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# Health-Related Predictive Factors of Brazilian Children With Early Onset Scoliosis Using the EOSQ-24 and CHQ-PF50 Questionnaires

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## ABSTRACT

**Background:** Assessing the quality of life (QOL) of children with early onset scoliosis (EOS) has been discussed recently. Therefore, the study aimed to apply and correlate the 24-item Early Onset Scoliosis Questionnaire (EOSQ-24) with the 50-item Childhood Health Questionnaire (CHQ-PF50) to find predictive factors impacting QOL.

**Methods:** Cross-sectional study involving a population of caregivers of patients with EOS. The sample consisted of 72 patients. Two research assistants applied the Portuguese version of the EOSQ-24 and CHQ-PF50 in 3 treatment centers. The EOSQ-24 assesses the subjective response of children with EOS from the parent's point of view. The CHQ is a self-administered questionnaire or parental proxy assessment of the psychological and social status of children aged 5 to 18 years.

**Results:** Of 72 patients, 41 (56.9%) were females, mean age of  $11.9 \pm 4.2$  years. The most common scoliosis was of neuromuscular origin (32%). The CHQ-PF50 showed that family-related items had significant scores. The most affected subcategory was physical function (45.5), and the least affected was mental health (90.8). Thus, the CHQ-PF50 PhS summary index was 27, and the CHQ-PF50 PsS was 71.7. Moreover, the critical categories for the EOSQ-24 questionnaire were daily life and physical function (45.1 and 47.8, respectively), and the least affected categories were transfer and pulmonary function (70.8 and 68.9, respectively). Four subcategories showed a strong correlation between both questionnaires: general health ( $r = 0.749$ ,  $P < 0.001$ ), physical function ( $r = 0.645$ ,  $P < 0.001$ ), bodily pain ( $r = 0.714$ ,  $P < 0.001$ ), and mental health ( $r = 0.424$ ,  $P < 0.001$ ). Using CHQ-PF50 as a dependent variable in multiple regression analysis ( $P = 0.028$ ), the only variable affecting the scores was syndromic scoliosis ( $P = 0.019$ ; 95% CI  $-27.4$  to  $-2.5$ ).

**Conclusion:** A strong correlation between both questionnaires was seen for general health, physical function, bodily pain, and mental health. Syndromic scoliosis was a predictor of worse QOL according to the CHQ-PF50.

**Level of Evidence:** 2.

Other and Special Categories

Keywords: early onset scoliosis (EOS), quality of life, EOSQ-24, CHQ-PF50, validation, cross-cultural adaptation, spine, Brazilian Portuguese translation

## INTRODUCTION

Early onset scoliosis (EOS) with progressive spinal deformity involves a group of diverse etiologies and natural history that may evolve into thoracic insufficiency syndrome. This syndrome affects lung development and thoracic growth, often requiring repetitive surgeries in childhood and adolescence.<sup>1,2</sup> As for the neuropsychomotor development and associated comorbidities, a range of disease progressions are observed, leading to different conformations of the spine curvatures.<sup>3</sup> The

heart and lung function development represent 2 of the most severe consequences of this deformity.<sup>2,4-6</sup> The most common causes of EOS are idiopathic, congenital, neuromuscular, or syndromic.<sup>7</sup> The Spinal Growth Committee of the Scoliosis Research Society (SRS) published an update on the disease's impact on treatment and survival.<sup>8,9</sup>

In recent years, there has been a growing interest in assessing the QOL of children with EOS. In the 1990s, the assessment was traditionally focused on radiographic measurement and disease progression. Currently, these

studies are outdated, and the incorporation of estimates of physical and psychosocial functioning in patient-centered health assessments has been emphasized.<sup>10–12</sup> Therefore, psychological factors became the focus of treatment, and the 24-item Early Onset Scoliosis Questionnaire (EOSQ-24), developed by Corona et al,<sup>10</sup> is now the specific instrument for assessing patients' quality of life (QOL) with EOS and is applied to caregivers of children.<sup>10,13</sup> The questionnaire consists of 24 items in 11 domains and was designed to evaluate children's QOL and their caregivers' burden. The tool was initially applied in English and had high internal consistency and reliability,<sup>10</sup> in addition to validation and application in other languages, such as Chinese,<sup>14</sup> Spanish,<sup>15</sup> Turkish,<sup>16</sup> Norwegian,<sup>17</sup> German,<sup>18</sup> Arabic,<sup>19</sup> Dutch,<sup>20</sup> and Persian.<sup>21</sup>

Machado et al<sup>22</sup> translated the 50-item Child Health Questionnaire (CHQ-PF50), a generic health instrument designed to understand both physical and psychosocial well-being, assuming the underlying disease as irrelevant. The Brazilian Childhood Health Assessment Questionnaire (CHAQ) was revalidated, while the CHQ-PF50 was derived from the children's questionnaire in the Portuguese version. It was concluded that the Brazilian versions of the CHAQ and CHQ-PF50 were reliable and, therefore, are valid tools for the psychosocial and physical assessment of children. These questionnaires were validated in patients with juvenile rheumatoid arthritis.<sup>23</sup>

In Brazil, the availability of this cross-cultural instrument validated for our language by internationally established standards is recent.<sup>11</sup> Thus, we can objectively assess the outcome of any intervention in Brazilian children and compare the treatment with international publications. Currently, patient-centered functional outcomes through questionnaires are the most accepted way to validate the quality-of-care assessment protocols and define funding policies from paying sources.

Therefore, our study objective involves applying and correlating the EOSQ-24 with the generic CHQ-PF50. Furthermore, we hypothesized whether there are predictive factors that impact QOL involving age, sex, Cobb angle, or curve magnitude, as well as etiology, treatment, and deambulatory status.

## METHODS

For this cross-sectional study, we recruited a population composed of consecutive patients with EOS and their caregivers. There was prior multicenter approval from the ethics and research committee (approval number 56858516.0.0000.5479).

The sample consisted of 72 consecutive patients who met the predefined inclusion criteria, which were as follows: age younger than 10 years and diagnosis of early onset scoliosis. Additionally, the caregivers of patients with EOS were required to perform outpatient follow-up and sign the Free and Informed Consent Form. Exclusion criteria included patients with caregivers who did not agree to sign the Free and Informed Consent Form, patients diagnosed with scoliosis after age 10 years, and patients with spinal deformities resulting from trauma or tumor. Patient characteristics of age, gender, diagnosis, ambulatory status, spine curvature were recorded. The Portuguese version of the EOSQ-24 and CHQ-PF50, scored from 0 to 100, were administered in 3 deformity treatment centers by 2 research assistants.

### EOSQ-24

The EOSQ-24 is the main instrument in studies involving children with EOS. The questionnaire assesses the subjective response of children with EOS from their caregiver's point of view and is carried out through interviews with caregivers. It consists of 24 items in 11 subdomains: general health, pain, lung function, transference, physical function, daily life, fatigue, emotion, parental burden, financial burden, and satisfaction. The 3 domains are QOL, burden, and patient satisfaction.<sup>10</sup> The EOSQ-24 Portuguese version is similar to the original EOSQ-24 scoring system.

Each item's scores ranged from 1 to 5, involving a relevant classification system, with lower scores meaning higher disability. Domain scores were calculated as follows:  $(\text{value of the chosen item} - 1) / 4 \times 100$  for domains with 1 item and  $(\text{algebraic mean of items} - 1) / 4 \times 100$  for domains composed of more than one item, varying from 0 to 100. The EOSQ-24 total score is the average of 11 subdomain scores calculated using:  $(\text{average item points for subdomains} - 1) / 4 \times 100$ , rescaling the scoring metric from 1–5 to 0–100. The clarity of the EOSQ-24 translated into the Portuguese version was assessed using the 5-point Likert scale for parents and guardians.<sup>12</sup>

### CHQ-PF50

The CHQ-PF50 is a self-administered questionnaire or parental proxy assessment of the psychological and social status of children aged 5–18 years. The questionnaire contains 15 categories related to physical and emotional well-being. Global general health, physical function, role emotional, role physical, bodily pain, emotional behavior, global emotional behavior, mental

health, health change, self-esteem, general health, emotional impact on parents, impact on parent's time, family activity, and family cohesion are the items evaluated. The maximum possible score of all sections is 100, and the worst possible score is 0. The questionnaire measures a child's general health status and was developed by researchers and clinicians to study children's functional activities. Mothers were informed in detail about the protocol before completing it and then informed about the final score. The cross-cultural adaptation and validation of the CHQ-PF50 Portuguese version in Brazil have been published.<sup>22</sup>

### Statistical Analyses

Continuous data from both questionnaires were summarized through means and SDs, and categorical data were described as absolute and relative frequency. Using Pearson's correlation test, a correlation analysis was performed between the EOSQ-24 and CHQ-PF50 and for each subcategory.

Additionally, a linear multiple regression analysis was performed to verify possible clinical-outpatient factors that could influence the EOSQ-24. The regression analysis used a standard data entry model, and the authors determined the independent variables from the perspective of biological plausibility. No sign of collinearity was found between the variables. Data independence was formally tested using the Durbin-Watson test for data collected cross-sectionally. Homoscedasticity and noise were analyzed using scatterplots between each independent variable and the dependent variable, that is, the EOSQ-24. None of the leverage and outlier data were significant. Values of  $P < 0.05$  were considered statistically significant. Data analyzes were performed using SPSS 23.0 for the MAC program (IBM SPSS Inc., Chicago, IL).

## RESULTS

Seventy-two cases of scoliosis were studied, 41 (56.9%) of which were female. The mean population age was  $11.9 \pm 4.2$  years, with the minimum and maximum ages of 3 and 24 years. The most common scoliosis origin was neuromuscular (23 [32%]), followed by congenital (19 [26.4%]). More details are seen in Table 1.

Family-related items scored above 75 points for the CHQ-PF50 (Table 2). The most critical subcategory was physical function, scoring 45.5, and the best was mental health, scoring 90.8. Thus, the CHQ-50 physical health summary index (PhS) summary index was 27.1,

**Table 1.** Demographic and clinical characteristics of patients with early onset scoliosis.

Baseline	N = 72
Age, y, mean (SD)	11.9 (4.2)
Gender, n (%)	
Female	41 (56.9)
Male	31 (43.1)
Underlying disease, n (%)	
Idiopathic	5 (6.9)
Neuromuscular	23 (32)
Congenital	19 (26.4)
Syndromic	10 (13.9)
Other unidentified	15 (20.8)
Cobb angle, n (%)	
<30°	16 (22.3)
>30°	56 (77.7)
Ambulation, n (%)	
Yes	42 (58.3)
No	30 (41.7)
Treatment, n (%)	
Observational	47 (65.3)
Bracing	3 (4.2)
Growing	5 (7)
Definitive	17 (23.5)

and the CHQ-PF50 psychosocial summary index (PsS) was 71.7.

The most affected subcategories for the EOSQ-24 (Table 3) were daily life and physical function (45.1 and 47.8, respectively). The least affected were transfer and pulmonary function (70.83 and 68.92, respectively).

Pearson correlation analysis for the overall mean score for both questionnaires was 0.652 ( $P < 0.0001$ ; Figure). Several correlations were found with a low Pearson correlation coefficient of around 0.30. Four subcategories showed the strongest correlations: global health (CHQ-PF50)  $\times$  general health (EOSQ-24); physical function (CHQ-PF50)  $\times$  physical function (EOSQ-24), bodily pain (CHQ-PF50)  $\times$  pain discomfort (EOSQ-24), and role emotional behavioral (CHQ-PF50)  $\times$  emotion (EOSQ-24) (Table 4).

**Table 2.** Child Health Questionnaire (CHQ-PF50) scores by subcategory.

CHQ-PF50 Subcategory	Mean $\pm$ SD
PhS	27.05 $\pm$ 15.40
PsS	71.72 $\pm$ 20.70
Global health	64.51 $\pm$ 25.40
Physical function	<b>45.52 <math>\pm</math> 35.22<sup>a</sup></b>
Role emotional behavioral	55.56 $\pm$ 41.57
Role physical	52.31 $\pm$ 42.08
Bodily pain	61.25 $\pm$ 25.56
Behavior	76.81 $\pm$ 18.20
Global behavior	77.50 $\pm$ 24.67
Mental health	<b>90.83 <math>\pm</math> 23.90<sup>b</sup></b>
Self-esteem	68.87 $\pm$ 23.35
General health perception	60.29 $\pm$ 16.04
Parental impact emotional	59.26 $\pm$ 34.64
Parental impact time	52.66 $\pm$ 23.81
Family activities	77.31 $\pm$ 25.34
Family cohesion	75.35 $\pm$ 25.14

Abbreviations: PhS, physical summary index; PsS, psychosocial summary index.

<sup>a</sup> The most critical subcategory was physical function.

<sup>b</sup> The best subcategory was mental health.

**Table 3.** 24-Item Early Onset Scoliosis Questionnaire (EOSQ-24) subcategory scores.

EOSQ-24 Subcategory	Mean $\pm$ SD
General health	57.12 $\pm$ 19.99
Pain/discomfort	55.73 $\pm$ 23.36
Pulmonary function	68.92 $\pm$ 26.12
Transfer	70.83 $\pm$ 29.67
Physical function	47.80 $\pm$ 33.65
Daily living	45.14 $\pm$ 33.27
Fatigue	61.46 $\pm$ 26.85
Emotion	60.76 $\pm$ 27.22
Parental impact	59.72 $\pm$ 22.20
Financial impact	53.13 $\pm$ 29.05
Satisfaction	59.20 $\pm$ 29.52

A multiple regression analysis was performed to identify possible predictive factors that could affect the scores and QOL. The independent variables used in the study were age, sex, Cobb angle, etiology (idiopathic, neuromuscular, and syndromic), treatment (surgical vs nonsurgical), and deambulatory status (present vs absent). The model was statistically significant using CHQ as the dependent variable ( $P = 0.028$ ). The only variable affecting CHQ values was scoliosis of syndromic origin ( $P = 0.019$ ), with a coefficient of  $-14.96$  (95% CI  $-27.4$  to  $-2.5$ ). The results are shown in Table 5.

In contrast, when adopting the EOSQ-24 as the dependent variable, the model was not statistically significant ( $P = 0.087$ ). However, considering that 8.7% is very close to the accepted type I error of 5% in this study, we suggest

**Table 4.** Significant correlations found between the associated subcategories of the EOSQ-24 and the CHQ-40 questionnaires.

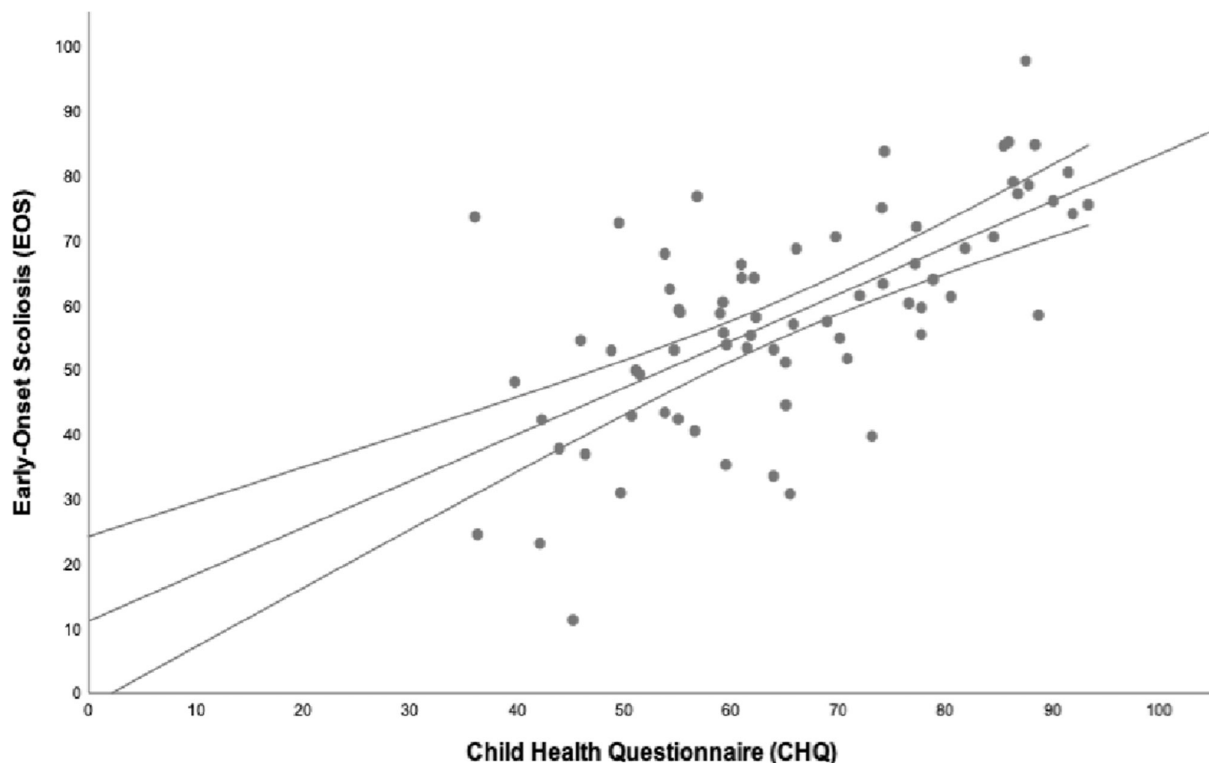
Subcategory	<i>r</i>	<i>P</i> Value
General health	0.749	<0.001
Physical function	0.645	<0.001
Bodily pain	0.714	<0.001
Mental health	0.424	<0.001

Abbreviations: CHQ-PF50, 50-item Child Health Questionnaire; EOSQ-24, 24-item Early Onset Scoliosis Questionnaire.

that the syndromic etiology was again a factor showing a marginally significant coefficient for the EOS questionnaire at  $-5.935$  (95% CI  $-19.59$  to  $7.72$ ).

## DISCUSSION

Our results show that 4 domains of the EOSQ-24 and the generic CHQ-PF50 questionnaire were significantly correlated: general health, physical function, bodily pain, and mental health. Therefore, the questionnaires match these domains. Moreover, syndromic scoliosis was a predictive factor for decreased QOL according to the CHQ-50 PF questionnaire and marginally significant for the EOSQ-24 questionnaire. Therefore, syndromic scoliosis strongly affects the QOL of EOS patients, which was not seen for neuromuscular or congenital scoliosis.

**Figure.** Pearson correlation equation found between the early onset scoliosis and Child Health Questionnaires (CHQ) domains.



**Table 5.** Multiple linear regression analysis for the 50-item Child Health Questionnaire and the associated dependent variables.

Variable	Nonstandardized Coefficients		Standardized Coefficients	<i>t</i>	<i>P</i>	95% CI	
	B	Error	$\beta$			Lower Limit	Upper Limit
Constant	68.32	7.50		9.108	0.000	53.32	83.32
Age (y)	-0.29	0.49	-0.074	-0.586	0.560	-1.27	0.70
Gender (female)	6.54	3.90	0.213	1.676	0.099	-1.27	14.34
Cobb angle (degree)	-1.34	4.33	-0.039	-0.310	0.758	-9.99	7.31
Etiology (neuromuscular)	-4.09	5.05	-0.127	-0.809	0.422	-14.20	6.02
Etiology (congenital)	7.65	5.37	0.222	1.424	0.160	-3.10	18.39
Etiology (syndromic)	-14.97	6.23	-0.348	-2.403	0.019	-27.42	-2.51
Treatment modality (surgery)	2.12	4.13	0.064	0.512	0.610	-6.15	10.37
Ambulatory status (ambulatory)	-1.47	5.34	-0.048	-0.274	0.785	-12.15	9.22

Previous studies found a strong correlation between the domains of physical function, pain, and mental health for SRS-22 and EOSQ-24 questionnaires.<sup>24</sup> Our results point to a similarly strong correlation between these domains, with the addition of the general health domain found in our study. Unfortunately, QOL measures are difficult to assess due to population heterogeneity, and health status measures in adults are not helpful for assessing children. The EOSQ-24 was designed to solve this issue through a psychometric approach to the children population.<sup>25,26</sup> Thus, based on this crosscultural study and the adaptation of the original English version of the EOSQ-24 to the Brazilian Portuguese version, with excellent reliability and capacity discriminative, it is now possible to carry out clinical studies in this population.<sup>11</sup>

The SRS-30 questionnaire and its variants (SRS-22 or SRS-24) include 7 postsurgical questions, limiting their application to patients who have not undergone surgical treatment.<sup>27</sup> Other non-EOS-specific questionnaires could also be used to assess the results of surgical treatment for adolescent idiopathic scoliosis, such as the SRS-24, SRS-22, SF-12, or SF-36. Therefore, these questionnaires could be applied prospectively before and after surgery to obtain accurate measurements of health-related QOL.<sup>27</sup>

EOS is a condition that limits children's daily activities, leading to a significant impact on caregivers' QOL. Early morbidity and mortality justify the search for interventions to change the natural history of this potentially lethal deformity.<sup>28</sup> A short and decompensated trunk, in addition to aesthetic issues, leads to respiratory failure syndrome and dysfunctions that inevitably impact the lives of these children.<sup>7</sup> Pulmonated parenchyma develops up to 10 years of age, and arthrodesis before that age is associated with adverse functional outcomes of lung function.<sup>3</sup> Interventions should reduce or stabilize the evolution of the deformity, improve body function, and psychosocial issues related to the aesthetic-functional improvement of these

children.<sup>11</sup> Options for this clinical condition include serial plasters and instrumentation systems to allow the spine to grow with periodic distensions. However, frequently described adverse effects are reported, such as implant loosening, skin lesions, infections, and the impossibility of controlling the progression of the spine curve.<sup>3,6,7,28</sup>

Currently, there is no consensus on the optimal intervention or the best treatment for children with EOS. Numerous procedures involving sedation and anesthetics can impact the psychological dynamics of the growing brain and the family.<sup>12</sup> The results are always multidimensional and include critical aspects for children and caregivers. The quality intervention has outcomes that impact the child's life, involving aspects besides radiological results. This criterion is recommended for evidence-based medicine and decision-making from funding-paying sources.<sup>4,28</sup>

Our study has limitations. First, we used a small number of patients because it is a rare disease, although it involved 3 academic reference centers in São Paulo. Second, we present a heterogeneous study population with different etiologies (neuromuscular, syndromic, idiopathic, and congenital) that were not separated. Third, none of the 5 patients who underwent growth rods were graduated for definitive arthrodesis, as they were pooled from a one-time assessment. Regarding the criteria for choosing the severity cutoff point, we observed that patients with a spine curve  $>30^\circ$  had the worst follow-up grades, most likely due to the heterogeneity of the spine curve pattern. In addition, our sample of syndromic patients involved a wide range of diagnoses, such as Goldenhar syndrome, Klippel-Feil, arthrogryposis, Down syndrome, Marfan syndrome, Escobar syndrome, and neurofibromatosis. Likewise, variations in the neuromuscular group, for example, Progressive Spinal Atrophy (I and II) and dysgenesis of the corpus callosum, were grouped. Finally, patients who attended the outpatient clinics in our service had a low socioeconomic/educational status. During the explanations,

the interviewees needed further clarification, possibly affecting the results.

## CONCLUSIONS

There was a significant correlation between 4 domains of the EOSQ-24 and CHQ-PF50: general health ( $r = 0.749$ ,  $P < 0.001$ ), physical function ( $r = 0.645$ ,  $P < 0.001$ ), bodily pain ( $r = 0.714$ ,  $P < 0.001$ ), and mental health ( $r = 0.424$ ,  $P < 0.001$ ). In addition, syndromic scoliosis was a predictive factor for the worse QOL, according to the CHQ-PF50. For the EOSQ-24, syndromic scoliosis was marginally significant as well.

Functional outcomes focused on patients are the most recent and accepted measure for validating QOL protocols and defining funding policies from paying sources. Questionnaires provide an excellent way to objectively assess the outcome of any intervention in EOS in children and to compare treatment across different countries.

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