

STUDY ON PEDIATRIC SCOLIOSIS PATIENTS AT HOSPITAL SANTA CASA DE MISERICÓRDIA IN SÃO PAULO

ESTUDO SOBRE PACIENTES COM ESCOLIOSE PEDIÁTRICA NO HOSPITAL SANTA CASA DE MISERICÓRDIA DE SÃO PAULO

ESTUDIO SOBRE PACIENTES PEDIÁTRICOS CON ESCOLIOSIS EN EL HOSPITAL SANTA CASA DE MISERICÓRDIA DE SÃO PAULO

FELIPE NEVES SIMÕES MONTEIRO¹ , MURILO ALEXANDRE¹ , WILLIAM ZARZA SANTOS¹ , RODRIGO GÓES MEDEA DE MENDONÇA¹ , ALBERTO OFENHEJM GOTFRYD¹ ,
MARIA FERNANDA SILBER CAFFARO¹ , ROBERT MEVES¹ 

1. Irmandade da Santa Casa de Misericórdia de São Paulo, Department of Orthopedics and Traumatology, Spinal Surgery Group, São Paulo, SP, Brazil.

ABSTRACT

Objective: To carry out registration of patients with scoliosis under 18 years old, followed in a quaternary hospital of high complexity, who need surgical treatment, aiming to identify the reasons for the delay in treatment. **Methods:** Data collection was carried out in person and by spontaneous demand at the spinal orthopedic specialty outpatient clinic in a tertiary hospital of high complexity from January 2021 to December 2022. The results were compiled in the networked database (Red Cap®). **Result:** 59 patients were evaluated, 45 female (77.9%) and 14 male (22.1%), with a mean age of 13.7 years. **Etiology:** 30 idiopathic (50.8%), eight syndromic (13.5%), 11 neuromuscular (18.6%), and ten congenital (16.9%). Of the total, 46 (77.9%) were awaiting surgery and 13 (22.1%) were undergoing conservative treatment. The main causes of treatment delay: unavailability of intraoperative neurophysiological monitoring (19 - 41.3%); unavailability of specific surgical material (16 - 34.8%); difficulty of referral to our institution (6 - 13.1%); loss to follow-up (3 - 6.5%) and limitation in casting making (2 - 4.3%). The mean time between diagnosis and the first consultation is 17.25 months (0 - 140). The average surgical wait until December/2022 was 38.4 months (1 - 156). **Conclusion:** There is a lack of assistance in the steps of monitoring and treatment in the public health system, from directing the patient with scoliosis to the specialized center to performing the surgical procedure, mainly due to limitations in the use of intraoperative neurophysiological monitoring and the unavailability of specific materials to perform highly complex surgeries. **Therapeutic Studies - Investigating the Results of Treatment.**

Keywords: Spine; Scoliosis; Minors; Surgical Procedures, Operative; Unified Health System.

RESUMO

Objetivo: Descrever a epidemiologia de pacientes, menores de 18 anos, com escoliose que aguardam cirurgia em hospital quaternário de alta complexidade e observar os motivos que acarretam atrasos no tratamento. **Métodos:** Coleta de dados presencial e espontaneamente no ambulatório de ortopedia da coluna vertebral num hospital de alta complexidade, de janeiro de 2021 a dezembro de 2022. Os resultados foram compilados no banco de dados (Red Cap®). **Resultados:** Foram avaliados 59 pacientes, 45 mulheres (77,9%) e 14 homens (22,1%), com média etária de 13,7 anos. **Etiologia:** 30 idiopáticas (50,8%), 8 síndromicas (13,5%), 11 neuromusculares (18,6%) e 10 congênitas (16,9%). Do total, 46 (77,9%) aguardam cirurgia e 13 (22,1%) estavam em tratamento conservador. As principais causas de atraso do tratamento cirúrgico foram: indisponibilidade de monitoração neurofisiológica intraoperatória (19 - 41,3%); indisponibilidade de implantes para escoliose (16 - 34,8%); dificuldade no referenciamento para instituição (6 - 13,1%); perda de seguimento (3 - 6,5%) e limitação na confecção de colete (2 - 4,3%). **Tempo médio entre diagnóstico e primeiro atendimento de 17,25 meses (0 - 140). A média de espera cirúrgica até dezembro/2022 era 38,4 meses (1 - 156). Conclusão:** Há carência assistencial nas etapas do acompanhamento e no tratamento no Sistema Único de Saúde, desde o direcionamento do paciente com escoliose ao centro especializado até a realização do procedimento cirúrgico, sobretudo devido à limitação na utilização de monitoração neurofisiológica intraoperatória e indisponibilidade de materiais específicos para realização de cirurgias de alta complexidade. **Estudos terapêuticos - Investigação dos resultados do tratamento.**

Descritores: Coluna Vertebral; Escoliose; Menores de Idade; Procedimentos Cirúrgicos Operatórios; Sistema Único de Saúde.

RESUMEN

Objetivo: Describir la epidemiología de los pacientes menores de 18 años con escoliosis en un hospital cuaternario de alta complejidad y observar los motivos que llevan a retrasos en el tratamiento. **Métodos:** Recolección de datos presencial y espontánea en el ambulatorio de ortopedia de columna, de enero 2021 a diciembre 2022. Los resultados fueron recopilados en la base de datos (Red Cap®). **Resultado:** Se evaluaron 59 pacientes, 45 mujeres (77,9%) y 14 hombres (22,1%), con una edad promedio de 13,7 años. **Etiología:** 30 idiopáticas (50,8%), 8 síndromicas (13,5%), 11 neuromusculares (18,6%) y 10 congénitas (16,9%). Del total, 46 (77,9%) estaban pendientes de cirugía y 13 (22,1%) estaban en tratamiento conservador. Las principales causas de retraso en el tratamiento quirúrgico fueron: indisponibilidad de

Study conducted by the Pavilhão Fernandinho Simonsen. Rua Dr. Cesário Mota Junior, 112 - Vila Buarque, São Paulo, SP, Brazil.

Correspondence: Felipe Neves Simões Monteiro. 61, Dr Cesário Motta Jr Street, Vila Buarque, São Paulo, SP, Brazil. 1221020. drfelipenevesmonteiro@gmail.com



monitorización neurofisiológica intraoperatoria (19 – 41,3%); indisponibilidad de implantes para escoliosis (16 – 34,8%); dificultad para hacer referencia a la institución (6 – 13,1%); pérdida de seguimiento (3 – 6,5%) y limitación en la confección de un chaleco (2 – 4,3%). Tiempo promedio diagnóstico y primera atención de 17,25 meses (0 – 140). Espera quirúrgica promedio: hasta diciembre/2022 fue de 38,4 meses (1 – 156). Conclusión: Existe falta de asistencia en las etapas de seguimiento y tratamiento en el Sistema Único de Salud, desde la dirección del paciente con escoliosis al centro especializado hasta la realización del procedimiento quirúrgico, debido principalmente a la limitación en el uso de instrumentos neurofisiológicos intraoperatorios. **Estudios terapéuticos - Investigación de los resultados del tratamiento.**

Descriptores: Columna Vertebral; Escoliosis; Menores; Procedimientos Quirúrgicos Operativos; Sistema Único de Salud.

INTRODUCTION

Scoliosis is defined by the Scoliosis Research Society (SRS) as a lateral curvature of the spine of 10° or more.¹ It may be associated with neuromuscular diseases, idiopathic, congenital, or related to syndromes.^{2,3} Adolescent Idiopathic Scoliosis is the most prevalent, with an incidence of 2-3% in the population aged 10-16 years⁴ and 0.1-0.3% in curves > 30°.⁵

In the Unified Health System (SUS), the difficulties in monitoring scoliosis range from the delay in initial diagnosis to delays in referral and admission to referral centers, as well as difficulties in carrying out treatments and underfunding the public health system.⁶ Delays in treatment lead to the progression of the deformity, which becomes more complex and morbid, leading to greater difficulty in treatment and, in surgical cases, an increase in the instrumentation level.⁷

To minimize the impact of delays in treatment, the Brazilian Spine Society (SBC) has set up a nationwide project to develop an epidemiological portrait of scoliosis sufferers in the country, compiling the waiting list of various reference centers for scoliosis treatment.

This article refers to structuring the waiting list for patients with scoliosis at the Santa Casa de Misericórdia Hospital outpatient clinic in São Paulo.

METHODS

This is a descriptive epidemiological study using a convenience sample. Patient data was collected by spontaneous demand at the spinal orthopedics outpatient clinic in the Fernandinho Simonsen Pavilion Orthopedics and Traumatology Department.

The institution's ethics committee approved data collection and analysis under CAAE number 35250220.2.1001.5479.

A list was started from the service's demand from January 2021 to December 2022.

Patients up to 18 years of age were included in the article because it was dedicated to cases of pediatric scoliosis.

A delay in waiting for treatment was considered to be those patients who had been waiting for more than six months, the ideal time recommended by Wright et al.⁸

The data was incorporated into the Red Cap® platform by the researcher responsible for the study and included age, gender, diagnosis according to the Scoliosis Research Society, date of collection, a form of referral to the reference center, date of first consultation with an orthopedic spine specialist, reason for delay in treatment of the pathology if any and, if female, date of menstruation.

This information was obtained in person from the patients and guardians after they had signed an informed consent form (ICF).

RESULTS

A total of 59 patients were assessed: 45 females (76.3%) and 14 males (23.7%), with a mean age of 13.7±3.1 years (3 - 18). Of the female patients, 82.2% had already had menarche (37). The etiology was divided into 30 idiopathic (50.8%), 11 neuromuscular (18.6%), ten congenital (16.9%), and eight syndromic (13.5%). (Table 1)

In total, 47 (79.66%) patients were awaiting surgery, 12 (20.34%) were undergoing conservative treatment, 1 with a brace, and 11 under observation. The patient was referred to the referral center in 24 (40.6%) cases, 15 (25.4%) were booked via SUS by the first place of assistance, 10 (17%) were advised to seek assistance without a referral, 5 (8.5%) had a medical referral on paper in which the patient

made an appointment, and 5 (8.5%) had appointments booked by the patient (by their means).

The main causes of delays in treatment were unavailability of intraoperative neurophysiological monitoring (16 - 42.1%), unavailability of specific surgical material (15 - 39.47%), difficulty in referral to our institution (3 - 7.89%), loss of follow-up (2 - 5.26%) and difficulty in scheduling surgery due to too many emergencies (2 - 5.26%). (Table 2)

The average time between diagnosis and first consultation is 17.25 months (0 - 140). The average waiting time for surgery until December 2022 was 38.4 months (1 - 156).

DISCUSSION

The results obtained in structuring the surgical waiting list for patients with pediatric scoliosis at Santa Casa de São Paulo exemplify the problems faced by the Unified Health System throughout the country, whose delays range from the patient's initial diagnosis to admission to referral hospitals for treatment.⁶ Once the patient has obtained care at the referral hospital, they face a long surgical waiting list of patients with the same pathology.

Although other countries, which also have a publicly funded health system, have long waiting times for scoliosis surgery (the United Kingdom 5 to 9 months,⁹ Canada 6 to 12 months¹⁰ and New Zealand 11 months),¹¹ the data obtained in this study is more alarming at 38.4 months, against the ideal recommended waiting time of 6 months by Wright et al.,⁸ and this list is made up of patients who are still waiting for the surgical procedure.^{12,13} The waiting time obtained in this article agrees with other articles that show the long waiting time in Brazil.^{6,12,14}

The etiology of scoliosis was similar to the data found by the Scoliosis Research Society for the 19,360 patients who underwent scoliosis correction surgery between 2004 and 2007,¹⁵ with idiopathic scoliosis being the majority, followed by neuromuscular and congenital scoliosis.

Table 1. Cross table (Reason for waiting for surgery X Waiting time).

Reason for waiting for surgical treatment	Waiting for surgery	
	No delay (n = 9)	Late (n = 38)
Delays in getting surgical equipment	1 (11.1%)	15 (39.47%)
Delay in entering the referral center	4 (44.4%)	3 (7.89%)
Difficulty scheduling surgery due to too many emergency rooms	0 (0%)	2 (5.26%)
Difficulty in obtaining intraoperative neurophysiological monitoring	2 (22.2%)	16 (42.1%)
Loss of follow-up	2 (22.2%)	(5.26%)

Table 2. Cross table (Scoliosis diagnostic classification X waiting time for surgery).

Diagnostic classification of scoliosis	Waiting for surgery	
	No delay (n = 9)	Late (n = 38)
Congenital	0 (0%)	8 (21%)
Idiopathic	8 (88.9%)	15 (39.5%)
Neuromuscular	0 (0%)	10 (26.3%)
Syndromic	1 (11.1%)	(13.2%)

The predominant reason for entering the specialized outpatient clinic was through in-hospital referrals (40.6%). The Santa Casa de Misericórdia Hospital in São Paulo is highly complex and has a high volume of outpatient care in various specialties.

The main reasons for the delay in performing the surgical procedure are the lack of intraoperative neurophysiological monitoring (42.1% of cases) and the delay in acquiring specific surgical equipment for highly complex procedures (39.47%), which together account for 81.5% of the reasons for the delay in surgical treatment for the individuals in this sample. This is mainly because the Unified Health System does not cover this equipment, which generates losses for the institution.

Due to the lack of coverage of this equipment, there is a low supply, which does not meet the service demand and results in surgical procedure delays. Consequently, the pathology of the patients waiting in the queue progresses, resulting in greater treatment complexity, increased levels of instrumentation required, and worsening the final result that can be obtained.^{7,10,12,16-18}

It is worth mentioning, as a specific characteristic of this service, that the emergency room attends to spontaneous demand predominantly from the central region of São Paulo and other regions, which implies the admission of urgent and emergency cases, generating a high demand for serious cases and unplanned delays in elective surgeries.

Using the reference of 6 months as the ideal time to perform the surgical procedure after its indication, recommended by Wright et al.,⁸ and specifying the etiologies defined in this collection, shows that all cases of congenital scoliosis (8 - 21%) and neuromuscular scoliosis (10 - 26.3%) are delayed. In idiopathic scoliosis, 15 (39.5%) cases have been waiting for more than six months, and in syndromic scoliosis, 5 (13.2%) cases. (Table 3)

The delays in follow-up and treatment became more serious with the occurrence of the COVID-19 pandemic,^{19,20} as it resulted in the cancellation of elective surgeries, the allocation of ICU beds, a reduction in the number of outpatient visits, as well as the loss of patient follow-up and the failure to refer new cases of scoliosis

Table 3. Table Absolute and Relative Frequency of Scoliosis Diagnostic Classification.

Diagnostic classification Scoliosis	Frequency	
	Absolute	Relative
Congenital	10	16.9%
Idiopathic	30	50.8%
Neuromuscular	11	18.6%
Syndromic	8	13.6%
Total	59	100.0%

to the referral center. After the restrictions imposed by the pandemic were lifted, and in conjunction with the national project of the Brazilian Spine Society (SBC) to formulate an epidemiological portrait of pediatric scoliosis patients in the country, the restructuring of the outpatient surgical waiting list for scoliosis patients began. Working with the SBC, patients seen at the orthopedic spine outpatient clinic at Santa Casa de São Paulo awaiting surgery were included in the Red Cap® digital platform. The end of the SBC project aims to analyze a nationwide panorama of the problems faced by the SUS in the monitoring and treatment of pediatric scoliosis.

CONCLUSION

There is a lack of assistance in the stages of monitoring and treatment in the single health system, from the referral of the patient with scoliosis to the specialized center to the surgical procedure, mainly due to the limited use of intraoperative neurophysiological monitoring and the unavailability of specific materials for highly complex surgeries.

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