.1	17	12.9	
leaving it")					
Shame	31	11.7	5	3.8	
Lack of time	21	8.0	11	8.3	
Others	7	2.7	4	3.0	
No response	165	62.5	95	72	
Total	264	100.0	132	100.0	

<sup>&</sup>lt;sup>a</sup>Unified Health System; <sup>b</sup>Supplementary Health System; <sup>c</sup>Standard Deviation

Most women (n=147) had their Pap smears regularly, every one or two years. However, 117 women (44.3%) from the SUS and 34 women (28.8%) from the SSS did not have their Pap smears regularly, were not in the habit of having the test or

had never had it. Among the reasons for not having the test, the majority (n=57, 48.8%) stated that it was due to a lack of commitment to their health, followed by

shame (n=36, 30.8%) and lack of time (n=32, 27.4%). They also mentioned that it was because they had no gynecological complaints or had difficulty accessing it (Table 1).

Stage of carrying out examinations and medical evaluation

The time to schedule and perform the Pap smear test, obtain the results and have it evaluated by a professional showed a statistically significant difference between the groups (Table 2).

**Table 2.** Comparison of time (in days) to perform and evaluate the Pap smear (n=396). Barretos, 2023.

Variables	SUS <sup>a</sup> (n=264)	SSS <sup>b</sup> (n=132)	p
Time (days) between scheduling and			0.04
performing the Pap smear			
Median	15.00	10.00	
Mean (SD <sup>c</sup> )	31.00 (50.00)	15.00 (15.00)	
Min-Max	1.00 - 330.00	1.00 - 120.00	
Time (days) for the Pap smear result to			0.001
arrive			
Median	15.00	15.00	
Mean (SD <sup>c</sup> )	29.00 (32.00)	46.00 (252.00)	
Min-Max	0.00-180.00	0.00 - 2555.00	
Time to schedule a medical appointment			< 0.0001
Median			
Mean (SD <sup>c</sup> )	90.00	30.00	
Min-Max	283.00 (868.00)	96.00 (184.00)	
	0.00 - 8760.00	0.00 - 1460.00	

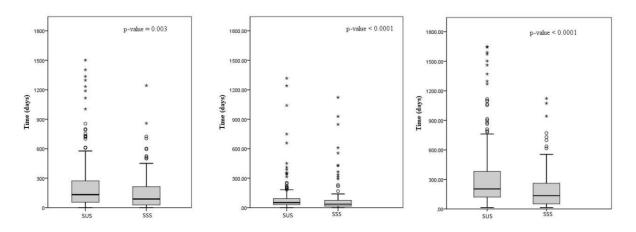
<sup>&</sup>lt;sup>a</sup>Unified Health System; <sup>b</sup>Supplementary Health System; <sup>c</sup>Standard Deviation

It was also observed that the time it took for women in the SUS to schedule an appointment after the onset of symptoms or the first altered Pap smear was greater than women in the SSS group and this difference was statistically significant (median 90.0 vs. 30.0 days, p < 0.001). The delay in diagnostic investigation, considered  $\geq 90$  days, occurred in 137 women (59.3%) from the SUS and 34 women (40.9%) from the SSS and this difference was statistically different (p = 0.004, significance level 5%).

#### Diagnostic process time

The description of the time between the first symptoms or the first altered exam until the biopsy; between the biopsy and the first consultation with the gynecological oncologist; as well as the total time of the diagnostic itinerary (first symptoms or the first altered exam until the first consultation with the gynecological oncologist) are described in Figure 1.

**Figure 1.** Box plot demonstrating the time between the start of the diagnostic process, biopsy and first consultation with the gynecological oncologist (n=396).



In the SUS group, women took, on average, 218.00 days between the onset of symptoms or the first abnormal exam until they were able to have a biopsy ( $\pm 265.00$ days, median 133 days, ranging from 0 to 1642 days); between the biopsy and the first with consultation the gynecological oncologist the average time was 78.02 days (±93.48 days, median 51 days, ranging from 0 to 749 days). Finally, the total diagnostic itinerary time for women in the SUS group was, on average, 316.82 days ( $\pm 320.78$  days, median 203 days, ranging from 14 to 1649 days).

In the SSS group, the time between the onset of symptoms or the first abnormal exam until a biopsy was performed was, on average, 162 days (±203 days, median 88 days, ranging from 0 to 1243 days); between the biopsy and the first consultation with the gynecological oncologist was, on average, 93.24 days (±180.26 days, median 36 days,

ranging from 0 to 1122 days); and the total diagnostic itinerary time for women in the SSS group was 205.46 days (±221.92 days, median 135 days, ranging from 0 to 1122 days). In all these variables, there was a statistically significant difference between the groups.

The results of the univariate analysis indicated that the variables education, work and type of care were possible significant indicators for the risk of delayed diagnosis, at a significance level of 20%. The age variable was categorized in order to perform the test.

For the multivariate model (Table 3), we tested the variables that were significant in the univariate analysis. The only variable that was significant, at a 5% level, was the type of care, with patients who received care through the SUS having a 1.74 times greater chance of delay compared to patients from the SSS (p-value = 0.05).

**Table 3** - Logistic regression (multivariate analysis) of the independent variables of the risk of delay in the diagnostic process (n=396). Barretos, 2023.

Variable	Odds Ratio	IC (95%)	p	
Education				
Illiterate (ref)	_	_	_	
Elementary Education	0.95	0.28 - 3.14	0.93	
High School	1.19	0.59 - 2.35	0.62	
Higher education	1.58	0.85 - 2.92	0.14	
Work situation				
Maid (ref)	_	_	_	
Unemployed	1.04	0.51 - 2.12	0.90	
Health License – Retired	1.11	0.53 - 2.33	0.77	
From home	1.76	0.86 - 3.59	0.11	
Service				
SUSa	1.74	0.99 - 3.04	0.05	
SSSb (ref)	_	-	-	

<sup>&</sup>lt;sup>a</sup>Unified Health System; <sup>b</sup>Supplementary Health System

An analysis was also carried out using a linear regression model, considering the total diagnostic itinerary time as the outcome, in order to assess the impact of the independent variables on time.

The results of the univariate analysis indicated that the same variables schooling, work and type of care can increase the total diagnostic itinerary time of women with

cervical cancer, at a significance level of 20%.

For the multivariate model, we also tested the variables that were significant in the univariate analysis. The two variables that proved to be significant, at a 5% level, were the type of care and the work situation, which can increase the total diagnostic itinerary time (p-value = 0.05) (Table 4).

Table 4 - Linear regression (multivariate analysis) of the impact of independent variables on

the total time of the diagnostic journey (n=396) Barretos, 2023.

	able	В	Standard Error	p
Education				
	Illiterate	-76.68	87.66	0.38
Elen	nentary Education	14.03	49.18	0.77
	High School	55.26	44.15	0.21
High	er Education (ref)	_	_	_
Work				
	Maid (ref)	_	_	_
	Unemployed	96.40	49.97	0.05
Health	License – Retired	23.60	52.43	0.65
	From home	50.24	47.19	0.28
Service				
	SUS	91.65	40.19	0.02
	SSS (ref)	_	_	_

<sup>&</sup>lt;sup>a</sup>Unified Health System; <sup>b</sup>Supplementary Health System

#### **DISCUSSION**

This study sought to describe and compare the diagnostic itinerary of women with cervical cancer who use the SUS and SSS. We found that the time of this itinerary (from the first symptoms or first abnormal exam to the first consultation with the oncological gynecologist) was significantly longer in the SUS group than in the SSS group, confirming our hypothesis.

Delay in diagnosis may occur due to insufficient number of services wellstructured health systems, well-established and effective care flows, in addition to the shortage of materials and human resources, scheduling making difficult and low availability of tests for diagnostic confirmation. 16-17

Furthermore, delayed diagnosis may be associated with socioeconomic factors, feelings and values of women, which may have direct effects on the low demand for screening tests. In this study, education, work and the health system in which they are treated were possible indicators for this delay. Long working hours, combined with the overload of responsibility of raising children and supporting the household may also discourage women from undergoing screening. Furthermore, several studies have shown that low education levels among women are considered an independent risk factor for late diagnosis. In this context, Primary Health Care professionals have a

fundamental role in establishing a bond of trust with this population, making appointment times more flexible and reducing bureaucracy, in order to make them feel welcomed and safe to report signs and symptoms of cancer, as well as undergo screening tests. 9,16,18

Studies that evaluated the journey of women with symptomatic cervical cancer showed that participants delayed seeking specialized care because they did not recognize the severity of their symptoms. Vaginal discharge was more common among patients who delayed seeking care than among those who did not delay seeking however reported care, many not recognizing it as a possible symptom of cancer. 12,16 In addition, symptomatic women not detected by screening possibly miss diagnostic opportunities during poorly resolved visits to primary and secondary care services, resulting in them arriving at oncological care at an advanced stage of the disease. 19 In the meantime, it is important to alert women about the most common signs and symptoms of cervical cancer, in order to encourage them to seek medical care, as well as undergo preventive examinations for investigation.

In Brazil, the waiting time for cancer treatment was determined by law on November 22, 2012, establishing that all cancer patients must begin their first treatment within 60 days from the date the

diagnosis of the disease is recorded in the patient's medical records. We evaluated the time between the biopsy data that diagnosed cancer and the first consultation with the gynecological oncologist, who determines the stage of the tumor and schedules the treatment. The time found was greater than the 60 days established by law for both suggesting that groups, the experienced during screening, regardless of the health system used, can directly contribute to the delay in starting treatment. A similar result was also found in a study conducted in Colombia, where women who were treated by the State plan had a longer time to start treatment than those who were treated by health insurance plans.<sup>20</sup>

Furthermore, the time elapsed in all stages analyzed in the diagnostic process was statistically higher for the SUS group, leading them to have a 1.74 times greater chance of delayed diagnosis compared to SSS patients. These failures in the process of tracking and monitoring altered cases also impacted the greater proportion of women diagnosed with advanced stages (III and IV) in this study, showing that an ineffective and unstructured care network can impact, even indirectly, the survival of these women.

Thus, it is observed that, despite women having the right to access screening tests, diagnostic confirmation and information, this process has been slow, directly impacting the staging and, possibly, the survival of these people.

#### CONCLUSION

Women treated by the SUS had to wait longer to schedule exams and consultations, took longer to seek medical care and were diagnosed later, with a more advanced stage, compared to women in the Supplementary Health System group.

There is a need to restructure the cervical cancer screening program in Brazil, focusing on organized screening, with welldefined care flows between the three types of care and with health professionals well trained to perform early diagnosis of precursor lesions and cervical cancer. In addition, the indicators should be reviewed: it is suggested that government information systems start to produce statistics based on the number of women who underwent these the exams, rather than number of cytopathological tests performed.

Specifically for the Supplementary Health System, it is suggested that a program be created to monitor women who use private health plans, so that professionals who serve them, at different levels of care, can see their history of exams and consultations and also make, more easily and frequently, referrals and counterreferrals to other health services.

This study has some limitations. Possible selection bias may have occurred

due to the different cities where diagnoses study performed. The were sample represents only those who were undergoing treatment at the study sites and does not represent the entire cervical cancer population in Brazil. Recall bias may also exist because the diagnostic trajectories were collected retrospectively.

New studies with a prospective design are needed to identify where the weaknesses lie in each stage of the diagnostic journey and the effects of this time on the survival of women with cervical cancer, in the different Brazilian health systems.

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