



Reliability and validity of the Chinese version of the Early-Onset Scoliosis Self-Report Questionnaire in children aged 8 to 18 years with early-onset scoliosis

Honghao Yang^{#^}, Lu Liu[#], Yong Hai^{*^}, Nan Kang^{*}

Department of Orthopedic Surgery, Beijing Chao-Yang Hospital, Beijing, China

Contributions: (I) Conception and design: Y Hai; (II) Administrative support: Y Hai, N Kang; (III) Provision of study materials or patients: Y Hai, N Kang; (IV) Collection and assembly of data: H Yang, L Liu; (V) Data analysis and interpretation: H Yang; (VI) Manuscript writing: All authors; (VII) Final approval of manuscript: All authors.

[#]These authors contributed equally to this work and should be considered as co-first authors.

^{*}These authors contributed equally to this work and should be considered as co-corresponding authors.

Correspondence to: Yong Hai, MD, PhD; Nan Kang, MD. Department of Orthopedic Surgery, Beijing Chao-Yang Hospital, Capital Medical University, Gongti South Rd., No. 8, Beijing 100020, China. Email: yong.hai@ccmu.edu.cn; kangnan166@163.com.

Background: The Early-Onset Scoliosis Self-Report Questionnaire (EOSQ-SELF) is a novel self-report instrument to evaluate the health-related quality of life (HRQoL) of early onset scoliosis (EOS) patients, as a complementary HRQoL assessment tool for the proxy-report 24-item Early-Onset Scoliosis Questionnaire (EOSQ-24). This study aimed to translate and adapt the EOSQ-SELF into a Chinese version and evaluate its reliability and validity in EOS patients.

Methods: A cross-sectional study was performed from July 2022 to September 2022. Patients aged 8 to 18 years with EOS were recruited. Forwards-backwards translation and cross-cultural adaptation of the original EOSQ-SELF were performed. The Chinese EOSQ-SELF was administered and collected twice through social media, with a 2 weeks interval. Reliability was evaluated by using internal consistency, and test-retest reliability was assessed by the intraclass correlation coefficient (ICC) of data between the two time points. A Delphi survey in the expert committee was used to investigate the content validity. SRS-22r, PedsQL4.0, and EQ-5D-Y scales were used to assess the criterion-related validity. Nonparametric tests and multiple linear regression were performed to evaluate the discriminative ability.

Results: A total of 101 valid responses from EOS patients were received. The mean age was 12.08±2.19 years, and 53.47% were female. The mean Cobb angle was 60.56°±19.48°. Floor effects of 0.00% to 7.92% and ceiling effects of 0.00% to 52.48% were observed. Excellent internal consistency and test-retest reliability of the Chinese EOSQ-SELF was observed, with a Cronbach's α coefficient of 0.942, McDonald's ω coefficient of 0.940, and ICC of 0.930. All domains of the Chinese EOSQ-SELF were significantly correlated with SRS-22r (0.709 to 0.878), PedsQL4.0 (0.568 to 0.718), and EQ-5D-Y (-0.598 to -0.625), depicting excellent criterion-related validity. Discriminative ability was validated in aetiology ($P<0.001$), severity of spinal deformity ($P<0.001$), treatment status ($P<0.001$), and ambulatory ability ($P<0.001$).

Conclusions: The Chinese EOSQ-SELF is a reliable and valid tool for the assessment of self-report HRQoL in patients aged 8 to 18 years with EOS. It can be easily applied in clinical settings and for research purposes, as a complementary tool for the proxy-report EOSQ-24.

Keywords: Early-onset scoliosis (EOS); health-related quality of life (HRQoL); Chinese; reliability; validity

[^] ORCID: Honghao Yang, 0000-0001-5300-1283; Yong Hai, 0000-0002-7206-325X.

Submitted Dec 08, 2022. Accepted for publication Jun 12, 2023. Published online Jul 27, 2023.

doi: 10.21037/tp-22-659

View this article at: <https://dx.doi.org/10.21037/tp-22-659>

Introduction

Early-onset scoliosis (EOS) is defined as a curvature of the spine $\geq 10^\circ$ in the frontal plane occurring before 10 years of age (1). EOS comprises a heterogeneous group of patients with aetiologies of idiopathic, congenital, syndromic, and neuromuscular scoliosis (2,3). The natural history of untreated EOS involves truncal shortening and profound cardiopulmonary compromise, which may increase mortality and impact health-related quality of life (HRQoL) (4). Various interventions have been applied for EOS patients based on the severity of spinal deformity, including bracing, growth-friendly surgery, and spinal fusion (5). The primary aim is to slow down the progression of scoliosis or correct the deformity, and the treatment effect is mainly evaluated by radiographic measurements during the follow-up. However, routine radiographic parameters, such as the Cobb angle, apical vertebral translation, C7 plumb line and center sacral vertical line, and sagittal vertical axis, could not demonstrate the full experience and impact of the illness on children's physical and psychological functions (6). Therefore, an increasing number of studies have begun to focus on patient-report outcomes, such as HRQoL, to evaluate patients'

health status more comprehensively (7-11).

Many healthcare charters, committees, and policy documents state that children's own views should be considered in the planning and delivery of pediatric care and children have the rights to participate in the shared decision-making, which is in line with the United Nations Convention on the Rights of the Child (12). With the considerable strides in abstract thinking and cognitive flexibility, children begin to understand and manage feelings, internal states, and manifest behaviors (13). Also, their own perspective about their health is developed, which is usually different from their parents' perspectives. Previous studies have suggested that a proxy's perception might not be an accurate reflection of how a child is functioning or feeling (14-17). Although it is important to involve parents in rating the HRQoL of their children, proxy-report and child self-report should be considered as complementary.

The Early-Onset Scoliosis 24-Item Questionnaire (EOSQ-24) is a proxy-report tool to investigate the HRQoL of patients with EOS and their family burdens (18). To date, the EOSQ-24 has been validated and translated into nine languages and is the most commonly used HRQoL assessment tool for EOS patients (19-27). Recently, the Early-Onset Scoliosis Self-Report Questionnaire (EOSQ-SELF) was developed and validated by Matsumoto *et al.*, as an instrument for measuring self-report HRQoL among EOS patients aged 8 to 18 years (28). Good validity and reliability were reported in their study, indicating that the EOSQ-SELF was adequate to gain direct insight into HRQoL from the target population.

For Chinese children of school age, they usually spend more time away from their family; therefore it is necessary to involve children's perspectives and views on healthcare (29). As there is a significant number of EOS patients in China and many researches have focused on this population, it is of paramount importance to translate and validate the Chinese version of EOSQ-SELF, as a complementary HRQoL assessment tool for the proxy-report EOSQ-24 (30-32).

The purpose of this study was to translate the original EOSQ-SELF into a Chinese version and evaluate its reliability and validity in children aged 8 to 18 years with EOS. We present this article in accordance with the SURGE reporting checklist (available at <https://>

Highlight box

Key findings

- The Chinese Early-Onset Scoliosis Self-Report Questionnaire (EOSQ-SELF) is a reliable and valid tool for the assessment of self-report health-related quality of life (HRQoL) in patients aged 8 to 18 years with early-onset scoliosis (EOS).

What is known and what is new?

- For Chinese children of school age, they usually spend more time away from their family; it is necessary to involve children's perspectives on healthcare.
- The EOSQ-SELF is a novel self-report instrument to evaluate the HRQoL of EOS patients.
- This study translated and cross-culturally adapted the EOSQ-SELF into a Chinese version and evaluated its reliability and validity in children with EOS.

What is the implication, and what should change now?

- The Chinese EOSQ-SELF can be easily applied in clinical settings and for research purposes, as a complementary tool for the proxy-report EOSQ-24.

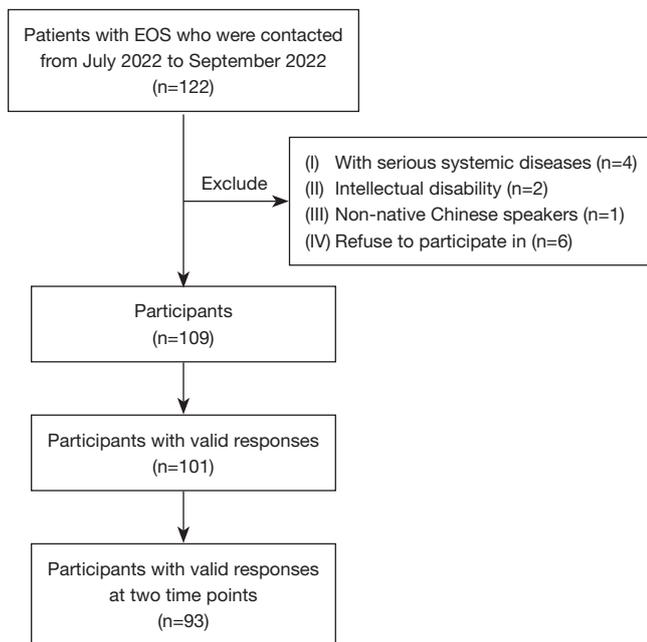


Figure 1 The flow chart of participants inclusion/exclusion and scale administration/collecton. EOS, early-onset scoliosis.

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Methods

Study design and participants

A cross-sectional study was performed from July 2022 to September 2022 in our hospital. A total of 122 patients with EOS were recruited for this study (Figure 1). The inclusion criteria were as follows: (I) diagnosis of EOS of any aetiology before 10 years of age; (II) age of 8 to 18 years; and (III) parents or caregivers from mainland China who speak Mandarin Chinese. Patients with serious systemic diseases that were not related to EOS or secondary to the treatment (e.g., tumor or autoimmune disease), with intellectual disability or those who were non-native Chinese speakers were excluded from this study. The purpose of this study was explained to the participants and their family members, and informed consent was obtained from the patients' family members. The scales were issued and collected through an online tool with a mandatory answer for each item. We assured all participants that their personal information would remain anonymous and that they could quit this study at any time. This study was conducted in accordance with the Declaration of Helsinki (as revised in 2013). This study

was approved by the Research Ethics Committee of Beijing Chao-Yang Hospital (No. 2022-07-01-2).

Study instruments

Demographic and clinical data

The current age and gender of the participants were recorded. The aetiology of the EOS was classified as idiopathic, congenital, syndromic, or neuromuscular. The severity of the spinal deformity was categorized according to the main curve Cobb angle of scoliosis ($\leq 50^\circ$ or $> 50^\circ$), which was measured on the anteroposterior radiography of the whole spine by an attending spine surgeon. The treatments included observation only, bracing, planned surgery, growing rod distraction, and spinal fusion. The ambulatory ability of participants was also collected, as complete-ambulatory, ambulatory with aid, or non-ambulatory.

EOSQ-SELF

The EOSQ-SELF was developed as a novel self-report instrument to directly evaluate the HRQoL of EOS patients (28). The EOSQ-SELF included 30 items across 12 domains: general health, pain/discomfort, pulmonary function, transfer, physical function/daily living, participation, fatigue/energy level, sleep, appearance, relationships, emotion, and satisfaction. Each item was scored on a five-point Likert-type scale, ranging from 1= "poor" to 5= "excellent". The score of each domain was the average score of the items in that domain, and the EOSQ-SELF total score was the average score of the domains. The raw scores (1 to 5) were converted into scale scores (0–100) using this equation: $(\text{algebraic mean} - 1)/4 \times 100$. A higher score indicated better HRQoL for EOS patients.

Development of the Chinese version of the EOSQ-SELF

We received access to the original English version of the EOSQ-SELF and the permission from the authors to translate the scale into Chinese. The guideline for the process of cross-cultural adaptation of self-report measures was followed in this study, and the development of the Chinese EOSQ-SELF was as follows (33).

Stage I: forward translation

The original English version of the EOSQ-SELF was independently translated into Chinese by two native Chinese-speaking translators. They were fluent in English, and one of them did not have a medical background. Their translations were compared and integrated. Discrepancies

were discussed with a bilingual Chinese- and English-speaking spine surgeon to form a consensus for the first draft of the Chinese EOSQ-SELF.

Stage II: back translation

Two native English-speaking translators, who were blinded to the original English version of the EOSQ-SELF and had no medical background, independently translated the first draft of the Chinese EOSQ-SELF back into English. After the integration of the two translators, the back-translations of the EOSQ-SELF were compared with the original English version. Any ambiguities and discrepancies were settled by a discussion among the five members, including the two native Chinese-speaking translators, the two native English-speaking translators, and the one bilingual Chinese- and English-speaking spine surgeon. Finally, the second draft of the Chinese EOSQ-SELF was formed.

Stage III: cultural adaptation

An expert committee consisting of two pediatric spine specialists, one psychologist, one physiotherapist, one methodologist, and one epidemiologist was organized. The experts were invited to individually assess the translation accuracy, grammar compliance, linguistic habits, content compliance, and equivalence on cultural background for each item between the second draft of the Chinese version and the original English version of the EOSQ-SELF. Through an in-depth discussion of the expert committee, a consensus was reached on the revision to improve the cross-cultural adaptation of the second draft of the Chinese EOSQ-SELF, and then the prefinal Chinese EOSQ-SELF was formed.

Stage IV: pilot study

Twenty patients with EOS who met the inclusion and exclusion criteria were informed for a pilot study. Semi-structured telephone interviews were conducted, and a five-point Likert-type scale was used to evaluate the relevance and clarity of each item. Any understanding difficulties and additional comments to each item were recorded.

Stage V: approval

According to the results of the pilot study and the feedback of the patients, the final Chinese EOSQ-SELF was finalized and approved for psychometric measurement by the expert committee.

Scoliosis Research Society-22 revised (SRS-22r)

The SRS-22r is a widely used scoliosis-specific and self-report instrument to assess the HRQoL (34). This scale contains 22 items across 5 domains, including pain, function, self-image, mental health, and satisfaction. Each item is

scored using a five-point Likert-type scale ranging from 1= “worst” to 5= “best”, with higher scores representing better HRQoL. The SRS-22r has been cross-culturally adapted into a Chinese version with excellent reliability and validity, and it has been used in numerous clinical studies to evaluate the outcomes of scoliosis management (35). The results of the SRS-22r scale can provide valuable information about the impact of scoliosis on patients’ daily lives and help guide treatment decisions. As the participants recruited in the current study were all patients with scoliosis, the SRS-22r was appropriate as a criterion-related scale.

Pediatric Quality of Life Inventory 4.0 (PedsQL4.0)

The PedsQL is a brief, generic, practical, and self-report instrument to assess the HRQoL of children (36). This scale can be utilized in both healthy school populations and pediatric patients with acute or chronic health conditions. Patients can complete the PedsQL by themselves. PedsQL4.0, which is the last version of PedsQL, contains 23 items across 4 domains, including physical, emotional, social, and school functioning. Each item is scored using a five-point Likert-type scale ranging from 0= “never” to 4= “almost always”, with higher scores indicating better HRQoL. The PedsQL4.0 can be used by healthcare professionals, researchers, and caregivers to identify areas of concern and monitor changes over time. PedsQL4.0 has been cross-culturally adapted into a Chinese version with high reliability and validity, and the Chinese version has been widely applied in pediatric patients with various diseases (37,38). As the participants recruited in the current study were all pediatric patients with EOS, the PedsQL4.0 was appropriate as a criterion-related scale.

EuroQol five-dimension instrument for youth (EQ-5D-Y)

The EQ-5D-Y is a HRQoL assessment instrument, designed for children aged 8 to 18 years (39,40). EQ-5D-Y consists of five domains, including mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. Each domain has only one item, and each item has three levels, corresponding to the score: 1= “no problem”, 2= “some problems”, 3= “a lot of problems”. The EQ-5D-Y can be applied in a wide range of health settings, including clinical trials, health surveys, and routine clinical practice. The Chinese EQ-5D-Y has been adapted and validated in scoliosis patients, with satisfactory reliability and validity (41). As the participants recruited in the current study were all aged 8 to 18 years, the EQ-5D-Y was also

used as a criterion-related scale.

Scale administration and data collection

The participants accessed the EOSQ-SELF, SRS-22r, PedsQL4.0, and EQ-5D-Y by scanning a QR code through a social media application (WeChat). These scales were issued at the beginning of the survey, and the participants were required to complete the EOSQ-SELF again after 2 weeks to determine the test-retest reliability. During the two weeks, the participants did not receive any new treatment, and the health conditions remained unchanged. Two investigators collected the demographic data, clinical data, and outcomes of the scales. The invalid responses, including repeated responses or those submitted within one minute, were excluded from the data collection.

Statistical analysis

The following descriptive statistics, including the mean, standard deviation, median and quartile, were calculated to determine the score distribution. All statistical analyses were performed utilizing SPSS version 25.0 (Chicago, IL, USA). P values of less than 0.05 were considered statistically significant.

The floor and ceiling effects

The floor and ceiling effects reflect the limitation of a scale to evaluate the whole spectrum of condition severity for its items. In general, acceptable values of floor and ceiling effects were <30% (42). In the current study, the floor and ceiling effects were computed as the percentage of the minimum and maximum scores for each item.

Reliability

The internal consistency was evaluated using the Cronbach's α coefficient and McDonald's ω coefficient, for which values >0.7 indicated desirable internal consistency (43).

In item analysis, the "Cronbach's α if the item was deleted" was calculated to assess the extent of each item contributing to the overall consistency of the scale; the corrected item-total correlation was also calculated to measure the strength of the relationship between an individual item and the total score of the scale. A value >0.3 is recommended for corrected item-total correlation (44).

As mentioned above, the data of EOSQ-SELF was

collected twice at two time points, with an interval of two weeks. The intraclass correlation coefficient (ICC) between data of the two time points was calculated to evaluate the test-retest reliability at the domain level, with values >0.8 indicating satisfactory reliability (45).

Construct validity

Content validity

The expert committee (six experts) was invited to perform a Delphi survey to evaluate the content validity of the Chinese EOSQ-SELF. A four-point Likert-type scale, ranging from 1= "irrelevant" to 4= "very relevant", was applied to calculate the item-level content validity index (I-CVI) and the scale-level content validity index (S-CVI). The I-CVI was computed as the proportion of experts who gave a relevance rating of 3 or 4 to each item, and the S-CVI was computed as the average of the I-CVI of all items (46).

Criterion-related validity

The criterion-related validity was assessed based on the correlation between the mean score of each domain in the Chinese EOSQ-SELF and the corresponding domains in the Chinese SRS-22r, PedsQL4.0, and EQ-5D-Y. As mentioned above, SRS-22r is a scoliosis-specific and self-report instrument but it is not specifically designed for pediatric patients. Both PedsQL4.0 and EQ-5D-Y are self-report instruments to assess the HRQoL of children but they were not specifically designed for scoliosis patients. Considering that all participants in the current study were pediatric patients with scoliosis while there is not yet a completely specific HRQoL scale for this population, we selected these three scales as the criterion-related scales. The Spearman correlation coefficient test was used. An absolute value of the correlation coefficient <0.5, between 0.5 and 0.7, and >0.7 indicated poor, good, and excellent validity, respectively (22).

Discriminative ability

Discriminative ability indicates the ability of a scale to differentiate respondents according to their demographic and clinical characteristics. The total scores of the Chinese EOSQ-SELF were compared based on age, gender, aetiology of EOS, severity of spinal deformity, treatment status, and ambulatory ability. The nonparametric Mann-Whitney U test was performed for comparisons between two groups. The Kruskal-Wallis test was used for comparisons among three or more groups, and subsequent

Table 1 Demographic and clinical data (n=101)

Characteristics	Values
Age at participation (years)	12.08±2.19
≤12	66 (65.35)
>12	35 (34.65)
Gender	
Male	47 (46.53)
Female	54 (53.47)
Aetiology	
Idiopathic	43 (42.57)
Congenital	39 (38.61)
Syndromic	6 (5.94)
Neuromuscular	13 (12.87)
Cobb angle (degrees)	60.56±19.48
≤50	32 (31.68)
>50	69 (68.32)
Treatment status	
Observation	16 (15.84)
Bracing	11 (10.89)
Plan to surgery	10 (9.90)
Growing rod distraction	29 (28.71)
Spinal fusion	35 (34.65)
Ambulatory ability	
Complete-ambulatory	81 (80.20)
Ambulatory with aid	15 (14.85)
Non-ambulatory	5 (4.95)

Data are presented as number (%) or mean ± standard deviation.

Bonferroni corrections were performed for multiple comparisons. The Spearman correlation coefficient test was used to investigate the correlations between the total scores of the Chinese EOSQ-SELF and the Cobb angle. Multiple linear regression also was applied to evaluate the discriminative ability of the Chinese EOSQ-SELF.

Results

Participant characteristics

A total of 109 patients signed informed consent forms

and responded to the Chinese EOSQ-SELF and other included scales. All the participants were of Han ethnicity. One hundred and one responses were valid, with a valid response rate of 82.79%. Ninety-three of the 101 patients returned the Chinese EOSQ-24 again 2 weeks after the first survey, with a response rate of 92.08%. The demographic and clinical characteristics of the patients are shown in *Table 1*. The mean age of the patients was 12.08±2.19 years (range, 8–17 years), and 53.47% were female. The mean Cobb angle was 60.56°±19.48° (range, 20.11°–113.18°). Of the patients, 43 had idiopathic scoliosis, 39 had congenital scoliosis, 6 had syndromic scoliosis, and 13 had neuromuscular scoliosis. Sixteen patients were under observation, 11 had brace treatment, 10 planned to receive surgery, 29 were undergoing serial growing rod distraction, and 35 had undergone posterior spinal fusion surgery. In terms of ambulatory ability, 5 patients were non-ambulatory.

Translation and cross-cultural adaptation

The original English version of the EOSQ-SELF was successfully translated into Chinese and cross-culturally adapted to form the prefinal Chinese EOSQ-SELF. None of the participants in the pilot study reported difficulties in understanding the prefinal Chinese EOSQ-SELF. The average scores of clarity and relevance for all items were 4.47 and 4.37, respectively.

Floor and ceiling effects

The median, quartile, and percentage of the ceiling and floor effects are presented in *Table 2*. The mean scores of the domains ranged from 41.75 (general health) to 77.50 (relationships), and the mean scores of the items ranged from 2.67 (Item 1 of general health) to 4.38 (Item 16 of sleep). Ten of the items had evenly distributed responses over the five possible answers. The median of Items 1, 8–10, 19, 29, and 30 was 3, and the median of Items 5, 6, and 25 was 3.5. The other items were all left-skewed, among which 19 items (Items 2–4, 7, 11–15, 17, 18, 20–24, and 26–28) had a median of 4, and 1 item (Item 16) had a median of 5. Floor effects of 0.00% to 7.92% and ceiling effects of 0.00% to 52.48% were observed in the patients. The most significant ceiling effect was observed in Item 16 (sleep) and Items 23,24 (relationships).

Reliability

The Cronbach's α coefficient and McDonald's ω coefficient

Table 2 Descriptive statistics of the Early-Onset Scoliosis Self-Report Questionnaire

Domain	Median	1 st quartile	3 rd quartile	Floor (%)	Ceiling (%)
General health					
Item 1	3	2	3	6.93	0.99
Pain/discomfort					
Item 2	4	3	5	0.00	27.72
Item 3	4	4	5	2.97	35.64
Pulmonary function					
Item 4	4	3	4.75	0.99	24.75
Transfer					
Item 5	3.5	3	4	3.96	16.83
Item 6	3.5	3	4	3.96	15.84
Physical function/daily living					
Item 7	4	3.25	5	0.00	28.71
Item 8	3	3	4	3.96	10.89
Item 9	3	2	4	5.94	18.81
Item 10	3	2	4	6.93	14.85
Item 11	4	3	5	0.99	28.71
Participation					
Item 12	4	3	4	1.98	18.81
Fatigue/energy level					
Item 13	4	3	4	0.99	23.76
Item 14	4	3	5	0.00	28.71
Sleep					
Item 15	4	3	4.75	0.00	24.75
Item 16	5	4	5	0.00	52.48
Item 17	4	4	5	0.00	34.65
Item 18	4	3	4	3.96	21.78
Appearance					
Item 19	3	2	3	3.96	0.00
Item 20	4	3	4	4.95	6.93
Item 21	4	3	4	1.98	2.97
Relationships					
Item 22	4	3	4	0.00	2.97
Item 23	4	4	5	0.00	43.56
Item 24	4	4	5	0.00	36.63

Table 2 (continued)

Table 2 (continued)

Domain	Median	1 st quartile	3 rd quartile	Floor (%)	Ceiling (%)
Emotion					
Item 25	3.5	3	4	1.98	1.98
Item 26	4	3	4	0.99	8.91
Item 27	4	3	4	0.00	19.80
Item 28	4	3	4	1.98	16.83
Item 29	3	3	4	7.92	2.97
Satisfaction					
Item 30	3	3	4	3.96	3.96

Table 3 Internal consistency and test-retest reliability

EOSQ-SELF	Cronbach's α coefficient	McDonald's ω coefficient	ICC
Domain			
General health	NA	NA	0.913
Pain/discomfort	0.894	0.893	0.898
Pulmonary function	NA	NA	0.818
Transfer	0.916	0.921	0.829
Physical function/daily living	0.903	0.899	0.924
Participation	NA	NA	0.915
Fatigue/energy level	0.917	0.912	0.874
Sleep	0.930	0.934	0.823
Appearance	0.892	0.889	0.901
Relationships	0.728	0.730	0.833
Emotion	0.921	0.918	0.818
Satisfaction	NA	NA	0.832
Total	0.942	0.940	0.930

EOSQ-SELF, Early-Onset Scoliosis Self-Report Questionnaire; ICC, intraclass correlation coefficient; NA, not available.

for the total score of the Chinese EOSQ-SELF were 0.942 and 0.940, respectively (Table 3). Among the 12 domains, the internal consistency could not be analyzed for the domains of general health, pulmonary function, participation, and satisfaction due to the involvement of only a single item in the domain. For the other domains, the Cronbach's α coefficient ranged from 0.728 to 0.930, and the McDonald's ω coefficient ranged from 0.730 to 0.934, which indicated excellent internal consistency. The Cronbach's α if the item was deleted ranged from 0.534 to 0.985, and the corrected item-total correlation

ranged from 0.472 to 0.910 (Table 4). The overall test-retest reliability was 0.930. The ICC of all domains was satisfactory, with values ranging from 0.818 to 0.924.

Construct validity

Content validity

The I-CVI of the 30 items ranged from 0.833 to 1.000, and the S-CVI was 0.939, which indicated that the items of the Chinese EOSQ-SELF were logical, comprehensible, and

Table 4 Item analysis for the EOSQ-SELF

EOSQ-SELF	Mean	SD	Corrected item total correlation	Cronbach's α if item deleted
Domain				
General health	41.75	19.48		
Item 1	2.67	0.78	0.631	0.984
Pain/discomfort	73.88	21.18		
Item 2	3.79	0.97	0.822	0.983
Item 3	4.12	0.81	0.822	0.984
Pulmonary function	69.75	22.56		
Item 4	3.79	0.90	0.783	0.982
Transfer	62.00	24.48		
Item 5	3.49	1.02	0.845	0.985
Item 6	3.47	1.02	0.845	0.983
Physical function/daily living	61.85	23.75		
Item 7	3.93	0.93	0.893	0.939
Item 8	3.37	0.92	0.841	0.947
Item 9	3.11	1.17	0.910	0.936
Item 10	3.16	1.13	0.895	0.938
Item 11	3.80	0.99	0.834	0.948
Participation	67.25	23.76		
Item 12	3.69	0.95	0.824	0.983
Fatigue/energy level	71.38	22.00		
Item 13	3.79	0.94	0.848	0.982
Item 14	3.92	0.90	0.848	0.981
Sleep	74.88	20.60		
Item 15	3.85	0.94	0.878	0.902
Item 16	4.38	0.75	0.844	0.920
Item 17	4.07	0.86	0.861	0.909
Item 18	3.68	1.04	0.834	0.924
Appearance	54.00	19.12		
Item 19	2.75	0.67	0.796	0.867
Item 20	3.37	0.96	0.839	0.813
Item 21	3.36	0.87	0.786	0.850
Relationships	77.50	11.70		
Item 22	3.62	0.55	0.557	0.635
Item 23	4.36	0.63	0.633	0.534
Item 24	4.32	0.57	0.472	0.729

Table 4 (continued)

Table 4 (continued)

EOSQ-SELF	Mean	SD	Corrected item total correlation	Cronbach's α if item deleted
Emotion	62.50	18.70		
Item 25	3.38	0.78	0.768	0.909
Item 26	3.59	0.81	0.750	0.912
Item 27	3.77	0.89	0.799	0.902
Item 28	3.74	0.93	0.821	0.898
Item 29	3.02	0.89	0.846	0.892
Satisfaction	54.00	21.53		
Item 30	3.16	0.86	0.789	0.985
Total	64.23	18.51		

EOSQ-SELF, Early-Onset Scoliosis Self-Report Questionnaire; SD, standard deviation.

Table 5 Construct validity of the EOSQ-SELF domains in relation with SRS-22r, PedsQL4.0, and EQ-5D-Y

EOSQ-SELF	SRS-22r			PedsQL4.0			EQ-5D-Y		
	Domain	r	P value	Domain	r	P value	Domain	r	P value
General health									
Pain/discomfort	Pain	0.768	<0.001	Physical	0.718	<0.001	Pain/discomfort	-0.613	<0.001
Pulmonary function				Physical	0.702	<0.001			
Transfer	Function	0.709	<0.001	Physical	0.689	<0.001	Mobility	-0.604	<0.001
Physical function/daily living	Function	0.723	<0.001	Physical	0.677	<0.001	Usual activities; self-care	-0.598; -0.619	<0.001
Participation	Function	0.710	<0.001	School	0.632	<0.001	Usual activities	-0.625	<0.001
Fatigue/energy level				Physical	0.624	<0.001			
Sleep				Emotional	0.671	<0.001			
Appearance	Self-image	0.821	<0.001						
Relationships	Self-image	0.862	<0.001	Social	0.568	0.005			
Emotion	Mental health	0.878	<0.001	Emotional	0.623	<0.001	Anxiety/depression	-0.611	<0.001
Satisfaction	Satisfaction	0.809	<0.001						

EOSQ-SELF, Early-Onset Scoliosis Self-Report Questionnaire; SRS-22r, Scoliosis Research Society questionnaire-22 revised; PedsQL4.0, Pediatric Quality of Life Inventory 4.0; EQ-5D-Y, EuroQol five-dimension instrument for youth.

adequate for measuring the HRQoL of EOS patients.

Criterion-related validity

All domains of the Chinese EOSQ-SELF were significantly correlated with the corresponding domains of the SRS-22r, PedsQL4.0, and EQ-5D-Y. The correlations between the relevant domains of the Chinese EOSQ-SELF and SRS-22r/PedsQL4.0/EQ-5D-Y are summarized in Table 5, depicting excellent criterion-related validity.

Discriminative ability

The total score of the Chinese EOSQ-SELF was significantly greater in patients with Cobb angles $\leq 50^\circ$ than in patients with Cobb angles $>50^\circ$ [85.83 (78.37, 90.28) vs. 59.65 (53.06, 64.01); $P<0.001$]. Specifically, there was a strong negative correlation between the Cobb angle and total score ($r=-0.795$, $P<0.001$). Significant differences also were detected in patients with different aetiologies ($P<0.001$), treatment statuses ($P<0.001$), and ambulatory

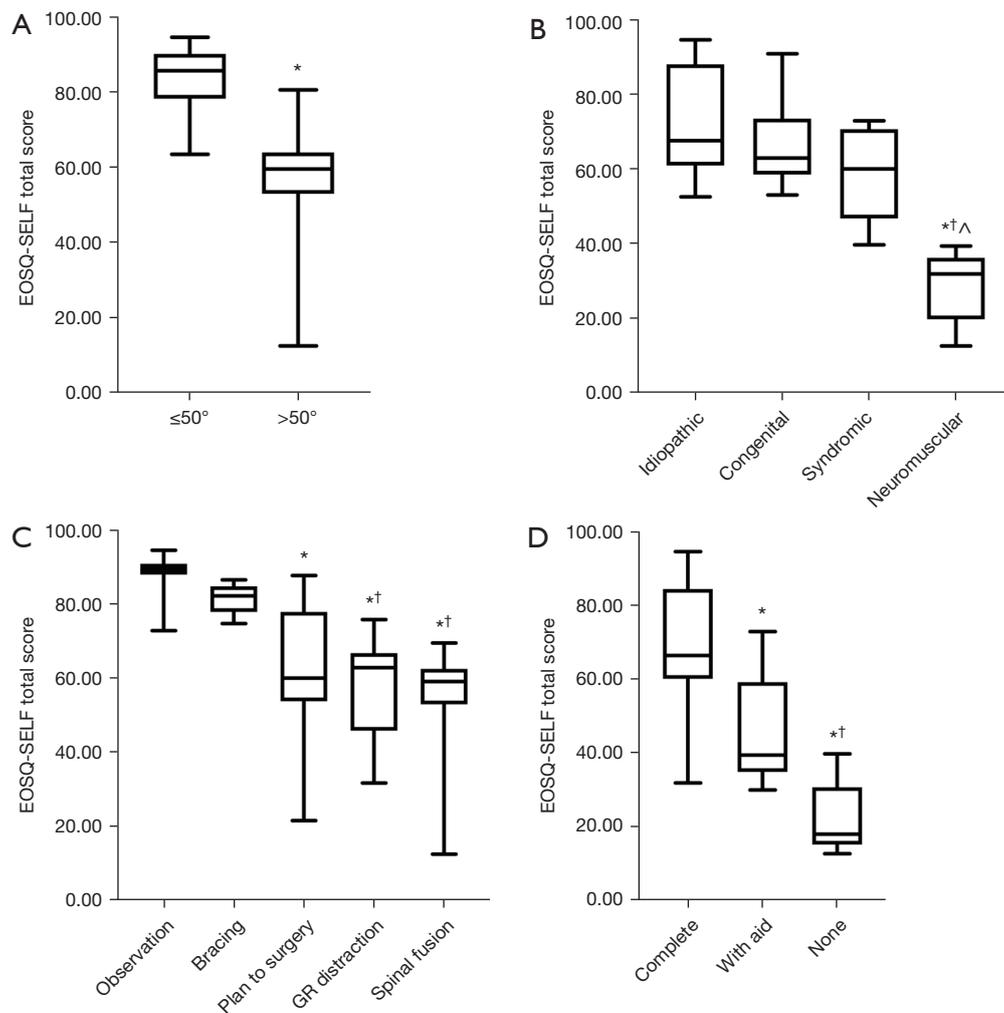


Figure 2 Comparison of total scores between early-onset scoliosis patients. (A) Cobb angle $\leq 50^\circ$ and $> 50^\circ$. *, vs. Cobb angle $\leq 50^\circ$ ($P < 0.001$). (B) Etiology. *, vs. idiopathic ($P < 0.001$); †, vs. congenital ($P < 0.001$); ^, vs. syndromic ($P < 0.001$). (C) Treatment status. *, vs. observation ($P < 0.001$); †, vs. bracing ($P < 0.05$). (D) Ambulatory ability. *, vs. complete-ambulatory ($P < 0.001$); †, vs. ambulatory with aid ($P < 0.05$). EOSQ-SELF, Early-Onset Scoliosis Self-Report Questionnaire; GR, growing rod.

abilities ($P < 0.001$) (Figure 2). The total score was significantly lower in patients with neuromuscular scoliosis but significantly greater in patients undergoing observation or brace treatment and those in the complete-ambulatory status. Multiple linear regression revealed that the discriminative ability of the Chinese EOSQ-SELF could be observed in aetiology, Cobb angle, treatment status, and ambulatory ability (Table 6).

Discussion

Patients with EOS are at a high risk of rapid deformity

progression and limited thoracic development. The impaired appearance, trunk balance, and cardiopulmonary function in patients with EOS significantly impact their HRQoL, especially in physical function and emotion (47). Therefore, the evaluation and treatment of EOS should focus on not only spinal deformities but also on HRQoL. However, the assessment of HRQoL in this heterogeneous population is not easy, and the standard adult HRQoL instrument is not appropriate for pediatric patients.

The EOSQ-24 is a solely illness-specific and validated psychometric tool to assess the HRQoL in this population and has been translated into various languages (18).

Table 6 Discriminative validity of the EOSQ-SELF total score

Variable	EOSQ-SELF total score [median (1 st , 3 rd quartile)]	P value [†]	β	95% CI	P value [‡]
Age (years)					
≤12	66.25 (58.39, 84.31)	0.071	Reference		
>12	59.69 (56.08, 67.40)		-0.021	-3.422 to 1.808	0.541
Gender					
Male	63.47 (58.85, 85.56)	0.193	Reference		
Female	62.95 (54.32, 75.02)		0.029	-0.966 to 3.079	0.302
Aetiology					
Idiopathic	67.64 (60.94, 88.13)	<0.001	Reference		
Congenital	62.95 (58.54, 73.54)		-0.055	-4.470 to 0.291	0.085
Syndromic	60.00 (46.79, 70.68)		-0.082	-11.924 to -1.915	0.007
Neuromuscular	31.84 (19.74, 36.18)		-0.509	-32.629 to -23.082	<0.001
Cobb angle (degrees)					
≤50	85.83 (78.37, 90.28)	<0.001	Reference		
>50	59.65 (53.06, 64.01)		-0.321	-16.381 to -9.204	<0.001
Treatment status					
Observation	89.65 (88.14, 91.08)	<0.001	Reference		
Bracing	82.34 (78.06, 84.96)		-0.089	-9.344 to -1.642	0.006
Plan to surgery	60.16 (53.88, 78.06)		-0.208	-17.564 to -7.935	<0.001
Growing rod distraction	62.95 (45.97, 66.89)		-0.310	-17.162 to -7.984	<0.001
Spinal fusion	59.20 (53.06, 62.60)		-0.395	-20.190 to -10.275	<0.001
Ambulatory ability					
Complete-ambulatory	66.48 (60.09, 84.53)	<0.001	Reference		
Ambulatory with aid	39.34 (34.76, 59.20)		-0.048	-6.205 to 1.229	0.187
Non-ambulatory	17.88 (15.00, 30.66)		-0.199	-22.916 to -10.785	<0.001

[†], P value by Mann-Whitney U test or Kruskal-Wallis test; [‡], P value by multiple linear regression. EOSQ-SELF, Early-Onset Scoliosis Self-Report Questionnaire; CI, confidence interval.

However, the limitation of the EOSQ-24 is that this scale is intended for only proxies to report the HRQoL of pediatric patients. With the psychological development and self-motivation in children, their perspective for physical mental health is usually different from that of their parents or caregivers (48). A previous study by Matsumoto *et al.* reported discrepancies in children's HRQoL between children and their proxies (49). Therefore, it is paramount to obtain the real HRQoL directly from the children's perspective, and recently, the EOSQ-SELF instrument

was developed (28). This study is the first to translate and culturally adapt the original EOSQ-SELF for Chinese EOS patients. The investigated Chinese version demonstrated excellent reliability and validity, which was adequate to measure the self-report HRQoL of patients aged 8 to 18 years with EOS.

Excellent internal consistency was observed in the Chinese EOSQ-SELF. The Cronbach's α coefficient for the total score of the Chinese EOSQ-SELF was 0.942, which demonstrated better internal consistency than the 0.896

by Cheung *et al.* (50) and the 0.893 by Gao *et al.* (25) in previous studies of the Chinese EOSQ-24. In comparison, the Cronbach's α coefficient of each domain in the Chinese EOSQ-SELF was better than that in the Chinese EOSQ-24, and the ICC was also superior to the results of the Chinese EOSQ-24 (25,47,50). These findings indicated that the self-report HRQoL possessed better consistency than the proxy-report outcomes for Chinese patients with EOS.

In previous studies that validated the translated versions of the EOSQ-24, the most commonly used proxy-report HRQoL tool was the Child Health Questionnaire-Parent Form-50 (CHQ-PF-50) (19,50). Because the EOSQ-SELF is a patient self-report HRQoL instrument, the Chinese SRS-22r, PedsQL4.0, and EQ-5D-Y were selected for validity construction. The SRS-22r is a scoliosis-specific scale, while the PedsQL4.0 and EQ-5D-Y are solely applied in pediatric patients (34,38,51). The results herein presented moderate to strong correlations among the related domains of the Chinese EOSQ-SELF, SRS-22r, PedsQL4.0, and EQ-5D-Y. Additionally, in terms of content validity, each item and the whole scale obtained a satisfactory I-CVI and S-CVI. These findings indicated that the Chinese EOSQ-SELF could cover the aspects related to the HRQoL of EOS patients and was appropriate for the Chinese cultural background.

The discriminative ability of the Chinese EOSQ-SELF total score was detected in aetiology, severity of spinal deformity, treatment status, and ambulatory ability. This study suggested that the total scores of patients with moderate scoliosis who underwent nonsurgical treatment were significantly greater than those who underwent spinal instrumentation for severe EOS. The indication for surgical intervention was a Cobb angle $>50^\circ$ (52). The mobility of the instrumented spine would be significantly reduced once the internal fixation was placed, and the HRQoL also would be impacted (53). Therefore, the Chinese EOSQ-SELF total score was consistent with the clinical settings. Regarding aetiology and ambulatory ability, we found that patients with neuromuscular scoliosis and non-ambulatory ability tended to have a lower total score. Patients with neuromuscular scoliosis usually concomitant with non-ambulatory status. Although spinal instrumentation can support the trunk and distract the thorax, pulmonary function needs at least one year to be recovered (54). Therefore, the HRQoL failed to improve as quickly as that of patients with idiopathic or congenital scoliosis (55). This study showed that the EOSQ-SELF could present these patients' perspectives and was adequate to be a self-report

HRQoL measuring tool for a heterogeneous Chinese EOS population.

There are some limitations in this study. First, this was a single-center study, of which the sample size was small. Therefore, a prospective multicenter study with a larger sample size is needed. Second, the changes in the EOSQ-SELF total score before and after treatment as well as its minimal clinically important difference (MCID) were not assessed in the current study, due to the cross-sectional design. A long-term follow-up is needed in further studies. Third, the SRS-22r is commonly used in adolescent idiopathic scoliosis, and the PedsQL4.0 and EQ-5D-Y have not been validated in EOS patients. Using these criterion-related scales to validate the EOSQ-SELF may impact the conclusions. However, the EOSQ-SELF is currently the only patient self-report and EOS-specific HRQoL assessment tool. Fourth, the most commonly used proxy-report EOSQ-24 should also be applied as a criterion-related scale to validate the patient self-report HRQoL scale, and the agreement between EOSQ-SELF and EOSQ-24 needs to be investigated in further studies. Last, when there is only one item in a domain of a scale, the factor analysis results may not be very reliable because there is no variation to capture. In this case, the single item may be seen as a reflection of a specific construct or variable, rather than a broader factor. This may lead to an overemphasis on the specific item and a failure to identify broader underlying factors or dimensions. In the original EOSQ-SELF scale, there were four domains (general health, pulmonary function, participation, and satisfaction) containing only a single item. Therefore, it may be not feasible to perform factor analysis to assess the construct validity (56). We hope that all items could be remained in the Chinese version of EOSQ-SELF, consistent with the original version; therefore, to improve the construction validity, several modifications to the original version may be necessary.

Conclusions

The Chinese EOSQ-SELF is reliable and a valid tool for the assessment of self-report HRQoL in patients aged 8 to 18 years with EOS. It can be easily applied in clinical settings and for research purposes, as a complementary HRQoL assessment tool for the proxy-report EOSQ-24. Future multicenter studies with long-term follow-up that focus on changes in the EOSQ-SELF total score before and after treatment and the minimally clinically important differences are needed.

Acknowledgments

Funding: None.

Footnote

Reporting Checklist: The authors have completed the SURGE reporting checklist. Available at <https://tp.amegroups.com/article/view/10.21037/tp-22-659/rc>

Data Sharing Statement: Available at <https://tp.amegroups.com/article/view/10.21037/tp-22-659/dss>

Peer Review File: Available at <https://tp.amegroups.com/article/view/10.21037/tp-22-659/prf>

Conflicts of Interest: All authors have completed the ICMJE uniform disclosure form (available at <https://tp.amegroups.com/article/view/10.21037/tp-22-659/coif>). The authors have no conflicts of interest to declare.

Ethical Statement: The authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. The study was conducted in accordance with the Declaration of Helsinki (as revised in 2013). The study was approved by the Research Ethics Committee of Beijing Chao-Yang Hospital (No. 2022-07-01-2). The patients' family members were aware of and agreed to this study, and signed the relevant informed consent.

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Cite this article as: Yang H, Liu L, Hai Y, Kang N. Reliability and validity of the Chinese version of the Early-Onset Scoliosis Self-Report Questionnaire in children aged 8 to 18 years with early-onset scoliosis. *Transl Pediatr* 2023;12(7):1336-1351. doi: 10.21037/tp-22-659