ORIGINAL ARTICLE
BASIC SCIENCES
http://dx.doi.org/10.1590/S1808-185120262503295443

# EPIDEMIOLOGICAL PORTRAIT OF PATIENTS WITH EARLY-ONSET SCOLIOSIS IN A TERTIARY HOSPITAL IN SÃO PAULO

## *RETRATO EPIDEMIOLÓGICO DE PACIENTES COM ESCOLIOSE DE INÍCIO PRECOCE EM HOSPITAL TERCIÁRIO DE SÃO PAULO*

## *RETRATO EPIDEMIOLÓGICO DE PACIENTES CON ESCOLIOSIS DE INICIO TEMPRANO EN UN HOSPITAL TERCIARIO DE SÃO PAULO*

LEONARDO SARDAS[1], WESLEY WILLIAN COSTA MARTINS[1], ANA CLARA BIASSI ORLANDI[1], LUCAS MALUF VENDAS[1], RAFAEL MORAES TRINCADO[1], JORGE RAFAEL DURIGAN[1], JOÃO TOMÁS FERNANDES CASTILHO GARCIA[1], RODRIGO GÓES MEDÉA MENDONÇA[1], ALBERTO GOTFRYD[1], MARIA FERNANDA SILBER CAFFARO[1], ROBERT MEVES[1]

1. Irmandade de Misericóridia da Santa Casa de São Paulo, São Paulo, SP, Brazil.

## ABSTRACT

Objective: To map obstacles in the diagnosis and treatment of early-onset scoliosis in patients treated through the Brazilian Public Health System (SUS) at a tertiary hospital in São Paulo, supporting action plans to improve treatment access. Methods: Descriptive epidemiological study with 24 patients treated between June and November 2024. Demographic variables, referral process, time to specialist consultation, and proposed treatment were analyzed. Statistical analysis included descriptive statistics for continuous and categorical variables. Normality was tested using Shapiro-Wilk, with $p \leq 0.05$. This is a descriptive epidemiological study with retrospective analysis, presenting level II evidence according to the Oxford classification Results: Most patients were female, with a median age of 24 months at the initial evaluation. The most common etiology was congenital (41.7%). The mean referral time to a specialized center was 61.9 months, with 70.8% arriving via direct medical referral, without official regulation. At data collection, 37.5% were still awaiting treatment, with an average wait time of 57.4 months. Conclusion: The study highlights delays in the diagnosis and treatment of early-onset scoliosis within the public health system, impacting patient access to care. Improvements in screening, referral, and specialized resources are essential to optimize care. ***Level of evidence II; retrospective study.***

**Keywords:** Early-onset scoliosis; Healthcare access; Public health; Scoliosis treatment; Epidemiology.

## *RESUMO*

*Objetivo: Mapear os principais obstáculos no diagnóstico e tratamento da escoliose de início precoce em pacientes atendidos pelo Sistema Único de Saúde (SUS) em um hospital terciário de São Paulo, para subsidiar planos de ação que melhorem o acesso ao tratamento. Métodos: Estudo epidemiológico descritivo com 24 pacientes atendidos entre junho e novembro de 2024. Foram analisadas variáveis demográficas, forma de encaminhamento, tempo até a consulta com especialista e tratamento proposto. A análise estatística incluiu estatística descritiva para variáveis contínuas e categóricas. A normalidade foi testada pelo Shapiro-Wilk, considerando $p \leq 0,05$. Trata-se de um estudo epidemiológico descritivo com análise retrospectiva, apresentando nível de evidência II de acordo com a classificação da Oxford. Resultados: A maioria dos pacientes era do sexo feminino, com mediana de 24 meses na primeira avaliação. A etiologia mais comum foi a congênita (41,7%). O tempo médio de encaminhamento ao centro de referência foi de 61,9 meses, e 70,8% dos pacientes chegaram por encaminhamento direto, sem regulação oficial. No momento da coleta, 37,5% aguardavam tratamento, com tempo médio de espera de 57,4 meses. Conclusão: O estudo evidencia atrasos no diagnóstico e tratamento da escoliose de início precoce no SUS, impactando o acesso dos pacientes. Melhorias na triagem, encaminhamento e ampliação dos recursos especializados são essenciais para otimizar o atendimento.* ***Nível de evidência II; estudo retrospectivo.***

***Descritores:*** *Escoliose de início precoce; Acesso aos serviços de saúde; Saúde pública; Tratamento da escoliose; Epidemiologia.*

## *RESUMEN*

*Objetivo: Mapear los obstáculos en el diagnóstico y tratamiento de la escoliosis de inicio temprano en pacientes atendidos a través del Sistema Único de Salud (SUS) en un hospital terciario de São Paulo, para respaldar planes de acción que mejoren el acceso al tratamiento. Métodos: Estudio epidemiológico descriptivo con 24 pacientes atendidos entre junio y noviembre de 2024. Se analizaron variables demográficas, proceso de derivación, tiempo hasta la consulta con el especialista y tratamiento propuesto. El análisis estadístico incluyó estadísticas descriptivas para variables continuas y categóricas. Se utilizó Shapiro-Wilk para evaluar la normalidad ($p \leq 0,05$). Se trata de un estudio epidemiológico descriptivo con análisis retrospectivo, que presenta un nivel de evidencia II de acuerdo con la clasificación de Oxford. Resultados: La mayoría de los pacientes eran mujeres, con una edad mediana de 24 meses en la primera evaluación. La etiología*

Study conducted by the Irmandade de Misericóridia da Santa Casa de São Paulo, São Paulo, SP, Brazil.
Correspondence: Leonardo Sardas. 473, Rua José Antonio Coelho, apt 153, São Paulo, SP, Brazil. 04011-061. leonardosardas@gmail.com





Received on 27/03/2025 accepted on 18/03/2026
Reviewed by: Alexandre Fogaça

*más común fue la congénita (41,7%). El tiempo medio de derivación a un centro especializado fue de 61,9 meses, y el 70,8% llegó mediante derivación directa, sin regulación oficial. En la recolección de datos, el 37,5% aún esperaba tratamiento, con un tiempo medio de espera de 57,4 meses. Conclusión: El estudio destaca retrasos en el diagnóstico y tratamiento de la escoliosis de inicio temprano en el sistema público de salud, afectando el acceso de los pacientes. Mejoras en cribado, derivación y recursos especializados son esenciales para optimizar la atención.* ***Nivel de evidencia II; estudio retrospectivo.***

***Descriptores:*** *Escoliosis de inicio temprano; Acceso a los servicios de salud; Salud pública; Tratamiento de la escoliosis; Epidemiología.*

## INTRODUCTION

Early-onset scoliosis (EOS) is defined as a curvature of the spine that manifests before the age of 10, with a curvature greater than 10 degrees.[1,2] This condition can have various etiologies, including congenital vertebral anomalies, neuromuscular diseases, syndromes associated with scoliosis, or idiopathic causes.[2] EOS is particularly concerning due to the risk of pulmonary development impairment, as the progressive deformity of the spine and thoracic restrictions occur during a critical period of development.[1,2]

The treatment of EOS is challenging due to the heterogeneity of the affected population and the medical complexity often associated with it. Historically, early spinal fusion was performed in severe cases, but this limited the growth of the spine and thorax, resulting in unfavorable pulmonary outcomes. Currently, the goal of treatment is to maximize the growth of the spine and thorax while controlling spinal deformity to promote normal pulmonary development.[1,2] Treatment options include conservative methods, such as the use of braces and casts, and surgical interventions with growth-favoring implants, such as growth rods, which have replaced early spinal fusion as the preferred surgical treatment.[1,2]

Although the prevalence of EOS in the global population is not widely documented, it is estimated to occur in about 1 in every 1,300 children under 10 years old.[3] However, in the Brazilian context, there is a lack of specific data on the prevalence of EOS, with existing studies primarily focused on adolescent idiopathic scoliosis (AIS).[4] This epidemiological gap highlights the need for studies investigating the prevalence and challenges faced by this population in Brazil.

In Brazil, most of the care for the population with Early Onset Scoliosis (EOS) is provided within the framework of the Unified Health System (SUS), which faces structural challenges that compromise its effectiveness. Among these challenges, chronic underfunding, inadequate resource management, unequal distribution of healthcare professionals, and regional disparities in access to services stand out.[5,6] Such limitations directly impact the quality and equity of care provided to children with EOS, emphasizing the importance of understanding the difficulties faced by this population within the context of SUS and seeking solutions that can optimize public health care.

Within this context, GEPEDI (Pediatric Scoliosis Deformity Group of the Brazilian Spine Society), after the success of the first large-scale multicenter study aimed at evaluating adolescent idiopathic scoliosis at the national level,[7] proposed a series of investigations focused on patients with EOS. The study described below is part of this broader effort and aims to evaluate the cases treated at a tertiary hospital in the city of São Paulo, whose population is exclusively served by SUS. The study aims to map the main obstacles in the diagnosis and treatment of early-onset scoliosis, with the purpose of serving as a basis for creating action plans that promote access to treatment for these patients.

## MATERIALS AND METHODS

This is a descriptive epidemiological study, with a convenience sample. Patient data were collected at the specialized spinal clinic located in the Orthopedics Department. Data collection occurred between June and November 2024.

The following variables were evaluated: age, sex, place of residence, classification according to C-EOS, method of referral to the reference center, date of the first consultation with the orthopedic spine specialist, proposed treatment in this initial consultation, and, if applicable, the reason for the delay in starting treatment.

Information was obtained through in-person interviews with patients and/or their guardians, with the proper signing of the Informed Consent Form (ICF).

Data were collected and stored on the RedCap® platform. They were then exported to Jamovi® software, which uses R language for data analysis.

Continuous data were described by the mean, standard deviation, minimum and maximum values, median, and the 25th percentile (p25) and the 75th percentile (p75). To compare these data, a normality distribution test, the Shapiro-Wilk test, was used.

Categorical data were described by their absolute frequency and their respective proportion within their categories.

It was considered statistically significant when the p-value was less than or equal to 0.05.

## RESULTS

Data were collected from a sample of 24 patients with early-onset scoliosis, who were analyzed retrospectively. 23 (95.8%) of the patients were from the state of São Paulo and 1 (4.2%) was from the state of Bahia.

The majority were female, and the average age at the first evaluation at the health center varied significantly, with a median of 24 months, and the time to referral to the orthopedic doctor had a median of 0 months, with a median of 1.5 months for patients to be seen at a referral center. However, there was a wide variability in this latency, as can be seen in Table 1.

Regarding how access to the reference center was, we can observe that in most cases, 70.8%, there was a medical referral

**Table 1.** Descriptive Statistics.

| | | | 95% Confidence Interval | | | | | Percentiles | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | N | Mean | Min. Lower | Upper | Standard Deviation | Minimum | Maximum | 25th | 50th | 75th |
| What is the age (in months) of the patient's first consultation at a health service, whose motivation was the spinal deformity? | 24 | 41.6 | 25.0 | 58.1 | 39.2 | 0 | 110 | 7.50 | 24.0 | 72.0 |
| What is the age (in months) of the patient's first consultation with an orthopedic doctor? | 24 | 45.0 | 29.0 | 60.9 | 37.8 | 0 | 110 | 12.00 | 30.5 | 73.0 |
| What is the age (in months) when the patient was referred to their Referral Center? | 24 | 61.9 | 39.9 | 83.9 | 52.1 | 0 | 182 | 16.50 | 59.0 | 99.0 |

Note. The confidence interval of the mean assumes that the sampling distribution of the mean follows a t-distribution with N-1 degrees of freedom.

on paper and the patient scheduled the appointment directly or by their own means. Only 1 case was correctly referred via UBS. As we see in Table 2.

Before the patient's referral to the reference center, 3 (12.5%) received treatment, 2 with TLSO brace and 1 observation (Table 3). Of the two patients who received treatment with a TLSO brace, 1 of them was not considered adequate.

The most frequent etiology of scoliosis was congenital, with 10 (41.7%) cases, followed by idiopathic, with 6 (25%). (Table 4)

The angle of curvature of the most frequent scoliosis was between 51 and 90º, 9 (37.5%), followed by curves greater than 90º, 7 (29.2%). (Table 5)

Regarding global kyphosis, we can observe that most were between 20 to 50º and greater than 50º. (Table 6)

Regarding the APR modifier, the most frequent was P0 < 10 degrees per year, 20 (83.3%) of the cases. (Table 7)

The most frequent treatment at the reference center was observation, 58.3%, followed by surgery, 25%, of the cases. (Table 8)

At the time of data collection, 9 (37.5%) of the individuals were awaiting treatment in the waiting list, and the description of the waiting time can be observed in the table below. (Table 9)

When treatment was not initiated, 8 (33.3%) the reason was due to an excess of patients on the waiting list, 7 (29.2%) due to a lack of slots in the surgical center, 1 (4.2%) due to a lack of pediatric implant, 1 (8.5%) due to a lack of intraoperative monitoring.

**Table 7.** Frequencies of APR Modifier - calculation: (Cobb scoliosis moment 2 minus Cobb scoliosis moment 1) X 12 months divided by the interval between moment 1 and 2 (in months).

| APR Modifier - calculation: (Cobb scoliosis moment 2 minus Cobb scoliosis moment 1) X 12 months divided by the interval between moment 1 and 2 (in months). | Counts | % of Total | % accumulated |
|---|---|---|---|
| P0 < 10 degrees per year | 20 | 83.3% | 83.3% |
| P1 10 to 20 degrees per year | 2 | 8.3% | 91.7% |
| P2 > 20 degrees per year | 1 | 4.2% | 95.8% |
| First consultation | 1 | 4.2% | 100.0% |

**Table 8.** Frequencies of What was the treatment initially indicated in your Reference Center?

| What was the treatment initially indicated in your Reference Center? | Counts | % of Total | % accumulated |
|---|---|---|---|
| Surgery | 6 | 25.0% | 25.0% |
| TLSO brace | 2 | 8.3% | 33.3% |
| Plaster brace | 2 | 8.3% | 41.7% |
| Observation | 14 | 58.3% | 100.0% |

**Table 2.** Descriptive Statistics.

| | | | 95% Confidence Interval | | | | | Percentiles | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | N | Mean | Min. Lower | Upper | Standard Deviation | Minimum | Maximum | 25th | 50th | 75th |
| Time from first medical consultation to orthopedic doctor | 24 | 3.38 | 0.418 | 6.33 | 7.00 | 0 | 30 | 0.00 | 0.00 | 4.00 |
| Time to referral to the orthopedic doctor's referral center | 24 | 16.96 | 0.977 | 32.94 | 37.85 | 0 | 158 | 0.00 | 0.00 | 7.25 |
| Time center reference of the doctor | 24 | 20.33 | 4.059 | 36.61 | 38.54 | 0 | 158 | 0.00 | 1.50 | 16.00 |

Note. The confidence interval of the mean assumes that the sampling distribution of the mean follows a t-distribution with N-1 degrees of freedom.

**Table 3.** Frequencies of How did the patient access their Reference Center?

| How did the patient access their Reference Center? | Counts | % of Total | % accumulated |
|---|---|---|---|
| Appointment scheduled directly by the patient by their own means | 6 | 25.0% | 25.0% |
| Referral from the UBS Unit via the regulation system by SUS | 1 | 4.2% | 29.2% |
| Medical referral on paper and the patient scheduled the appointment directly | 17 | 70.8% | 100.0% |

**Table 4.** Frequencies of Etiology.

| Etiology | Counts | % of Total | % accumulated |
|---|---|---|---|
| Congenital | 10 | 41.7% | 41.7% |
| Idiopathic | 6 | 25.0% | 66.7% |
| Neuromuscular | 3 | 12.5% | 79.2% |
| Syndromic | 5 | 20.8% | 100.0% |

**Table 5.** Frequencies of the Largest Angle of Scoliosis Curvature.

| Largest Angle of Scoliosis Curvature | Counts | % of Total | % accumulated |
|---|---|---|---|
| Between 20 and 50° | 6 | 25.0% | 25.0% |
| Between 51 and 90° | 9 | 37.5% | 62.5% |
| Greater than 90° | 7 | 29.2% | 91.7% |
| Less than 20° | 2 | 8.3% | 100.0% |

**Table 6.** Frequencies of Global Thoracic Kyphosis.

| Global Thoracic Kyphosis | Counts | % of Total | % accumulated |
|---|---|---|---|
| Between 20 and 50° | 11 | 45.8% | 45.8% |
| Greater than 50° | 10 | 41.7% | 87.5% |
| Less than 20° | 3 | 12.5% | 100.0% |

**Table 9.** Descriptive Statistics.

| | | | 95% Confidence Interval | | | | | Percentiles | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | N | Mean | Min. Lower | Upper | Standard Deviation | Minimum | Maximum | 25th | 50th | 75th |
| If yes, how long (in months)? | 9 | 57.4 | -8.28 | 123 | 85.5 | 0 | 240 | 1.00 | 6.00 | 96.0 |

## DISCUSSION

Initially, we assessed the population of our study. Of the 24 patients included, 10 (41.7%) had scoliosis of neuromuscular etiology, while 6 (25%) had idiopathic scoliosis. These data align with the literature, which identifies these as the most common causes of early-onset scoliosis (EOS).[3]

We observed that the majority of cases (75%) presented severe curves, with angles greater than 50º. On average, patients had their first medical consultation due to the deformity at 41.6 months of age, often with a pediatrician, who then referred them to the orthopedist. However, the first consultation in the specialized service occurred, on average, only at 61.9 months of age. This significant interval can be explained by the lack of a structured flow in the Unified Health System (SUS).

Only 1 patient from the study was correctly referred from the Basic Health Units. A substantial portion of the patients (70.8%) arrived at the specialized service with medical referral requests that had not

been regulated by the Central Regulation of Health Offers and Services (CROSS). This entity is responsible for the operationalization of the regulatory actions of the São Paulo State Health Department (SES/SP). As a result, patients faced long intervals between the first consultation motivated by the deformity and the start of specialized follow-up. Furthermore, it is likely that many other patients do not even have access to tertiary care.

Regarding treatment,[7] patients underwent surgery at ages considered appropriate. However, at the time of evaluation,[9] patients were still awaiting surgery, with an average waiting time of 57.4 months. This period far exceeds the average recommended interval of 6 months, as described by Wright and colleagues.[8] Public health systems in other countries have significantly shorter waiting times, such as the United Kingdom (5 to 9 months),[9] Canada (6 to 12 months)[10] and New Zealand (11 months).[11] However, in the Brazilian context, other studies have also reported similar scenarios of delay.[12,13]

Delays in performing surgery for indicated patients arise from various factors, the most frequent being the excess of patients on the surgical waiting list (88%) and the lack of availability in the surgical center (77%). This situation of overcrowding and delays is a striking reality in different regions of Brazil and is present at all stages of care, from the initial diagnosis to definitive treatment.[9,14]

The proposal of this new phase of the project by the Brazilian Spine Society (SBC) is to analyze, on a national level, the challenges faced by SUS in the follow-up and treatment of EOS. Considering that this condition begins at a very early age, the absence of timely diagnosis and treatment can lead to disastrous consequences. It is expected that the results of this study will contribute to the development of strategies that improve the flow of care and access to treatment, minimizing the impact of the disease on patients.

## CONCLUSION

This study highlights the difficulties faced by the SUS in managing early-onset scoliosis, with significant delays in diagnosis and treatment. These challenges mainly arise from the lack of structured flow between levels of care, the shortage of specialized resources, and the long waiting lists for surgical procedures.

To improve care, it is essential to invest in the training of primary care professionals for early diagnosis, implement clear referral protocols, and expand the availability of reference centers and surgical resources. These measures can optimize the flow between complaint, diagnosis, and treatment, ensuring faster and more effective access to the necessary care to minimize the impact of the disease on patients' lives.

### CONFLICT OF INTEREST

All authors declare no potential conflict of interest related to this article.

### CONTRIBUTIONS OF THE AUTHORS

Each author contributed individually and significantly to the development of this article. VL, BAC, and MW assisted with data collection. TR, DJ, and GT contributed to manuscript review. GR and GA were responsible for methodology and supervision. CM and MR conducted formal analysis and data curation. SL contributed to validation and writing—review and editing.

### DATA AVAILABILITY DECLARATION

The underlying contents of the research text are contained in the manuscript.

## REFERENCES


1. Yang S, Andras LM, Redding GJ, Skaggs DL. Early-Onset Scoliosis: A Review of History, Current Treatment, and Future Directions. Pediatrics. 2016;137(1). doi: 10.1542/peds.2015-0709.
2. Cunin V. Early-Onset Scoliosis: Current Treatment. Orthop Traumatol Surg Res. 2015;101(1 Suppl):S109-18. doi: 10.1016/j.otsr.2014.06.032.
3. AlNouri M, Wada K, Kumagai G, Asari T, Nitobe Y, Morishima T, et al. The Incidence and Prevalence of Early-Onset Scoliosis: A Regional Multicenter Epidemiological Study. Spine J. 2022;22(9):1540-50. doi: 10.1016/j.spinee.2022.03.016.
4. Penha PJ, Ramos NLJP, de Carvalho BKG, Andrade RM, Schmitt AC, João SMA. Prevalence of Adolescent Idiopathic Scoliosis in the State of São Paulo, Brazil. Spine. 2018;43(24):1710-8. doi: 10.1097/BRS.0000000000002725.
5. Silva APS, Silva E, Júnior OVP, Ramos V de BF, dos Santos CG, Bezerra L de AF, et al. DESAFIOS NA ATENÇÃO BÁSICA À SAÚDE NO BRASIL: ENFOQUE NA SAÚDE PÚBLICA. Braz J Implantol Health Sci. 2023;5(5):5065-73. doi: 10.36557/2674-8169.2023v5n5p5065-5073.
6. de Souza LEPF, Paim JS, Teixeira CF, Bahia L, Guimarães R, de Almeida-Filho N, et al. Os desafios atuais da luta pelo direito universal à saúde no Brasil. Ciênc Saúde Coletiva. 2019;24(8):2783-92. doi: 10.1590/1413-81232018248.34462018.
7. Meves R; Gepedi (Pediatric Scoliosis Deformity Group from Brazilian Spine Society). Causes of Delays in Treatment of Patients With Pediatric Scoliosis in the Brazilian Health System. Spine (Phila Pa 1976). 2024;49(10):741-2. doi: 10.1097/BRS.0000000000004885.
8. Wright JG, Li K, Seguin C, Booth M, Fitzgerald P, Jones S, et al. Development of pediatric wait time access targets. Can J Surg. 2011;54(2):107-10. doi: 10.1503/cjs.048409.
9. Bressan-Neto M, Herrero CF, Pacola LM, Nunes AA, Defino HL. Community Care Administration of Spinal Deformities in the Brazilian Public Health System. Clinics (Sao Paulo). 2017;72(8):485-90. doi: 10.6061/clinics/2017(08)06.
10. Monteiro FSN, Alexandre M, Santos WZ, Mendonça RGM, Gotfryd AO, Caffaro MFS, et al. Demographic study of patients with scoliosis awaiting a surgical procedure through the public health system at Hospital Santa Casa de Misericórdia in São Paulo. Coluna/Columna. 2023;22(3):e273284. doi: 10.1590/S1808-185120222203273284.
11. Clark S. Waiting times for scoliosis surgery. Lancet. 2008;371(9606):10-1. doi: 10.1016/S0140-6736(08)60047-1.
12. Ahn H, Kreder H, Mahomed N, Beaton D, Wright JG. Empirically derived maximal acceptable wait time for surgery to treat adolescent idiopathic scoliosis. CMAJ. 2011;183(9):E565-70. doi: 10.1503/cmaj.101511.
13. Calman R, Smithers T, Rowan R. Impact of surgical waiting time on paediatric spinal deformity patients. ANZ J Surg. 2013;83(12):929-32. doi: 10.1111/ans.12196.
14. Ferreira PGDS, Galvao TF, Silva MT. Pent-Up Demand for Surgery in the Manaus Metropolitan Region: A Population-Based Cross-Sectional Study. Medicine (Baltimore). 2017;96(31):e7660. doi: 10.1097/MD.0000000000007660.