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PROFILE OF THE WAITING LIST FOR EARLY-ONSET SCOLIOSIS SURGERY IN GOIÁS, BRAZIL

PERFIL DA LISTA DE ESPERA PARA CIRURGIA DE ESCOLIOSE DE INÍCIO PRECOCE EM GOIÁS, BRASIL

PERFIL DE LA LISTA DE ESPERA PARA CIRUGÍA DE ESCOLIOSIS DE INICIO PRECOZ EN GOIÁS, BRASIL

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ABSTRACT

Objective: To investigate the issues related to the waiting list of patients with early onset scoliosis awaiting surgical treatment through an epidemiological study conducted in a tertiary public hospital that is a reference center for spine care in the State of Goiás. Methods: An analytical cross-sectional epidemiological study was conducted with 73 patients diagnosed with early onset scoliosis referred to and treated at the only reference center in the State of Goiás. Results: The average age of the evaluated patients was 11.6 years, with a higher frequency of females (64.68%). The most common etiology was neuromuscular (54.79%), followed by idiopathic (26.03%). Almost half of the patients (49.32%) had a Cobb angle between 20 and 50º. The average waiting time between referral to the reference center and the consultation was 12 months. The most indicated treatment at the reference center for these patients was expectant treatment with serial observation (57.53%), followed by surgical treatment (34.25%). The majority (83.5%) had not undergone any type of treatment before being referred to the reference center. The only two patients who underwent surgery during the data collection had an average waiting time from the date of request to the procedure of 24 months. Conclusions: The waiting list for surgical treatment of EOS is generally composed of girls with neuromuscular scoliosis, with a longer waiting time than the average for EIA. This queue is fueled both by delays in diagnosis and in referrals to treatment reference centers, as well as by high demand overwhelming a single specialized center. Based on the analysis of this queue, it becomes more feasible to provide new fundamental elements for the development of guidelines and the reorganization of priorities in the waiting list, promoting greater efficiency and equity in the treatment of EOS. ***Level of Evidence IV; Descriptive Study.***

Keywords: Spine; Elective Surgical Procedures; Scoliosis; Patient Outcome Assessment.

RESUMO

*Objetivo: Investigar a problemática relacionada a fila de espera dos pacientes com escoliose de início precoce que aguardam tratamento cirúrgico por meio de um estudo epidemiológico realizado em um hospital público terciário centro de referência em coluna no Estado de Goiás. Métodos: Foi realizado um estudo epidemiológico analítico transversal com 73 pacientes diagnosticados com escoliose de início precoce encaminhados e tratados no serviço de ortopedia do único centro de referência do Estado de Goiás. Resultados: A idade média dos pacientes avaliados foi de 11,6 anos, sendo mais frequente o sexo feminino (64,68%). A etiologia mais comum foi a neuromuscular (54,79%), seguida pela idiopática (26,03%). Quase a metade dos pacientes (49,32%) apresentava o ângulo Cobb entre 20 e 50º. A média de espera entre o encaminhamento para o centro de referência e a consulta foi de 12 meses. O tratamento mais indicado no centro de referência para esses pacientes foi o tratamento expectante com observação seriada (57,53%); seguido pelo tratamento cirúrgico (34,25%). A maior parte (83,5%), não foi submetida a nenhum tipo de tratamento antes de serem encaminhados ao centro de referência. Os dois únicos pacientes operados, durante a coleta de dados, tiveram uma média de espera desde data da solicitação até procedimento de 24 meses. Conclusões: A fila de espera para tratamento cirúrgico da EOS é composta, no geral, por meninas com escoliose neuromuscular, com uma média de espera maior do que a média da EIA. Essa fila é nutrida tanto pelo atraso do diagnóstico, quanto no encaminhamento para centros de referência em tratamento, além da alta demanda sobrecarregando um único centro de especializado. Com base da análise desta fila torna-se mais possível fornecer novos elementos fundamentais para a elaboração de diretrizes e a reorganização das prioridades na fila de espera, promovendo maior eficiência e equidade no tratamento da EOS. **Nível de Evidência IV; Estudo Descritivo.***

Descritores: *Coluna Vertebral; Procedimentos Cirúrgicos Eletivos; Escoliose; Avaliação de Resultados da Assistência ao Paciente.*

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RESUMEN

Objetivo: Investigar la problemática relacionada con la lista de espera de los pacientes con escoliosis de inicio precoz que aguardan tratamiento quirúrgico, mediante un estudio epidemiológico realizado en un hospital público terciario, centro de referencia en columna en el Estado de Goiás. Métodos: Se realizó un estudio epidemiológico analítico transversal con 73 pacientes diagnosticados con escoliosis de inicio precoz, derivados y tratados en el servicio de ortopedia del único centro de referencia del Estado de Goiás. Resultados: La edad promedio de los pacientes evaluados fue de 11,6 años, con mayor frecuencia del sexo femenino (64,68%). La etiología más común fue la neuromuscular (54,79%), seguida de la idiopática (26,03%). Casi la mitad de los pacientes (49,32%) presentaba un ángulo de Cobb entre 20 y 50º. El tiempo promedio de espera entre la derivación al centro de referencia y la consulta fue de 12 meses. El tratamiento más indicado en el centro de referencia para estos pacientes fue el tratamiento expectante con observación seriada (57,53%), seguido del tratamiento quirúrgico (34,25%). La mayor parte de los pacientes (83,5%) no había sido sometida a ningún tipo de tratamiento antes de ser derivada al centro de referencia. Los dos únicos pacientes operados durante la recolección de datos tuvieron un tiempo promedio de espera, desde la fecha de la solicitud hasta el procedimiento, de 24 meses. Conclusiones: La lista de espera para el tratamiento quirúrgico de la EOS está compuesta, en general, por niñas con escoliosis neuromuscular, con un tiempo promedio de espera mayor que el promedio de la EIA. Esta lista se alimenta tanto del retraso en el diagnóstico como de la demora en la derivación a centros de referencia en tratamiento, además de la alta demanda que sobrecarga a un único centro especializado. Con base en el análisis de esta lista, se vuelve más factible aportar nuevos elementos fundamentales para la elaboración de directrices y la reorganización de las prioridades en la lista de espera, promoviendo mayor eficiencia y equidad en el tratamiento de la EOS. ***Nivel de Evidencia IV; Estudio Descriptivo.***

Descriptores: *Columna Vertebral; Procedimientos Quirúrgicos Electivos; Escoliosis; Evaluación del Resultado de la Atención al Paciente.*

INTRODUCTION

Scoliosis is a lateral deviation of the spine greater than 10º in the coronal plane, which can be classified according to its etiology as idiopathic, neuromuscular, congenital, or related to syndromes.[1] It can also be categorized by the onset of the deformity, such as Early Onset Scoliosis (EOS), which occurs before the age of 10.[2,3] When it arises early, especially before puberty, scoliosis can progress, even with conservative treatment, resulting in severe deformities.[3] Pehrsson *et al*. (1976) observed that mortality among patients with untreated idiopathic scoliosis was higher in EOS.[4] The issues associated with surgical treatment of EOS involve the high demand for procedures, the complexity of surgical and instrumental techniques, as well as the high financial costs involved, resulting in long waiting lists in countries with public health systems.[5,6,7]

In Brazil, among the main reasons for delays are the time taken to be referred to reference centers, difficulties in scheduling surgery, and other clinical challenges, such as comorbidities and the patient's clinical condition that prevented surgery, such as low weight, worsening pulmonary function, hemodynamic instability, or infection.[8-12] The delay for the procedure correlates with worsening of the angular deviation and, consequently, greater surgical complexity. This implies an increased likelihood of adverse events, greater surgical morbidity, and an increase in public health system costs.[10,13,14]

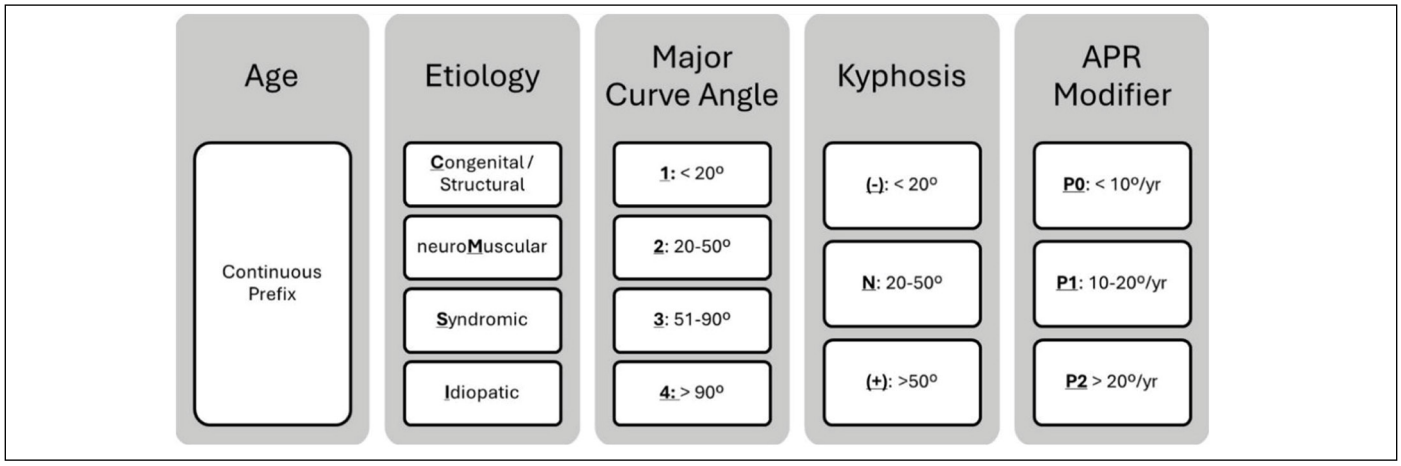
Although this is a reality in many countries with public health systems, there are few published studies on the impact of the waiting list in Brazil, and even rarer research on early-onset scoliosis. This is because, prior to the 2015 consensus,[15] age ranges were defined in very different ways, and there were variations in how the causes of diseases were classified, making it difficult to conduct an integrated epidemiological analysis.

The objective of this study is to investigate the issues associated with the high demand for EOS surgical procedures through an epidemiological study in a public hospital with a specialized spine service in the State of Goiás. The research aims to understand and evaluate patient demand in the Goiás territory, identify barriers to access and treatment, and analyze complications arising from this waiting list.

METHODOLOGY

The work was conducted with the approval of the ethics and research committee (CAAE: 84483924.5.2010.5361). The Informed Consent Form (ICF) was provided to the patients and their legal representatives. An analytical cross-sectional epidemiological study was conducted among 73 patients with EOS who were referred to and treated at the orthopedic service of the only reference center in the State of Goiás.

Data were collected in February 2024. All patients with scoliosis onset between 0 and 10 years were included. Data were collected (through interviews with the legal representative and access to medical records) on the following demographic variables: age at collection, city of origin, date of birth, and sex. Variables that constitute the Classification of Early-Onset Scoliosis (C-EOS), as shown in Figure 1, were also collected.[16]



Source: Adapted from the original article by Williams et al, 2014.16

Figure 1. The C-EOS classification developed by Williams et al., 2014.[16]

RESULTS

The average age of the evaluated patients was 11.6 years (range: 2-36 years), with a higher proportion of females (64.68%). Most patients were from Goiânia – GO, and only one patient was from another State, Samambaia-DF. The most common etiology was neuromuscular (54.79%), followed by idiopathic (26.03%). Almost half of the patients (49.32%) had a Cobb angle between 20 and 50º, as shown in Table 1.

Table 2 shows that the average age of consultations motivated by spinal deformity, as well as the average ages at which patients were referred and consulted at the reference center, with an average waiting time of 12 months between referral and consultation. The average follow-up time for patients in the service was 37.4 months, including those who had already undergone surgery, as demonstrated in Table 3.

The most indicated treatment at the reference center for these patients was expectant treatment with serial observation (57.53%), followed by surgical treatment (34.25%). The other patients were indicated for TLSO orthosis (5.48%) and plaster (2.74%).

All patients accessed the reference center via the Basic Unit, in accordance with the state's health regulation. The majority (83.5%) had not received any treatment prior to referral to the reference center. The treated patients did not undergo surgical procedures and were managed with orthoses or serial observation. Only two lacked the correct indication, as established in the literature.

Among patients with a surgical indication, the average waiting time for treatment, from the date of request to the date of data collection, was 11.4 months, with a range of 0-60 months. The average age of patients waiting for surgical treatment was 13 years (range 8 – 18 years), and 48% had a curve magnitude between 51 and 90º, with the majority being female (72%). The most predominant etiology was idiopathic (44%), followed by neuromuscular (40%). Those with an average curvature between 20 and 50º wait the longest, according to Table 4. The only two patients operated on during data collection had an average waiting time from the date of request to the procedure of 24 months: one with a wait of 6 months, who had already undergone surgical treatment prior to the study, and the other with a wait of 42 months.

Table 1. Epidemiological data of the patients.

	Freq.	%
Sex		
Female	47	64.38
Male	26	35.62
Etiology		
Congenital	10	13.70
Idiopathic	19	26.03
Neuromuscular	40	54.79
Syndromic	4	5.48
Cobb Angle		
Between 20 and 50°	36	49.32
Between 51 and 90°	21	28.77
Greater than 90°	10	13.70
Less than 20°	6	8.22
Total	73	100.00

Source: authors' own elaboration.

Table 2. Analysis of the ages (in years) of the patients.

	Average	DP	Min	Max
Age	11.66	5.00	2	36
Age of the first medical consultation motivated by spinal deformity	7.40	43.99	3	186
Age of the first consultation with an orthopedist motivated by spinal deformity	7.14	43.09	3	164
Age of the referral made to the reference center	7.79	46.07	3	186
Age of the first consultation at the reference center	8.63	48.69	2	204

Source: authors' own elaboration.

Table 3. Waiting time (in months).

	Average	DP	Min	Max
Waiting time between referral and first appointment at the reference center	12.00	18.94	0	96
Duration of follow-up at the reference center	37.41	40.32	0	204
Time on the waiting list for surgical treatment, considering the date of data collection	11.42	14.29	0	60
Waiting time for the surgical procedure of the 2 patients operated on during data collection	24.00	25.45	6	42

Source: authors' own elaboration.

Table 4. Relationship between the COBB angle of the largest curve and waiting time in months.

Between 20 and 50 °	16.56
Between 51 and 90°	8.67
Greater than 90°	8.80
Less than 20°	-
Total	11.42

Source: authors' own elaboration.

DISCUSSION

In this study, the predominant sex of EOS is female, with an average age of 11.6 years, and the most common etiology among patients was neuromuscular, followed by idiopathic. Such demographic data aligns with one of the few published studies on the epidemiology of EOS, which evaluated over two million patients, where the predominant sex was also female, and the most common etiology was neuromuscular.[13]

The best-known epidemiology of scoliosis is that of adolescent idiopathic scoliosis (AIS), which has a higher prevalence in females and an average age at onset of 15.5 years.[1,2,8] In two studies conducted in 2022 on pediatric scoliosis (0-18 years), including other etiologies beyond idiopathic, the majority of patients were also female with an average age of 13.5 years, with idiopathic being the most common etiology in both studies, differing from the most common etiology of EOS, which is neuromuscular. [9,10]

Regarding AIS, recent studies published in 2024 indicated that the average expected time for care at the specialized center was 9.4 months, with approximately 31.9% of patients waiting more than 6 months.[12] Meves *et al.*(2024), whose analysis included 651 patients from 21 reference centers in Brazil, found that the average wait time was 51.4 months, with 63% of patients waiting more than 12 months.[17] No studies were found regarding the waiting list for EOS in the general literature, making this one pioneering in this subject. Compared with studies on AIS, the average time between referral and consultation at the care center (12 months) was longer than in Northeast Brazil, but coincided with the majority of AIS patients in the country.

The delay in initial evaluation by specialists in patients with advanced skeletal maturation, and the absence of adequate criteria for prioritization and referral for scoliosis treatment at a reference center, allow the deformity to progress, increasing curve severity and necessitating greater surgical complexity.[17,18]

Of the 73 patients analyzed in this study, only 12% were treated before being seen at the reference center, and 34.25% had

indications for surgical treatment, with an average wait time of 11.4 months. In the study by Dorneles *et al.* (2022), which analyzed pediatric scoliosis, a significantly larger proportion of patients (78.3%) underwent therapeutic treatment before entering the reference center, with the vast majority transitioning to surgical indication, which had an average wait time of 22 months (6-40 months)[9]. In an AIS analysis, the average wait time for surgery was 16 months, with 38.2% waiting more than 12 months in a study conducted in Latin America.[14] In studies conducted in Canada, Ireland, and Scotland, the results found regarding the waiting list for AIS surgery were quite varied.

In Canada, the average wait time was 24 months (17-30 months),[18] while in Ireland[19] the average surgical wait time was 8.25 months, with the longest wait time recorded in the Irish study being 18 months. The shortest wait time was found in a study conducted in Scotland,[20] where the average wait was 12 months (6-16 months). It is already widely recognized that in patients where EOS shows progression, the earlier the onset of this process, the worse the final curvature and overall prognosis will be, tending to cause significant deformities, cardiopulmonary compromise, and reduced life expectancy.[21,22]

The very progression of the curvature, associated with the prolonged wait for treatment, is directly related to the worsening of the deformity, resulting in greater morbidity during the surgical procedure.[2,3,20,21] This implies a less effective final correction of the curvature, a greater need for arthrodesis, increased duration of surgery, greater intraoperative blood loss, and prolonged hospital stay, which in turn implies a considerable increase in surgical costs.[6,7,20,21]

In a study on the impact of waiting for surgical treatment in AIS,[21] it was concluded that among patients who waited more than six months in line, 14.8% required additional surgery due to curvature progression, compared with 1.6% among those who waited less than six months. An average wait time of three months for surgery in the treatment of AIS could eliminate the need for additional surgery, according to the same study, thereby reducing curvature progression. A shorter access time than the six months determined by expert consensus.[22] Given the more aggressive morbidity of EOS compared to AIS, such consequences would be even more severe in possible analyses.

The existence of waiting lists and delays in the performance of procedures is a consequence arising from public health systems, often justified by the need to optimize resources and control costs. The reference center under study is the only one responsible for surgeries of such complexity throughout the state, including in the Central-West region. It is estimated that 80 scoliosis surgeries will be performed this year, averaging two per week. About 30 patients are seen in the outpatient clinic weekly for evaluation and screening. The waiting list grows weekly, depending on the number of new cases.

This was a pioneering epidemiological study conducted on the impact of the surgical queue for early-onset scoliosis at both national and international levels. A limitation of this study is that the analysis is based on a single reference center, resulting in a partial view of the surgical queue for early-onset scoliosis in Brazil. Furthermore, the study did not obtain relevant information on queue management, the criteria used to select cases for surgery, or the total size of the waiting list for early-onset scoliosis surgery.

CONCLUSION

The waiting list for surgical treatment of early-onset scoliosis is generally composed of girls with neuromuscular scoliosis, and the average wait time is longer than for idiopathic scoliosis. This queue is fueled both by delays in diagnosis and in referrals to treatment reference centers, as well as by high demand overwhelming a single specialized center. Based on the analysis of this queue, it becomes more feasible to introduce new fundamental elements to develop guidelines and reorganize priorities in the waiting list, thereby promoting greater efficiency and equity in the treatment of EOS.

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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. DMT: Methodology and supervision; OJL: formal analysis, statistical analysis, and data curation; validation and writing – review and editing; ATM: review and writing; MN: Review and writing; MLJA: writing; FSD: data collection and discussion; BF: data collection and discussion; FREJ: data collection and writing; TLS: data collection and writing; MT: data collection, discussion, review; JPF: review and validation; MLL: methodology; SPHM: data collection, discussion.

DATA AVAILABILITY DECLARATION

The underlying contents of the research text are available in the text.

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