

ECONOMIC AND CLINICAL IMPACT OF LONG WAITING LISTS FOR SCOLIOSIS SURGERY

IMPACTO ECONÔMICO E CLÍNICO DAS LONGAS LISTAS DE ESPERA PARA CIRURGIA DE ESCOLIOSE

IMPACTO ECONÓMICO Y CLÍNICO DE LAS LARGAS LISTAS DE ESPERA PARA CIRUGÍA DE ESCOLIOSIS

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ABSTRACT

Objectives: To evaluate the implications of waiting lists for Adolescent Idiopathic Scoliosis (AIS) surgery in the Unified Health System (SUS), from the perspective of managers and physicians, and to propose cost-effective solutions. **Methods:** The study was conducted in two stages: (1) an electronic questionnaire was sent to identify the main challenges related to waiting lists and (2) a focus group was organized to discuss proposals for reducing and eliminating these lists. **Results:** Long waiting lists for AIS surgery in the SUS are mainly caused by the high cost of implant materials, low medical remuneration, and difficulties in accessing adequate referral centers. Delayed treatment leads to progression of the deformity, increasing the complexity and cost of surgical procedures and negatively impacting patients' quality of life. In addition, the judicialization of health has been a frequent consequence of these delays. **Conclusions:** Current prioritization criteria for surgical treatment are inadequate, often based only on waiting time, without considering the severity of the case. Structural reforms in the SUS are necessary, including the creation of a national platform for better screening and prioritization, as well as improvements in infrastructure and remuneration of health professionals. **Level of Evidence V; Expert Opinion.**

Keywords: Scoliosis; Orthopedic Procedures; Unified Health System.

RESUMO

Objetivos: Avaliar implicações das listas de espera para cirurgia de Escoliose Idiopática do Adolescente (EIA) no Sistema Único de Saúde (SUS), sob a perspectiva de gestores e médicos, e propor soluções econômicas. **Métodos:** O estudo foi realizado em duas etapas: (1) um questionário eletrônico foi enviado para identificar os principais desafios relacionados às listas de espera e (2) um grupo focal foi organizado para discutir propostas de redução e eliminação dessas listas. **Resultados:** As listas de espera prolongadas para cirurgia de EIA no SUS são causadas principalmente pelo alto custo dos materiais de implante, baixa remuneração médica e dificuldades de acesso a centros de referência adequados. O atraso no tratamento leva à progressão da deformidade, aumentando a complexidade e o custo dos procedimentos cirúrgicos e impactando negativamente na qualidade de vida dos pacientes. Além disso, a judicialização da saúde tem sido uma consequência frequente desses atrasos. **Conclusões:** Os critérios atuais de priorização para tratamento cirúrgico são inadequados, muitas vezes baseados apenas no tempo de espera, sem considerar a gravidade do caso. Reformas estruturais no SUS são necessárias, incluindo a criação de uma plataforma nacional para melhor triagem e priorização, além de melhorias na infraestrutura e remuneração dos profissionais de saúde. **Nível de Evidência V; Opinião de Especialistas.**

Descritores: Escoliose; Procedimentos Ortopédicos; Sistema Único de Saúde.

RESUMEN

Objetivos: Evaluar las implicaciones de las listas de espera para cirugía de Escoliosis Idiopática del Adolescente (EIA) en el Sistema Único de Salud (SUS), desde la perspectiva de gestores y médicos, y proponer soluciones costo-efectivas. **Métodos:** El estudio se realizó en dos etapas: (1) se envió un cuestionario electrónico para identificar los principales desafíos relacionados con las listas de espera y (2) se organizó un grupo focal para discutir propuestas para reducir y eliminar estas listas. **Resultados:** Las largas listas de espera para cirugía de AIS en el SUS son causadas principalmente por el alto costo de los materiales para implantes, la baja remuneración médica y las dificultades de acceso a centros de referencia adecuados. El tratamiento tardío conduce a la progresión de la deformidad, aumentando la complejidad y el costo de los procedimientos quirúrgicos e impactando negativamente en la calidad de vida de los pacientes. Además, la judicialización de la atención sanitaria ha sido una consecuencia frecuente de estos retrasos. **Conclusiones:** Los criterios actuales de priorización del tratamiento quirúrgico son inadecuados, basándose muchas veces únicamente en el tiempo de espera, sin considerar la gravedad del caso. Son necesarias reformas estructurales en el SUS, incluida la creación de una plataforma nacional para una mejor detección y priorización, así como mejoras en la infraestructura y remuneración de los profesionales de la salud. **Nivel de Evidencia V; Opinión de Expertos.**

Descriptores: Escoliosis; Procedimientos Ortopédicos; Sistema Único de Salud.

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INTRODUCTION

Adolescent idiopathic scoliosis (AIS) is a complex 3D structural disorder of the spine greater than a Cobb angle of 10° and accompanied by vertebral rotation,¹ seen in children from 10 years old until skeletal maturity.^{2,3} Between 0.35% and 5.2% of children under age 16 have AIS,⁴ representing 84 to 89% of all individuals with scoliosis.⁵ Early diagnosis and management are crucial for a better functioning and quality of life, given the various manifestations that may arise, such as chest deformities, protuberances, and asymmetries, neurological disorders, pain, respiratory muscle weakness, restricted ventilation, and even psychological problems.⁶

The probability of progression of the scoliotic curve is a fundamental point in the therapeutic approach to AIS. At present, according to the 2016 AIS Consensus, follow-up and management include observation, bracing or surgery.⁷ Treatment can be performed by orthosis when the deformity is progressive, with scoliosis curvature between 25° to 40° and the patient is far from skeletal maturity (Risser 2).¹ The surgical indication is supported by the literature whenever the curve is greater than 40° - 50° , with trunk deviation, coronal decompensation and cosmetic deformity.^{6,8}

Several types of surgical treatments have been proposed for AIS. Over the last decade, there has been significant progress in the surgical treatment of these patients due to the introduction of several new techniques such as robotic-assisted approaches, growth-modulating methods, and fusionless surgeries.⁹ Spinal fusion by arthrodesis after distraction, translation and defect correction has been the most successful procedure in recent years.^{10,11} Currently, the so-called third-generation instruments allow not only the effective correction of the deformity, but also a more satisfactory aesthetic result.^{12,13}

One of the major problems with the surgical treatment of AIS is related to the high demand, complexity of surgical and instrumental techniques, and the high cost of procedures. Particularly in the Brazilian context, those problems generate undesirable consequences such as long waiting time until the ultimate treatment with its negative impact on the results of procedures.¹⁴

Prolonged surgical waiting lists have become an inevitable product of publicly insufficient funded health care systems and more recently have been under increased scrutiny. The search for solutions that could minimize this growing and serious public health problem has been the subject of studies in many countries.¹⁵⁻¹⁷ Prioritizing clinical needs in the waiting list should take into consideration the views of the different stakeholders involved which include health policy decision makers, healthcare professionals and patients.¹⁸

Furthermore, the human factors, including engagement of all parts to give and support from program leaders and staff have been widely recognized to be key factors in sustainability of health service interventions.^{19,20} While it is known that long waiting lists can contribute to workload, retention, and job dissatisfaction issues,²¹ limited research has specifically focused on health professionals' and managers' perspectives regarding waiting lists for AIS surgery. Therefore, our aim was to evaluate the waiting list problem for AIS surgery in the Unified Health System (Sistema Único de Saúde - SUS) from the perspective of managers and physicians, and raise possible solutions and adaptations to this process.

METHODS

This is a descriptive observational study, using quantitative and qualitative methodology. Data collection occurred between January 2020 and December 2021. The study included physicians and managers working in the SUS at the federal, state or municipal levels (such as: Health Secretaries, Technical Area of Health for People with Disabilities Coordinators and Technical Coordinators of the Service), hospital units in the own or contracted network by SUS.

Data collection and analysis were divided into two stages. Initially, an electronic form was sent to all physicians and managers who agreed to participate in the study, accompanied by a specific Informed Consent Form that should be signed via email. The form was composed of objective and open questions that aimed to identify the main barriers

and implications related to the waiting list for AIS surgery to allow as much freedom as possible in the answers. At this stage, objective responses were analyzed using absolute and relative frequencies. For open responses, the thematic content analysis technique was adopted, following the recommendations of content analysis.²²

Then, new data were collected through a focus group, whose central discussion point was the elaboration of proposals for the reduction/elimination of waiting lists for AIS surgery. For systematization and presentation of the contents developed in the focus group, the cognitive mapping technique was used, configured as a research tool that seeks to graphically portray the shared contents and the relationships established between them.²³

This study complied with the ethical standards of the Declaration of Helsinki and the norms of Resolution 466/12, was submitted and approved by the local Research Ethics Committee (CAEE: 27816320.3.0000.5520, approval number: 3.819.338).

RESULTS

In the first stage of the study, the sample consisted of 28 orthopedic surgeons and 17 managers/administrators, totaling 45 participants. Among them, 34 (75.6%) consider that the problem involving the waiting list for AIS surgery in their area of operation have a serious or very serious nature. Regarding the aspects that potentiate this queue problem, 40 (88.9%) participants pointed out the existence of financial issues related to implants and/or medical fees, 36 (80%) identified difficulties related to access to the surgical center, ICU or other infrastructure resources and 16 (35.6%) considered the availability of trained surgeons as a barrier. Figure 1 presents a visual representation of the main aspects raised by them.

The existence of long queues has implications for both patients and the health system. Figure 2 presents the identified implications and the frequency with which they were mentioned by the participants.

Faced with the impacts that the long stay on the waiting list for surgery entails, especially for patients and their families, a question that becomes central refers to the selection and prioritization of patient systems to perform the surgery. According to the participants, the most widely adopted criterion has been the queue time, followed by the severity case criterion and the case judicialization. It should be noted that some participants mentioned that there is no explicit criterion for the selection/prioritization of cases in their acting region and still others reported not having knowledge about the adopted criteria (Figure 2). Regardless of the selection/prioritization system adopted, all participants classified them as bad or terrible.

In view of this, the second stage of the study was carried out, which consisted of conducting a focus group for a joint discussion on possible solutions to the AIS waiting list problem. (Figure 3)

In summary, the existence of three groups of agents that may be involved in the process in different lines of action were identified. The first group is represented by the Brazilian Spine Society (Sociedade Brasileira de Coluna - SBC), which can play an important role with

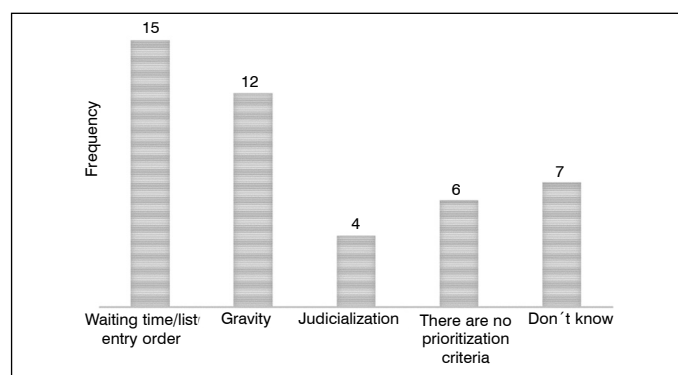


Figure 1. Visual representation in word cloud format pointed out by the participants as potentiating aspects of the long waiting time for AIS surgery.

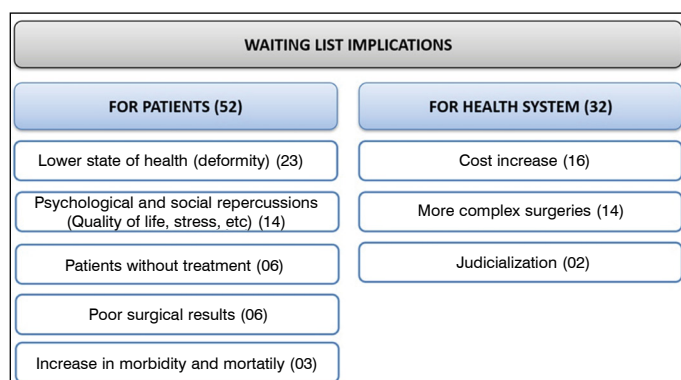


Figure 2. Implications of AIS delay treatment for patients and health systems.

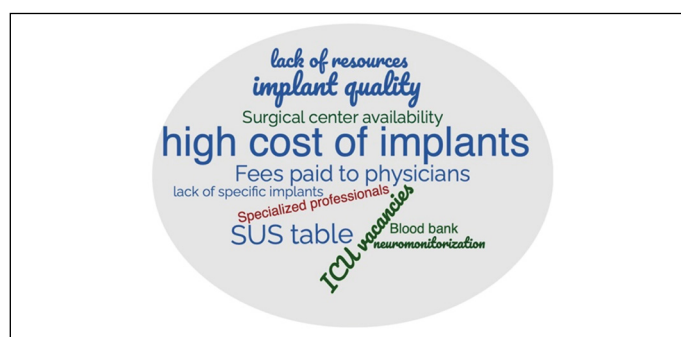


Figure 3. Criteria pointed out by participants for prioritizing patients for AIS surgery in their region of operation.

regard to the consolidation of fundamental data for thinking and giving greater visibility to the AIS waiting list problem. Among the actions of the SBC are carrying out a more accurate and real survey of the reality of the disease in the country, including the number of cases and the existing reference centers, as well as an assessment of the quality of these centers. In addition, a point also considered urgent is the updating of the SUS Table, with the main objective of enabling better surgical results.

In the second group, there are public managers, who can implement improvements in the registration of cases – especially through the creation of a single form, capable of generating interoperability of systems and, consequently, the viability of a Single National Platform. In addition, the need for greater investment in research was evident, which unfolds in two actions: the first refers to the inclusion of AIS in SUS Department of Informatics (DATASUS) registries (favoring access and information dissemination and research with these secondary data), and the second refers to funding prospective longitudinal studies. Finally, the role of public management was to facilitate joint efforts for surgery for adolescent idiopathic scoliosis, which is a way of operating on a large scale and, consequently, reducing the waiting list.

Finally, the group formed by physicians and other health professionals has as a critical point the need for training aimed at efficient performance in primary care, not only for the physician, but for the entire multidisciplinary team (with an emphasis on nursing) to that diagnoses and referrals are carried out faster and more appropriately. Here, a point worth noting is the possibility of using telemedicine as a tool to optimize patient screening and classification.

Figure 4 presents a conceptual map with an action summary suggested by the focus group.

DISCUSSION

Our results evidenced that the long waiting list for AIS is a serious problem in the Brazilian Health System, mainly caused by the high financial cost of implant materials, low payment of medical fees and difficulty in accessing reference centers with adequate

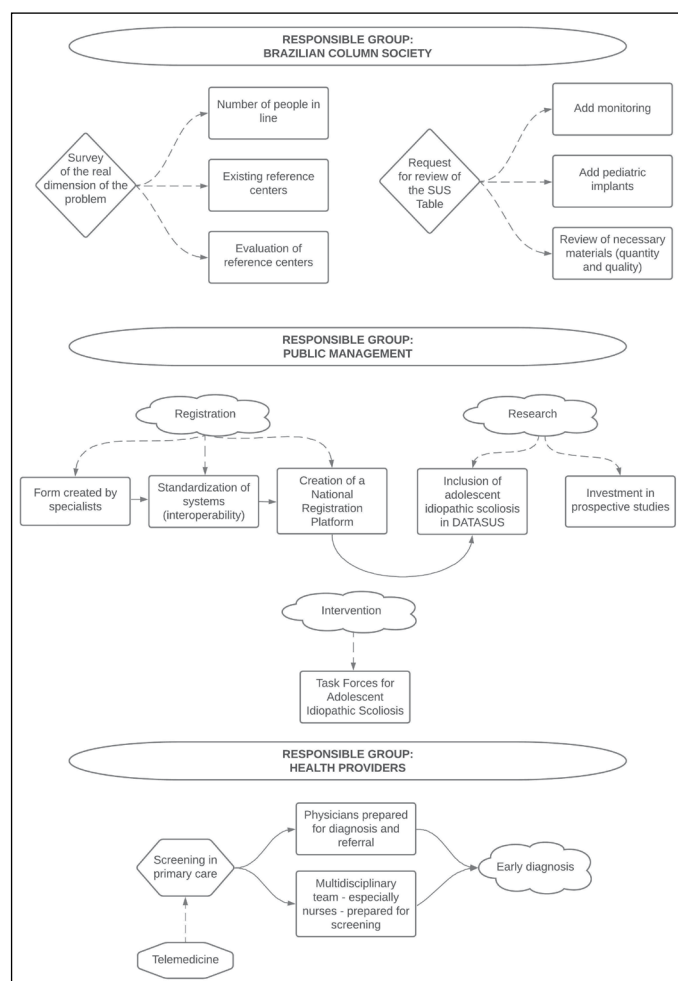


Figure 4. Conceptual map with an action summary suggested by the focus group as possible solution ways to reduce long time waiting lists for AIS surgery.

expertise and infrastructure. The delay in taking care of the patients causes progression of the deformity with repercussions on the patients' health related quality of life. Surgical procedures become more complex and difficult as well as more expensive. Besides, the delay in treatment has caused the phenomenon of judicialization of health in Brazil. The current study also emphasized that the criterion for prioritizing surgical treatment is inadequate, and many centers simply select patients primarily based on the waiting time.

Our study sought to expand knowledge about the potentiating aspects of the long wait for AIS surgical treatment and to explore possible solutions to these problems. Several studies in different countries aimed to estimate the waiting time for AIS surgery, the impacts on the patients' health related quality of life and the prognosis regarding treatment.^{14,17,24} Furthermore, insights into the causes and consequences of the long waiting list for AIS surgery, identified by most clinicians and managers as a serious or very serious problem, also provides a means to assess its impact on the quality of health services.

Long waiting lists for elective treatment pose a challenge to the quality of public health care services with which patients, doctors, and responsible health authorities have to deal.^{25,26} An extended waiting period can be harmful due to worsening symptoms and increased treatment costs. Additionally, it has negative effects on the mental health and quality of life of these patients.²⁶⁻²⁸ The previous studies give credence to the fact that patients waiting for a long time worsen their mental health and health related quality of life, generating more complex and expensive procedures with modest results.²⁵⁻²⁸ The analysis of waiting lists for AIS surgeries within the

SUS extends beyond clinical implications, encompassing critical economic considerations for public health decision-making. Delayed treatment not only exacerbates the clinical condition of patients, leading to more complex and costly interventions, but also generates a substantial economic impact on the healthcare system as well as on patients and their families.

It is well known that in less developed countries, such as most of Latin America, financial issues and health resources are scarce and play a relevant role in delaying AIS surgery.¹⁴ Waiting lists are used extensively as part of hospital or regional responses to limited budgets.²⁹ The high cost of implants, which is related to lack of resources, quality of implants or lack of specific implants, in addition to the low fees paid to physicians and surgeons and a gap in the reference values of the Management System of the Table of Procedures of SUS were the main financial aspects pointed out by the participants of our study. However, financial issues were not the only factors responsible for delaying AIS surgery, but also organizational and infrastructural difficulties, such as availability of access to the surgical center, vacancies in the ICU, blood bank, neuromonitoring, etc. Taken together, these issues lead to a cycle of loss: low investment → long waiting for treatment → increased costs.

The cost of conservative treatment of AIS was estimated at around USD 10,815.00 over two years, despite not showing clinical or health related quality of life improvement for patients after this approach.¹⁵ Surgery, in turn, promotes clinical, radiographic and health related quality of life improvement, however it has hospital costs between USD 29,955.00 to 60,754.00. These costs are basically influenced by the implant material and days spent in the intensive care unit.¹⁶ For example, an annual savings of US\$11 to \$20 million was observed by changing from all pedicle screws to an alternating screw pattern,³⁰ and a significant positive association between increased spending on implants per level fused and the % Cobb angle correction.³¹

In a hospital, the surgical block can be considered one of the most critical and expensive resources, representing about 40% of total expenses.^{32,33} Good planning is essential for the management of the surgical block, mainly because it is a service that demands high levels of quality and productivity. This planning must meet the needs of patients and professionals who make up the surgical team, always taking into account costs, structure and human resources. In addition, the availability of trained surgeons was also mentioned as a barrier. The findings of this study highlight the need to increase the availability of surgical services for the treatment of AIS in Brazil. One way this can be done is by improving your AIS treatment training programs.

The phenomenon of health judicialization in Brazil is an increasing problem. Judicialization is caused by lack of adequate

assistance which in turn is a reflection of lack of resources. Judicialization would be beneficial because it guarantees faster right to health care, diminishing morbidity and mortality; On the other hand, it would produce unequal treatment among citizens.³⁴ Therefore, judicialization is far from being an adequate way to prioritize treatment. The health system should deal with this issue by addressing some of the problems the current study has shown as the key points, such as creating a universal list based on severity of the cases, and solving the problems of demands and fundings for the health system.

We used a cross-sectional design in order to provide relevant insight into the health problems of patients on AIS surgical waiting lists. Additionally, we used a self-made questionnaire to measure the perceptions of clinicians and managers about waiting. Although the questionnaire provides clear information for a qualitative study, it is not fully validated. The limitations of our methodology include bias in the interpretation of the qualitative data, and impossibility to address all the key personnel involved in the process. Despite the limitations, the questionnaire provides clear and consistent information for a qualitative study, unfolding coherent data about the long list of patients waiting for AIS treatment.

Our study suggested a comprehensive analysis that combines both clinical and economic perspectives, highlighting the need for interventions that can optimize resource allocation and reduce costs by preventing the worsening of the disease. Thus, it contributes to the discussion on how health policies can be improved to balance equitable access to services with economic efficiency, proposing strategies aimed not only at enhancing clinical outcomes but also at optimizing the use of public resources.

CONCLUSION

The main point for improving the long waiting list of patients seems to depend on several factors. Professionals and patients should raise awareness of the problem of AIS in national and regional levels; there should be platforms (including telemedicine strategies) that allow the screening, registration and prioritization of the cases to give faster access to reference centers that could perform large-scale procedures; the system should provide adequate resources for training multidisciplinary team, for creating hospitals infrastructure, and for better remuneration of health professionals (including surgeons); optimize and standardize the costs and quality of surgical implants.

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