Unmet Needs of Surgical Care for Children: A Case Study in the Brazilian Publicly-Financed Health System*

Necessidades não atendidas de cuidados cirúrgicos para crianças: Estudo de caso no Sistema Único de Saúde financiado pelo governo no Brasil

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Abstract

Objective To measure and document the clinical impact of the waiting time for surgical treatment of patients with spinal deformities in a quaternary center in Brazil.

Methods In total, 59 patients with spinal deformity waiting for surgery on our hospital's list were evaluated to observe the impact of the waiting time on the progression of the deformity. Patient evaluation was performed using the SRS-22r questionnaire for health-related quality of life (HRQL) and radiographic images to evaluate the deformity of the spine at the time the patients were included in the waiting list and at the most recent appointment. The radiographic parameters selected for comparison were: Cobb angle of the primary and secondary curves, coronal alignment, apical vertebral translation, pelvic obliquity, sagittal vertebral axis, kyphosis (T5-T12), and lordosis (L1-S1).

Results Low HRQL scores according to the SRS-22r questionnaire were observed in patients waiting for surgery. The radiographic parameters showed progression of the deformity on the initial evaluation when compared with the most recent follow-up evaluation.

Conclusion The patients waiting for surgical treatment of spinal deformities in our center showed relatively low HRQL scores and radiographic progression of the deformity.

Keywords
- spine
- scoliosis
- waiting list
- vertebral curvatures
- health policy

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Resumo

Objetivo Medir e documentar o impacto clínico do tempo de espera para tratamento cirúrgico de pacientes com deformidades na coluna vertebral em um centro quaternário no Brasil.

Métodos No total, 59 pacientes com deformidade espinhal à espera de cirurgia na lista do nosso hospital foram avaliados para observar o impacto dos tempos de espera na progressão da deformidade. A avaliação do paciente foi realizada utilizando o questionário SRS-22r para qualidade de vida relacionada à saúde (QLRS), e imagens radiográficas para avaliar a deformidade da coluna vertebral quando os pacientes foram incluídos na lista de espera e na consulta mais recente. Os parâmetros radiográficos selecionados para comparação foram: ângulo de Cobb de curvas primárias e secundárias, alinhamento coronal, translação de vértebra apical, obliquidade pélvica, eixovertebral sagital, cifose (T5-T12), e lordose (L1-S1).

Resultados Baixos escores de QLRS segundo o questionário SRS-22r foram observados em pacientes que aguardavam cirurgia. Os parâmetros radiográficos mostraram progressão da deformidade na avaliação inicial em comparação com a avaliação de seguimento mais recente.

Conclusão Os pacientes que aguardavam tratamento cirúrgico de deformidade espinhal em nosso centro apresentaram escores de QLRS e progressão radiográfica de deformidade relativamente baixos.

Palavras-chave

- coluna
- escoliose
- listas de espera
- curvaturas vertebrais
- política de saúde

Introduction

The organization of the Brazilian Unified Health System (Sistema ùnico de Saúde, SUS, in Portuguese) determines that the surgical treatment of spinal deformities should be performed in specialized tertiary centers.[1] The patients referred to tertiary centers are then placed on a waiting list.

The surgical treatment of spinal deformities has special features (long duration of surgeries, the requirement of specialized human resources, high cost of the implants and technical resources). This, associated with the underfunding of SUS, has led to a steadily increase in the surgical waiting list.[2,3]

Emerging evidence suggest that the treatment for scoliosis is time-sensitive, as scoliosis worsens with spinal growth and over time.[4–7] As patients wait for treatment, particularly children and youths, their spine deformities deteriorate, becoming more complex and morbid, thus causing undue emotional distress for the patients and their families.[8] Moreover, the risk of complications of the surgical treatment of larger spinal deformities is substantially higher,[9] and so is the cost of the treatment.[10,11] A few studies have shown the impact of long waiting times for the surgical treatment of scoliosis in Canada[4,7,12] and in Brazil.[3,13,14]

Despite improvements in primary health care, the SUS has faced challenges in delivering universal and equitable health care to 209 million Brazilians.[15] Allocation decisions and planning occur at National Health Conferences, which are held every four years in accordance with a federal law.[16] The current decision-making process for the allocation of health resources for the SUS has systematically failed to account for unmet needs of surgical care for children and youths who are disproportionally burdened with the lack of access to hospital care in Brazil.[17–19]

In one of the largest quaternary academic hospitals in Brazil, one of the senior authors noticed over the last ten years a dramatic impact of the growing burden of scoliosis as a result of the current public health policy, or the lack thereof, to allocate surgical resources for children and youths with spinal deformities. The purpose of the present case study is to measure and to document the clinical impact of surgical waiting times for the treatment of patients with complex spinal deformities in a quaternary center in Brazil.

Materials and Methods

The present retrospective case series was approved by the ethics and research committee under number 833.475. We evaluated a cohort of 59 patients with spinal deformities on the surgical waiting list as of December 2013 in a quaternary center in Brazil. Only pediatric deformities, defined by the age and etiology of the diagnosis, were considered in the study. Adult or degenerative deformities were excluded, as well as one patient who was on the waiting list, but had already undergone surgery in another hospital.

The medical records and spine radiographs of the patients were reviewed. The main outcome measures included the waiting time for the surgery (how long the patients had been waiting for the surgical treatment until December 2013) and health-related quality of life (HRQL) using the SRS-22r® questionnaire validated in Portuguese.[20] The questionnaire was applied to patients aged more than 10 years with full cognitive function.

The radiographic images were evaluated at the time the surgical treatment was recommended (inclusion in the waiting list) and at the most recent follow-up appointment. The radiographic measurements were performed manually

on printed and digital radiographic images[21] using the Osirix software (Pixmeo Sarl, Bernex, Switzerland). The radiographic parameters selected for comparison were: Cobb angle of the primary and secondary curves, coronal alignment, apical vertebral translation, pelvic obliquity, sagittal vertebral axis, kyphosis (T5-T12) and lordosis (L1-S1). For patients with neuromuscular scoliosis, the pelvic obliquity was evaluated according to Gupta et al.[22]

We analyzed the data using the John's Macintosh Project (JMP, SAS Institute, Inc., Cary, North Carolina, US) software. We used the Student *t*-test for averages and standard deviations for the normal distribution data. For data with non-parametric distribution, we calculated medians and interquartile ranges (IQRs), which were analyzed with analysis of variance (ANOVA) and the Mann-Whitney U-test (intergroup analysis). Paired Student *t*-tests were used for the intragroup analysis. The matching analysis was described with the average difference and 95% confidence interval (95%CI). The significance level (α) was established as 0.05.

Results

In total, 59 patients (40 females) who were on the surgical waiting list for the treatment of spinal deformities on December 31, 2013 were evaluated. The age of the patients ranged from 3 to 23 years (average: 13.5 ± 3.7 years). The etiology of the deformities was: neuromuscular (17 patients; 28.3%), congenital (16 patients; 26.7%), idiopathic (15 patients; 25.0%), syndromic (10 patients;16.7%), Marfan syndrome (1 patient; 1.7%) and neurofibromatosis (1 patient; 1.7%). The waiting time for surgery in December 2013 ranged from 2 to 117 months (median: 13.5; IQR: 13.8 months).

The HRQL evaluation was performed with the SRS-22r questionnaire in 36 patients with the following etiologies: 11 (30.6%) – neuromuscular; 10 (27.8%) – idiopathic; 8 (22.2%) – congenital; 5 (13.9%) – syndromic, 1 (2.8%) – Marfan syndrome; and 1 (2.8%) – neurofibromatosis. The median score for each category was: function – 3.60 (IQR: 1.00); pain – 4.00 (IQR: 1.40); self- image – 3.00 (IQR: 0.80); mental health – 3.80 (IQR: 1.00); and satisfaction – 4.00 (IQR: 1.00) (►**Fig. 1**).

The radiographic parameters showed statistically significant differences comparing the evaluation at the time of the surgical indication and the follow-up assessment. A statistical difference was observed in the coronal and sagittal parameters, indicating the progression of the deformity (►**Table 1**, ►**Figs. 1**, **2**, **3** and **4**). Among the skeletally-immature patients at the initial evaluation, 18 (58.1%) reached skeletal maturity while waiting for surgery.

On the coronal plane, the Cobb angle of the main deformity increased an average of 18.6° (95%CI: 13.9° to 23.4°"; $p < 0.0001$). The increase in the deformity was observed in all etiologies (►**Fig. 5**). The Cobb angle of the secondary curve increased an average of 10.7° (95%CI: 7.7° to 13.6°; $p < 0.0001$) (►**Fig. 6**).

Discussion

The present study documents the impact of the long waiting time for the surgical treatment of spinal deformities in

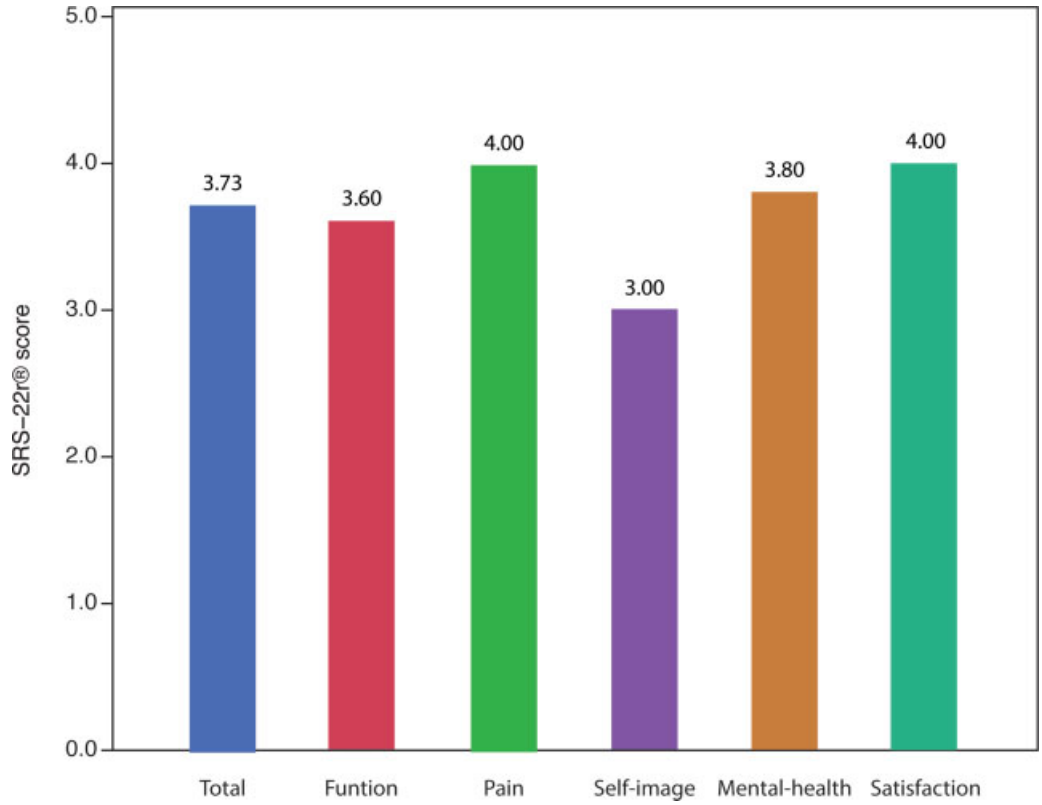

Fig. 1 Outcomes of the patients on the surgical waiting list according to the scores on the SRS-22r questionnaire. Each bar corresponds to the average score of each domain in the questionnaire.

Table 1 Summary of the radiographic parameters on the initial and final evaluations, average difference, 95% confidence interval and *p* value for the paired analysis

Radiographic parameters	Initial	Final	Average difference	95%CI	*p*-value
Coronal plane					
Main curve	61.19°	79.81°	18.61°	13.88°–23.35°	< 0.0001*
Secondary curve 1	39.07°	49.73°	10.66°	7.73°–13.58°	<0.0001*
Secondary curve 2	21.16°	26.78°	5.63°	1.54°–9.72°	0.0086*
C7–CSVL (millimeters)	21.54	31.73	10.20	2.44–17.95	0.0113*
AVT (millimeters)	38.56	55.85	17.28	8.6–25.97	0.0003*
Pelvic obliquity (horizontal)	8.88°	12.68°	3.80°	0.43°–7.17°	0.0287*
Pelvic obliquity (T1)	12.44°	16.48°	4.04°	0.27°–7.81°	0.0369*
Sagittal plane					
SVA (millimeters)	29.53	41.00	11.47	1.55–21.39	0.0245*
Kyphosis (T5–T12)	33.74°	39.62°	5.88°	-0.04°–11.80°	0.05
Lordosis (L1–S1)	-54.80°	-57.05	-0.25°	-6.59°–6.09°	0.937
Main sagittal deformity	69.15°	87.92°	18.77°	10.51°–27.03°	0.0003*

Abbreviations: 95%CI, 95% confidence interval; AVT, apical vertebral translation; CSVL, central sacral vertical line; SVA, sagittal vertical axis. **Note:** * statistical significance.

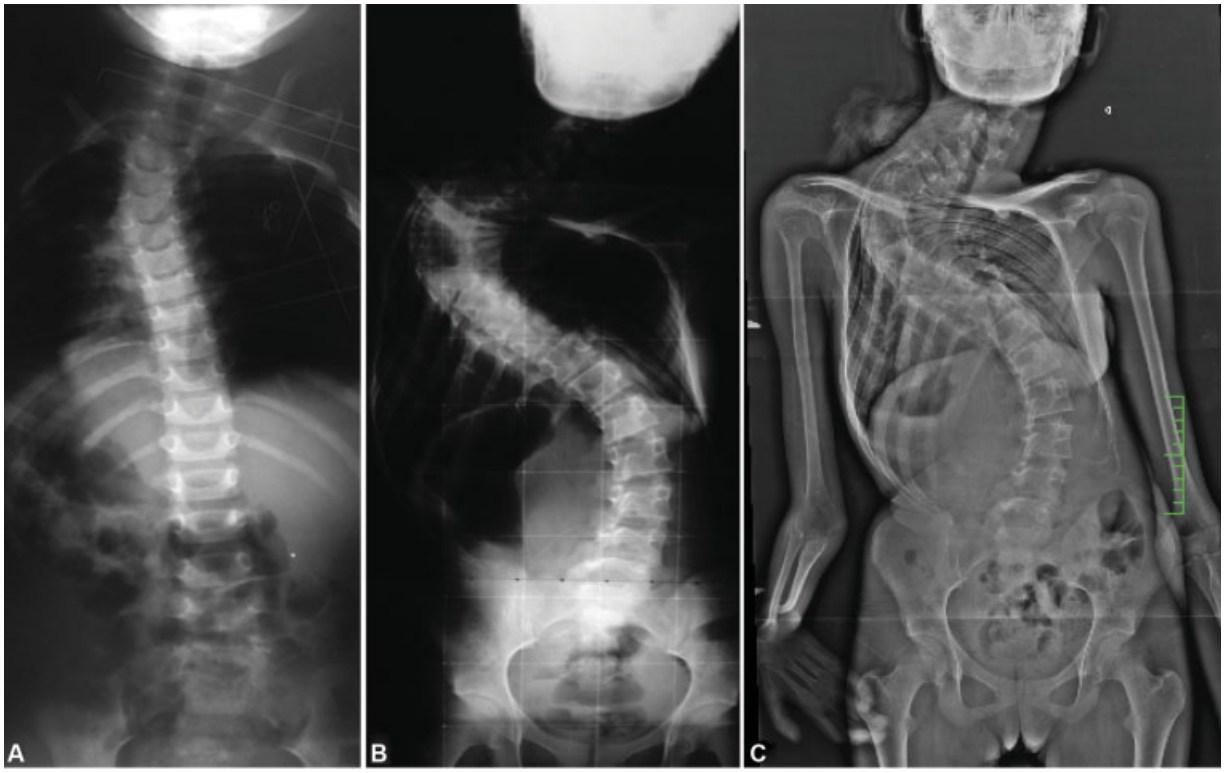

Fig. 2 Radiographic progression of adolescent idiopathic scoliosis from 2005 (**A**), in 2010 (**B**), and in 2013 (**C**).

children and youths in a quaternary center in the Brazilian publicly-financed health care system (SUS). The evaluation of the patients in our waiting list showed progression of the deformities and a decrease in the HRQL scores. We challenge the term "waiting for surgery" because many patients have never been operated on to date. Performing surgical treatment for larger vertebral deformities, as they progress with time, represents increased cost and morbidity, and, in some extreme cases, the high risk of life-threatening complications may prevent the surgeons from performing the recommended surgical treatment. The growing number of judicial proceedings for hospital medical treatment in Brazil[23] illustrates this complex health policy problem and the challenges involved in incorporating technology and complex

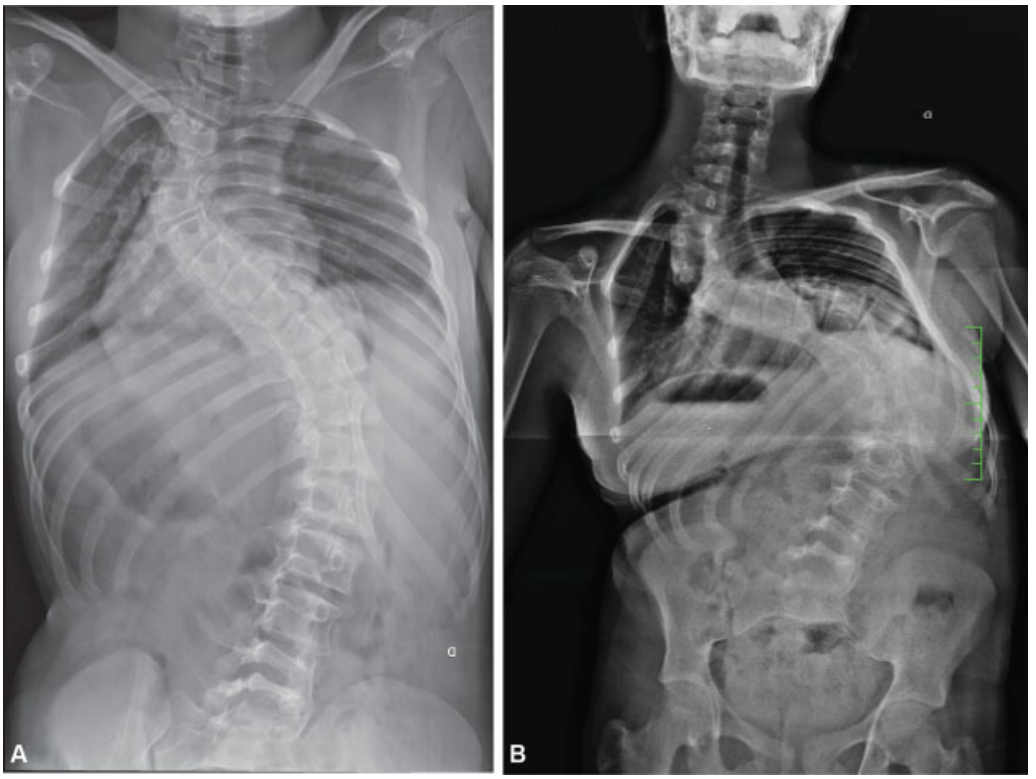

Fig. 3 Progression of syndromic scoliosis in a 10 year-old female patient from February 2013 (**A**) to January 2014 (**B**).

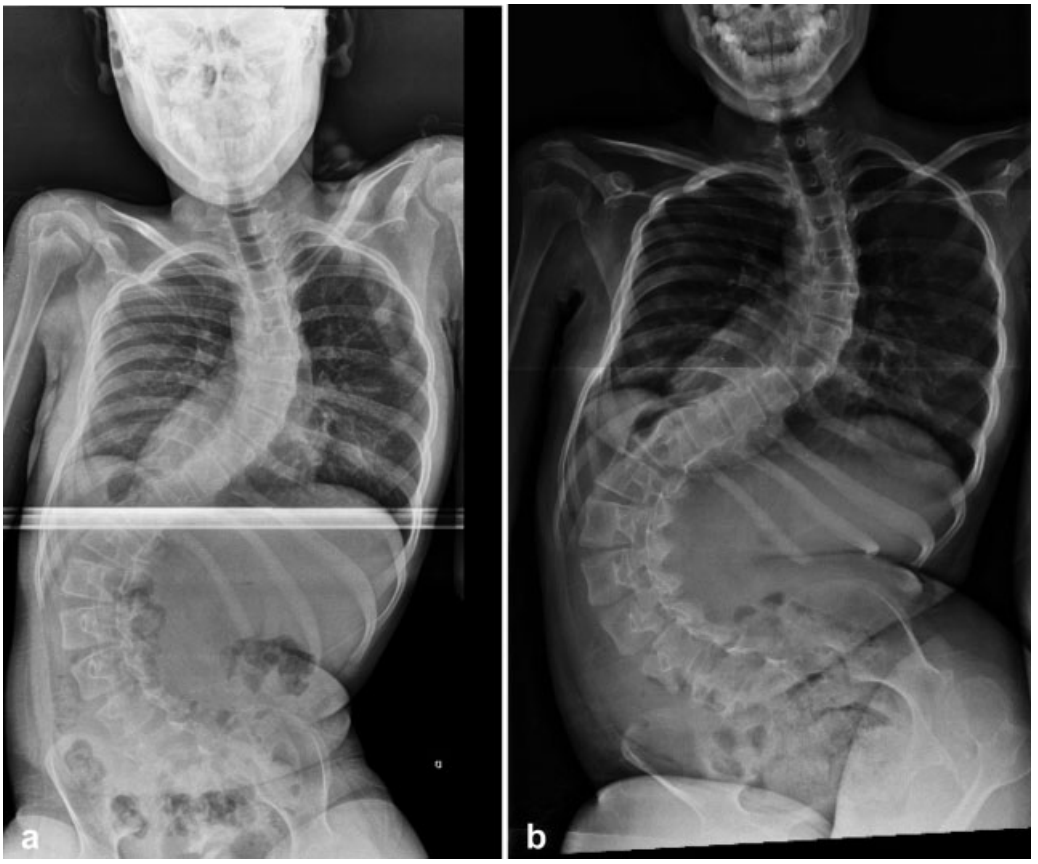

Fig. 4 Progression of the deformity from January (**A**) to October 2013 (**B**) in a patient with spinal amyotrophy.

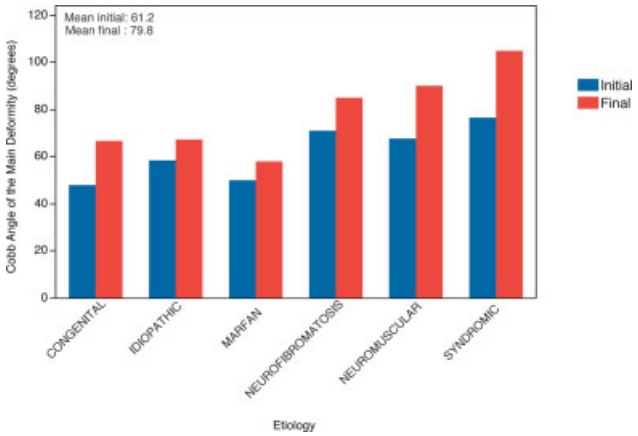

Fig. 5 Comparison between the initial and final Cobb angles of the main deformity curve in the different etiologies, showing worsening of the deformity in all subgroups of patients.

treatments (and their inherent costs) in a health care system with limited financial resources.[24]

The patients on the waitlist in the present study were managed according to current SUS health policies; however, this approach has not been effective, as our data shows. The SUS was created after the 1988 Brazilian Constitution recognized health as a citizen's right and duty of the state.[15,16] Problems related to waiting times for the treatment of spinal deformities have been reported in Brazil[3,13,14] and in other countries like Canada, the United Kingdom,[10] and New Zeland.[8] The average waiting time was of 1 year in Canada,[4,7,12] of 5 to 9 months in the United Kingdom (according to Clark[10]), and of 2.5 weeks to 2.9 years in New Zeland.[8] The hazards of prolonged waiting times are all too well-known and characterized by curve progression, increase in symptoms, and a negative impact on the mental health and quality of life of the patients.[6,7,25] The results observed in the present study just corroborate and agree with the previous reports.

While studying the HRQL of patients on the waiting list, we could observe low scores on the specific HRQL questionnaire for patients with spinal deformities (SRS-22r). Accordingly, Calman et al.[8] evaluated the impact of delaying the surgical treatment for patients with idiopathic scoliosis, which correlated with progressive worsening of the HRQL. In the present study, by the time the surgical decision was made, there were no baseline HRQL data, and this is a limitation. Regardless of this, we could observe lower SRS-22 scores than those described in the literature. Camarini et al.,[20] in the study that resulted on the validation of the SRS-22r for the Brazilian population, applied the questionnaire to patients with idiopathic scoliosis and obtained higher scores than those of the present study, except in the categories "pain " and "mental health", which were the same as ours. Farley et al.[26] applied the

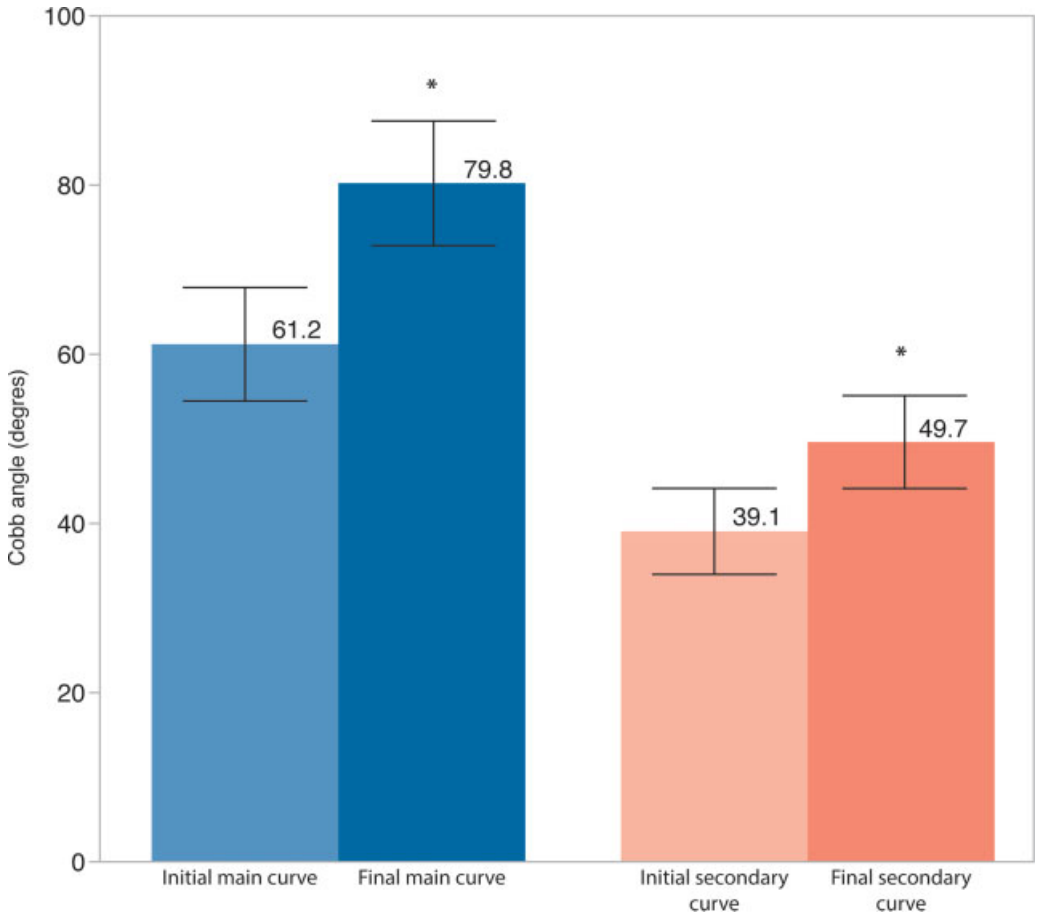

Fig. 6 Comparison between the initial and final Cobb angles of the main and secondary curves. The bars and numbers represent the average Cobb angle and the error bars represent the 95%CI. The asterisk (*) indicates statistical difference.

Table 2 Comparison between the score on the SRS-22r questionnaire and literature data

Domain (SRS-22r)	Surgical waiting list (clinical evaluation)†	Idiopathic scoliosis[20]	Congenital scoliosis[26]
Function	3.60 (1.00)	4.08 ± 0.75	4.64 ± 0.5
Pain	4.00 (1.40)	3.99 ± 0.87	4.53 ± 0.47
Self-image	3.00 (0.80)	3.53 ± 0.83	3.73 ± 0.85
Mental health	3.80 (1.00)	3.73 ± 0.75	4.21 ± 0.59
Satisfaction	4.00 (1.00)	4.28 ± 0.83	4.02 ± 0.88
Total	3.73 (0.91)	Unavailable	4.23 ± 0.52

†Data expressed as median and interquartile range (in parenthesis); *data expressed as average and standard deviation; adapted from Camarini et al.[20] and Farley et al.[26]

SRS-22r questionnaire to patients with congenital scoliosis and obtained higher scores in every category (►**Table 2**).

The evaluation of the radiographic consequences showed worsening og the deformities of the patients while they were waiting for the surgical procedure. There was an increase in the angles of the primary and secondary deformities, progression of the unbalance on the coronal and sagittal planes, and an increase in the number of patients with pelvic obliquity. Accordingly, Dabke et al.[6] performed a retrospective analysis on adolescent patients with idiopathic scoliosis treated surgically, and reported significant worsening of the deformity while waiting for surgery, resulting in more complex surgeries to be performed than the ones previously planned in 16.7% of the cases. Miyanji et al.[9] reviewed the treatment of 325 patients with idiopathic scoliosis and correlated the deformity increase with the surgical time, the number of levels included in surgery, and the risk of need for blood transfusion. Even though the study did not include an analysis of the surgical costs, the authors concluded that the increase in the use of resources results in an increase in treatment expenses. In another study, Miyanji et al.[7] analyzed the perspective of the surgeons responsible for the treatment of patients with spinal deformities, and stated that the increase in the severity of the deformity while waiting for the surgical procedure leads to surgeons planning for a more difficult and morbid procedure. In other words, according to the literature, the radiographic worsening observed in the present study means more complex procedures, with clinical consequences for patients and financial consequences for the health system. In the present study, beyond the rise in the severity of the deformity and consequent imbalance observed while the patients wait for the surgical treatment, there was also an increase in the number of patients with pelvic obliquity who needed spinal-pelvic instrumentation. The inclusion of the pelvis leads to an increase in surgical timing, blood loss, and risk of infection.[27–30] Martin et al.[31] analyzed a multi-centric database with 1,890 patients submitted to surgery due to pediatric spinal deformity, and identified an increase in the complexity of the procedure, particularly among patients who included pelvic fixation, as a risk factor for unplanned hospital readmission on the first 30 postoperative days. Since it results in higher risk of complication, hospital readmission and higher costs of the pelvic implant, the authors concluded that patients with pelvic obliquity will need more expensive surgeries.

Waiting lists are common in all publicly-funded services worldwide.[25,32] Long waiting times for surgical treatment have eroded the confidence of the citizens in the health care system.[33] As such, surgical waiting times have become an important social and political issue. The negative impact of prolonged waiting times for spine deformity surgery has been recognized. Attempts have been made to establish a maximal acceptable waiting time based on minimizing the risk of additional surgery due to progression of the deformity. As an example, the Canadian Pediatric Surgical Times Project proposed a maximum waiting time of six months based on the opinion of an expert opinion, which has been challenged and revised to three months based on empirical data.[4]

In the present study, we evaluated all the patients who were waiting for surgical correction of their deformity, not only the patients who did receive the treatment. We acknowledge that the waiting time for surgery and the consequences of this delay may be underestimated. However, some of these patients may never receive the desired treatment, and would, otherwise, not be recognized. The present study adds to the literature calling for improved health policies to account for the unmet needs of surgical care for Brazilian children and youths. Further research on this topic is needed to facilitate evidence-informed health policy making in Brazil.

Conclusion

In the present study, with the median waiting time of 13 months for the surgical treatment of spinal deformities of diverse etiologies, we have documented the worsening of the deformities and the deterioration of the HRQL of the patients, which is in agreement with previous studies. This represents a preventable increase in the burden of disease and in the cost of the treatment. Public health policies regarding the management of patients with spine deformities in Brazil should aim at improving the access to surgical care for children and youths to mitigate this preventable burden.

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Conflict of Interests
The authors have no conflict of interests to declare.

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