ORIGINAL ARTICLE
DEFORMITIES
http://dx.doi.org/10.1590/S1808-185120222203273410

EPIDEMIOLOGICAL PORTRAIT OF PEDIATRIC SCOLIOSIS IN A TERTIARY HOSPITAL IN BRAZIL

RETRATO EPIDEMIOLÓGICO DE ESCOLIOSE PEDIÁTRICA EM UM HOSPITAL TERCIÁRIO NO BRASIL

RETRATO EPIDEMIOLÓGICO DE ESCOLIOSIS PEDIÁTRICA EN UN HOSPITAL TERCIARIO EN BRASIL

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ABSTRACT

Objective: To trace the epidemiological profile of patients with pediatric scoliosis in a tertiary hospital in the region of Campinas - SP, seeking to understand and evaluate the demand of these patients, the results of delay in treatment, and its impact on the progression of the deformity. Methods: An epidemiological, observational, and cross-sectional study was carried out in a digital database, including patients from 0 to 18 years of age, where sociodemographic variables, scoliosis classification, and institutional follow-up and treatment data were collected. Results: The sample had 30 patients who met the inclusion criteria. The age of the patients ranged from 5 years to 18 years, with a mean of 12.8 years. Neuromuscular scoliosis was the most prevalent etiology (40%), followed by congenital scoliosis (36.6%) and, to a lesser extent, idiopathic scoliosis (23.3%). The patient follow-up time between the first and last appointment has an average of 74.7 months. When the specialty monitors the patient, the initial and final Cobb angles are evaluated in degrees, with a percentage increase of 40.3%. Delay in care (outpatient care, conservative treatment, or surgery) was identified in 25 patients (83.3% of the sample). Conclusion: Most of the patients evaluated showed evolution of the scoliosis condition, especially due to the delay in care, failure to obtain surgical treatment, or even conservative treatment in an adequate time, with an increase in the magnitude of the curve and greater severity of the case. ***Level of Evidence III; Observational, Cross-Sectional Study.***

Keywords: Scoliosis; Child Health; Adolescent; Assessment, Benefit-Risk.

RESUMO

Objetivo: Traçar o perfil epidemiológico dos pacientes portadores de escoliose pediátrica em um hospital terciário na região de Campinas – SP, buscando conhecer e avaliar a demanda destes pacientes, os resultados do atraso no tratamento e seus impactos na progressão da deformidade. Método: Foi realizado um estudo epidemiológico, observacional e transversal em um banco de dados digital, incluindo pacientes de 0 a 18 anos de idade, onde foram coletadas avaliação, variáveis sociodemográficas, classificação da escoliose e dados do acompanhamento e tratamento institucional. Resultados: A amostra contou com 30 pacientes que preenchiam os critérios de inclusão. A idade dos pacientes variou entre 5 anos e 18 anos, com média de 12,8 anos. A escoliose neuromuscular a foi a etiologia mais prevalente (40%), seguido de escoliose congênita (36,6%) e, em menor número a escoliose idiopática (23,3%). O tempo de acompanhamento do paciente entre a primeira e última consulta possui média de 74,7 meses. Durante o tempo que o paciente é acompanhado pela especialidade, avaliou-se o ângulo de Cobb inicial e o final, em graus, com aumento percentual de 40,3%. Foi identificado atraso na assistência (atendimento ambulatorial, tratamento conservador ou cirurgia), em 25 pacientes (83,3% da amostra). Conclusão: A maioria dos pacientes avaliados apresentou evolução do quadro de escoliose, especialmente devido ao atraso na assistência, na falta de obtenção de tratamento cirúrgico ou mesmo de tratamento conservador em tempo adequado, com aumento da magnitude da curva e maior gravidade do caso. ***Nível de Evidência III; Estudo Observacional, Transversal.***

Descritores: *Escoliose; Saúde da Criança; Adolescente; Classificação de Risco.*

RESUMEN

Objetivo: Rastrear el perfil epidemiológico de pacientes con escoliosis pediátrica en un hospital terciario en la región de Campinas - SP, buscando comprender y evaluar la demanda de estos pacientes, los resultados de la demora en el tratamiento y su impacto en la progresión de la deformidad. Método: Se realizó un estudio epidemiológico, observacional y transversal en una base de datos digital, incluyendo pacientes de 0 a 18 años, donde se recolectaron variables sociodemográficas, clasificación de la escoliosis y datos de seguimiento y

Study conducted by the Hospital das Clínicas of the School of Medical Sciences of the Universidade Estadual de Campinas - HC/FCM/UNICAMP, Campinas, SP, Brazil.
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Received on 03/28/2023 accepted on 08/25/2023
Reviewed by: Marcelo Wajchenberg

tratamiento institucional. Resultados: La muestra estuvo conformada por 30 pacientes que cumplieron con los criterios de inclusión. La edad de los pacientes osciló entre 5 y 18 años, con una media de 12,8 años. La escoliosis neuromuscular fue la etiología más prevalente (40%), seguida de la escoliosis congénita (36,6%) y, en menor medida, la escoliosis idiopática (23,3%). El tiempo de seguimiento del paciente entre la primera y la última cita tiene una media de 74,7 meses. Durante el tiempo que el paciente está en seguimiento por la especialidad se evaluaron los ángulos de Cobb inicial y final, en grados, con un porcentaje de incremento del 40,3%. Se identificó retraso en la atención (ambulatoria, tratamiento conservador o cirugía) en 25 pacientes (83,3% de la muestra). Conclusión: La mayoría de los pacientes evaluados presentaron evolución del cuadro de escoliosis, sobre todo por la demora en la atención, la no obtención de tratamiento quirúrgico o incluso en el tratamiento conservador en tiempo adecuado, con un aumento de la magnitud de la curva y una mayor gravedad del caso. ***Nivel de Evidencia III; Estudio Observacional, Transversal.***

Descriptores: *Escoliosis; Salud Infantil; Adolescente; Calificación de Riesgo.*

INTRODUCTION

Scoliosis is a prevalent pathology in orthopedic care for pediatric and adolescent patients and is characterized as the most common type of pediatric spinal deformity.[1] It is defined as a three--dimensional spine deformity with a lateral deviation of more than 10 degrees in the coronal plane.[2]

Pediatric scoliosis (PS) is diagnosed in patients before adulthood, i.e., at 18 or younger. The descriptors "infantile", "juvenile" and "adolescent" are used to refer to the age of the patient at the time of diagnosis, with scoliosis being considered "infantile" when diagnosed between 0 and 3 years, "juvenile" between 4 and 9 years, and "adolescent" between 10 and 17 years.[3] It is known that age at diagnosis alone cannot adequately guide treatment, but it is important in assessing the natural history of progression.[4]

PS can be classified according to its etiology and related conditions. It can result from congenital malformations, neuromuscular conditions, dysplasias, hereditary bone syndromes, and idiopathic cases with no underlying disease.[5]

In a Brazilian study, there was a higher incidence of congenital and neuromuscular scoliosis, with a mean age of 15.3 years in a general sample.[6] However, it is known that the prevalence of idiopathic scoliosis in adolescents is estimated at between 2 and 5.2%, with curves greater than 30 degrees having a prevalence of 0.1 to 0.3%.[7] This condition progresses in 10 to 15% of cases over time.[8]

Understanding the natural history of the deformity, the behavior of the curve, and its progression is a fundamental point in the therapeutic approach to PS as it allows for a proper understanding of the prognosis and a more assertive treatment decision.[9,10]

Because it has a wide variety of etiologies, the natural history of PS varies. In the absence of treatment, progressive curves have the potential to reach significant magnitudes. It is accepted that curves greater than 50 degrees can continue to progress up to 1 degree per year and that curves above 80 degrees can cause increased morbidity and mortality, restrictive structural alterations of the rib cage with consequent cardiopulmonary deterioration, and a strong psychosocial impact.[11,12]

The main aim of treating PS is to prevent the deformity from progressing. The therapeutic options consist of clinical and radiographic monitoring and orthoses or surgery. Curves above 50 degrees are generally indicated for surgical treatment, with posterior arthrodesis being the technique of choice in most cases.[13]

The problem with these treatments lies in the need for specialized care, the high demand and complexity of the surgical techniques and instruments, and the high cost of the procedures. Patients with spinal deformities, especially progressive and complex pediatric or neuromuscular cases, who require specialized care are referred to highly complex centers.[14]

Surgical procedures to correct scoliosis require investment in specialized and experienced professionals, technical resources, and expensive implants. Underfunding in the public health system in this area leads to long waiting lists for patients awaiting definitive treatment, with potential damage to the severity of the deformity, increased costs, and worsening quality of life.[15-17]

Surgical costs can vary from USD 29,955.00 to USD 60,754.00 but promote clinical, radiographic, and quality of life improvements.[18] These values change according to the implant material used and the days spent in intensive care.[19] In Brazil, costs are around R$35,000.00 per hospital procedure, and the Unified Health Service (SUS) has covered around 25% of this amount.[6,20] There is no official data on this subject, but it is estimated that the growth in cases has been geometric in recent years. Cost and demand are not the only problems, but also the lack of adequate technology, shortage of hospital beds, ICU, orthoses, traction tables for serial casts, insufficient training for conservative treatment, and failure to include more modern instruments and procedure codes.[6,20]

Waiting too long for treatment leads to increased morbidity and mortality, longer surgery times, more transfusions, a greater number of vertebrae to be instrumented and, consequently, more synthetic material. In addition, symptoms worsen, causing negative impacts on patients' mental and psychological health and quality of life.[21-23] In extreme cases of progression of the curve, which require a more aggressive procedure that increases the risk and size of the surgery, associated with coexisting comorbidities and patients' delicate clinical status, surgery may not be feasible, so the risks outweigh the benefits. Furthermore, the rates of complications, such as pseudarthrosis and junctional kyphosis, for the same procedure in adults are higher than in immature individuals.[24]

Many countries are looking for solutions to minimize this growing and serious public health problem.[25] Studies on allocating resources to the SUS have shown a deficit in tertiary health care for Brazilian children and adolescents. This and other gaps in care stem from the lack of tools for planning and prioritizing resources based on epidemiological and administrative evidence.[21]

Therefore, in this current scenario, it is essential to know the factors associated with the cause, severity, and progression of PS, to map the difficulties of the SUS and service providers, to recognize the difficulty of patient access, and the impacts of waiting on functionality, quality of life, psychosocial health and, above all, its negative repercussions on surgical treatment.[6,20]

This study aims to conduct an epidemiological analysis in a tertiary hospital in the Campinas region of São Paulo to document the demand for and problem of scoliosis in pediatric patients. In addition, the study aims to evaluate the waiting time for surgical treatment of these patients and assess the impacts of delays in treatment.

METHOD

This is an epidemiological, cross-sectional study of patients being treated for scoliosis at the Orthopedics and Traumatology Department of a tertiary-level hospital in São Paulo, approved by the Research Ethics Committee (CAAE 35250220230075404).

The inclusion criteria were that patients aged between 0 and 18 years were included in the sample, with the application of an assent form, where appropriate, and a free and informed consent form, which the guardians signed.

The exclusion criteria were patients over 18, those who did not agree to the consent and informed consent forms, patients who were lost to follow-up, or those who did not have complementary imaging tests available.

The research was carried out using data obtained from patients and guardians undergoing treatment for PS, through data obtained

directly by medical professionals attending the hospital, during outpatient consultations, or by electronic means. The categorical variables collected were age at the time of the last consultation, gender, diagnosis according to the *Scoliosis Research Society* and its date, city of origin, a form of referral, waiting time for treatment at the referral center, treatment carried out before referral to the referral center, reasons for non-treatment and delay in treatment, the magnitude of the curve assessed by measuring the Cobb angle, indication for treatment at the initial consultation at the referral center, waiting time for surgical or conservative treatment (orthosis, serial plaster casts in traction), defined months from the date of indication for treatment to the date of treatment or last consultation, and the need for and availability of suitable material for treatment.

The local evaluating physician carried out the clinical and radiological evaluation based on a physical examination and analysis of the curvature in radiographic images, according to the criteria of the *Scoliosis Research Society*.

Statistical analysis was carried out to present continuous variables as mean and standard deviation when normal or median and interquartile range when non-parametric. Discrete variables were presented in absolute numbers and frequency distribution (%).

RESULTS

The sample of this study included 30 patients who met the inclusion criteria. Of these, 21 were female (70%) and nine male (30%), with an average age of 12.8 ± 3.7 years. Of the 21 women, 11 reported menarche (52% of all women). The age of the patients ranged from 5 years to 18 years, with an average of 12.8 years. The etiology of the scoliosis of the patients in the population sample is shown in Table 1.

Risser's sign type I was seen in 2 patients (6.66%), type II in 3 patients (10%), type III in 3 patients (10%), type IV in 6 patients (20%), and type V in 6 patients (20%). Finally, thoracic kyphosis was present in 7 patients (23.3%).

Regarding how they were referred to the referral center, 19 patients (63.3%) had their appointment made by internal, in-hospital referral. One patient (3.4%) made an appointment based on a direct medical referral via an external medical request, and ten patients (63.3%) were referred via the Health Services Supply Regulation Center (CROSS).

The time between the date of the initial referral, the date of the first consultation with the spinal surgery specialist, the date of the indication for treatment, and the date of the last consultation were evaluated in months and their ratios. The average time it takes for a patient to enter the referral center and be evaluated by a spine specialist is 28.13 months. After the patient is referred for treatment, the average time until the last appointment is 36.5 months. Finally, the average follow-up time between the patient's first and last visit was 74.7 months. When the patient is followed up by the specialty, the initial and final Cobb angles were assessed in degrees, with a percentage variation of 40.3%. (Table 2, Figure 1)

As for the treatment indicated before the referral center, observation was indicated for all 30 patients (100%). Of the total number of patients, 20 had indications for surgical treatment and are awaiting surgery (66.6%), while 6 (20%) have indications for conservative treatment. Between the start of data collection and the end of the analysis, two patients underwent surgical treatment and were therefore not waiting in line for a surgical procedure. For one patient, due to clinical conditions, the magnitude of the curve, and the size of the surgery, it was decided to contraindicate surgical treatment and keep the patient under observation. For one patient, despite the indication for surgery, the family did not want surgical treatment.

Table 1. Etiology.

Etiology	Number of patients N(%)
Neuromuscular scoliosis	12 (40%)
Congenital Scoliosis	11 (36.6%)
Idiopathic Scoliosis	7 (23.3%)
Total	30 (100%)

Table 2. Follow-up data.

	Lowest value	Highest value	Average	Median
Time between date of referral and date of appointment with a specialist (months)	0	134	28.13	3.5
Time between first visit and last visit (months)	8	175	74.7	72.5
Time between indication for treatment and date of last consultation (months)	1	169	43.73	36.5
Initial Cobb (degrees)	25	130	58	56.5
Most current Cobb (degrees)	43	149	83	81.4
Cobb variation (degrees)	2	65	18.9	13

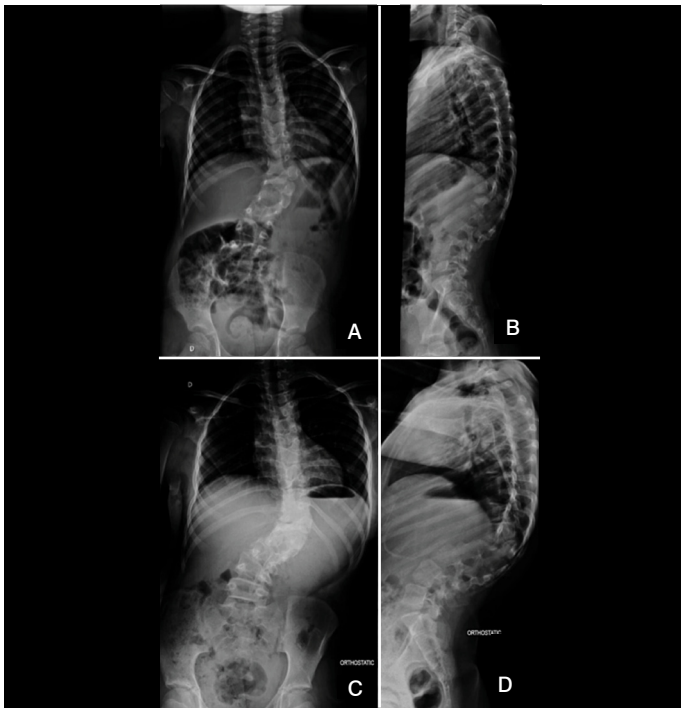

Figure 1. Radiographic progression of congenital scoliosis, between the initial consultation in February 2018 (A and B) and the last consultation in March 2023 (C and D).

As for the fact that there was a delay in care (consultation, conservative treatment, or surgery), this was identified in 25 patients (83.3% of the sample), with varying causes that coexisted most of the time. Among the causes identified were delays in entering the referral center, difficulties in getting plaster casts made or in obtaining suitable surgical materials compatible with the patient's needs, lack of hospital beds/blocking of elective surgeries, lack of cooperation identified in some patients who do not return at the correct intervals or with requested tests, the need for stabilization/clinical releases, difficulties in obtaining neurophysiological monitoring, and difficulties in making a pediatric intensive care unit (ICU) available.

DISCUSSION

This study evaluated the epidemiological profile of 30 patients with pediatric scoliosis in a tertiary hospital in the region of Campinas - SP. The study's results were compared with the existing literature on the subject. While the literature points to idiopathic scoliosis as the most common cause of spinal deformity in pediatric patients, accounting for 80% of cases,[26] and neuromuscular scoliosis only 2.5%,[27] the most prevalent diagnosis in our sample was neuromuscular scoliosis (40%). The second most common diagnosis was congenital etiology

due to insufficient hemivertebra formation. These results are compatible with other Brazilian studies by Bressan-Neto et al,[22,23] and can be attributed to the fact that the studies were carried out in tertiary hospitals, which treat highly complex cases, including patients with non-idiopathic scoliosis and curves of high magnitude.[28]

The Risser sign is widely used to assess skeletal maturity and as a predictor of the risk of scoliosis progression and is used to determine the surgical threshold. According to Cheung JPY et al,[29] patients with Risser's sign-up to stage 3 have a higher risk of curve progression. In this study, most patients had a Risser sign in stages IV and V, indicating skeletal maturity and a lower risk of curve progression. Chen ZQ et al,[30] skeletal maturity state, represented by Risser V, can significantly affect flexibility, which should be considered when indicating treatment and preoperative planning. The results obtained in this study highlight the importance of skeletal maturity in treatment decision-making, the patient's skeletal maturity through the Risser sign, and flexibility. These factors are crucial in determining the most appropriate course of treatment for each patient with scoliosis, emphasizing the need for an early and individualized approach.

The role of general practitioners in public health systems, such as Canada, is fundamental in diagnosing and referring patients with scoliosis for orthopedic care.[31] In Brazil, Primary Health Care is the gateway to the public health system. General practitioners are responsible for meeting most patients' health needs and referring them to other levels of care if necessary.[32] The main objectives of regulating access to health services in Brazil are to guarantee access, quality of care, and health care organization. The Central de Regulação de Ofertas e Serviços de Saúde (CROSS) is responsible for managing access to public health network units in the context studied.[33]

During the analysis of the results, it was observed that most patients with suspected deformities were referred internally, i.e., within the hospital (63.3%), through the attending specialty. A smaller proportion of patients (33.3%) were referred via the CROSS system. Notably, these figures do not represent the regular flow of patients since the outpatient clinic is closed to new external cases to meet the internal demand of patients awaiting treatment. This situation also affected the sample collected since new patients were not being admitted, and some patients awaiting definitive treatment were not included in the sample because they were over 18, although they were admitted as children.

The high demand for scoliosis surgery affects the individual and places a burden on the healthcare system and an institution's resource capacity. According to Anthony et al,[34] more than 90% of the surgeries a spine surgeon performs each year are related to the late referral of patients with adolescent idiopathic scoliosis (AIS). This can lead to access challenges for other patients with spinal deformities who require timely intervention, burdening the healthcare system and hindering equal access to medical resources.

When evaluating the results, it was noted that all the patients were only recommended for observation before being assessed by a specialist. It is important to note that in Brazil, there is no policy for the early detection of scoliosis, which can result in failures in the early identification of the condition.[35] Studies show that thoracic curves between 30° and 50° have an average progression of 10° over a 40-year period, while curves between 50° and 75° have an average progression of 29°.[36] Efforts to maintain curves or start treatment below 50° are justified, reaffirming the importance of early curve detection and timely treatment prescription.

Late referral in scoliosis is a problem that can lead to the need for surgical treatment. According to Anthony et al.[34] it is defined as failure to recognize the curve early enough to start conservative treatment, with a curve that exceeds the effective indication for conservative treatment with orthosis (greater than 40 degrees in patients with skeletal immaturity) or in growing or non-growing patients, with curves greater than 50 degrees. In line with this, we observed that most patients who entered the specialized care system were referred late, with 70% presenting curves greater than 40° and 56.6% presenting curves greater than 50° at the initial assessment.

The BrAIST study, a multicenter randomized clinical trial, showed that patients with remaining growth potential use of orthoses avoided surgery by 72%, compared to only 48% of patients who did not receive treatment.[37] Furthermore, Adobor et al. (2013)[31] reported in a prospective study that many patients with scoliosis were diagnosed late, with 60% of cases presenting a Risser sign of 3 or more and 78% of girls being post-menarcheal, which limits the potential for conservative treatment. In this study, we identified a worrying trend of late detection and referral of scoliosis in patients who access the specialized care system. Most of our patients showed limitations in growth potential, with 60% having a Risser sign equal to or greater than 3 and 52% being post-menarcheal, indicating advanced skeletal maturity and limited remaining growth potential. The results suggest that many patients missed the opportunity for conservative treatment, highlighting the importance of early detection of scoliosis and raising awareness among health professionals and the general public about the warning signs of this condition.

The study by Miyanji et al.[38] highlights the worrying association between long waiting times for surgical treatment of scoliosis and worsening morbidity and mortality, types of surgery, additional surgical procedures, prolonged operative times, increased blood loss, and greater likelihood of adverse events. These results corroborate the findings of Henry Ahn et al.[39] from the University of Toronto, who also point to the need to reduce waiting times to avoid unnecessary complications and the need for additional unplanned surgery beyond that foreseen at the first consultation. When evaluating our sample, 70% arrived at the time of surgical treatment, and 66% are still awaiting definitive treatment. Patients wait an average of 58 months from the time treatment is indicated until their last appointment, with an average progression of 18.9 degrees during the waiting period. These results reinforce the importance of reducing waiting times for surgical treatment in patients with scoliosis to minimize the negative effects on the quality of life of patients and their families and avoid the need for additional surgical procedures and associated complications. Timely treatment avoids the risks associated with surgery and reduces the burden of a long recovery that can affect social participation, school, and extracurricular activities.[40]

Finally, the reasons for these delays in treatment are multiple and often coexist, some of the most notable being the lack of beds, hospitalization and ICU, and the blocking of elective surgeries.[22,23] It is a fact that the recent coronavirus pandemic (COVID-19) has affected all levels of healthcare. In the context of health care, the changes have been even more intense, exploiting its capacity and highlighting the weaknesses of the health system, especially the public health system, bringing up discussions about insufficient care and the poor distribution of beds. It is known that patients undergoing deformity correction surgery require longer hospital stays and intensive support, which can put a strain on the overburdened healthcare system. Practical and administrative changes were necessary in the spinal surgery area, reducing the clinical and surgical load. Elective surgeries were rescheduled or postponed, especially for deformities and complex revisions.[41]

CONCLUSION

Our study found that a significant proportion of patients are referred to specialized care late, with high angular value curves and advanced skeletal maturity, which prevents them from receiving timely treatment. In addition, the long wait for surgical treatment of the deformity has been documented, which leads to progression and increased severity. We conclude that this data contributes to increased morbidity and mortality, makes treatment more complex, and represents a challenge for accessing patients with spinal deformities who need timely intervention, overburdening the health system.

ACKNOWLEDGMENT

Thanks to the Brazilian Spine Society for financial support for the research.

The authors declare that Medtronic provided resources to SBC - GEPEDI to provide logistical support for this study.

CONTRIBUTIONS OF THE AUTHORS: Each author has made an individual and significant contribution to the development of this article. SCMM: the idealization of the work, writing of the project, search and collection of data, statistical analysis, and final writing. SM, IGV, AFR, MCL, MAT, and WP: the idealization of the work and final conference. MRIN: idealization of the work, drafting of the project, monitoring of the data collection and checking process, final drafting, and final checking.

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