Disease-Specific Outcome Measures Evaluating the Health-Related Quality of Life of Children and Adolescents with Idiopathic Scoliosis and Scheuermann’s Kyphosis: A Literature Review

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Abstract:
Adolescent idiopathic scoliosis (AIS) and Scheuermann’s kyphosis (SK) are the most common types of spinal deformities in adolescents, and both have substantial ramifications on health-related quality of life (HRQoL) parameters. Various questionnaires have been developed to assess HRQoL in age-group populations with spinal deformity. Nevertheless, there remains a lack of consensus across the literature as to which instrument is the most suitable for evaluating the HRQoL of this cohort. Thus, this literature review was conducted to present disease-specific questionnaires for children and adolescents with AIS and SK to provide their psychometric characteristics (validity, reliability, and responsiveness) across different languages. A literature search was performed in the Medline (PubMed), Scopus, EMBASE, and Google Scholar databases. Studies that outlined the development and application of questionnaires evaluating HRQoL of children and adolescents with spinal deformity were included, and data on their validity and reliability in different translated languages were collected. A total of 10 disease-specific questionnaires were identified. Except for one questionnaire that was a proxy-reported measure, the other questionnaires were self-reported. We determined that selecting the proper questionnaire for clinical and research purposes requires careful consideration of various factors including the type of treatment intervention planned as well as various patient demographic factors. For children with early-onset scoliosis, the ideal questionnaire to evaluate their HRQoL is the Early-Onset Scoliosis Questionnaire-24. For adolescents with AIS and SK who are potential candidates for surgical intervention, the use of Scoliosis Research Society-22, Scoliosis Japanese-27, and Quality of Life Profile Spinal Deformity questionnaires is appropriate. For patients who are under nonsurgical treatment, the Brace Questionnaire and Italian Spine Youth Quality of Life questionnaires can be utilized. Nonetheless, when the specific intent of a study is to evaluate the self-image perception of patients, the use of drawing-based questionnaires may be the optimal choice.

Keywords:
Adolescent idiopathic scoliosis, Scheuermann Disease, Questionnaire, Quality of life

Introduction
Adolescent idiopathic scoliosis (AIS) and Scheuermann’s kyphosis (SK) are the most common types of spinal deformities in adolescents1. Treatment options for individuals with AIS and SK include medical observation, bracing, and surgical intervention2. Extensive research has shown that bracing is the most effective nonsurgical intervention for controlling the progressive AIS and SK curves in immature patients3-6. If left untreated with a suitable brace, the progressive curves can easily worsen during the patient's period of rapid adolescent growth7. Furthermore, the main benefit
of surgical intervention for AIS and SK is to reduce rib prominence and diminish spinal deformity. Nevertheless, AIS and SK as well as the myriad therapeutic modalities utilized in spinal deformity treatment may have serious effects on a patient’s health-related quality of life (HRQoL) parameters. Previous work has revealed that wearing a spinal corrective brace in the adolescent cohort may lead to various maladaptive psychosocial reactions such as negative thoughts, increased stress, and disturbance of self-image and self-esteem. Thus, increased attention has been placed on HRQoL as an important therapeutic outcome in these groups.

Given heightened awareness regarding the evaluation of HRQoL in children and adolescents with spinal deformities in the clinical setting as well as in the context of research, various specific questionnaires have been designed to assess HRQoL in children and adolescents with spinal deformities. Nevertheless, there remains a lack of consensus across the literature as to which instrument is most suitable for evaluating the HRQoL in these cohorts. Among the available questionnaires, the 22-item Scoliosis Research Society Questionnaire (SRS-22) is the most widely used and is considered to be the gold standard in measuring the HRQoL in patients with spinal deformities. In recent years, however, it is demonstrated using the Rasch analysis of the SRS-22 that this questionnaire lacks robust metric properties to measure HRQoL in AIS. The Rasch analysis is a statistical method used to assess and design questionnaires. According to this method, the ordinal scores can be converted into interval measures. It has been demonstrated using the Rasch analysis that the SRS-22 lacks the rich metric properties required to appropriately measure HRQoL in AIS. In fact, the suitability of the SRS-22 for this application has become a debated topic, considering its multidimensionality, nonlinearity, and inclusion of multiple questions, which have been regarded unnecessary. To address this issue, the Scoliosis Research Society-7 (SRS-7) questionnaire was designed from the original SRS-22 and was based on the principles of Rasch analysis. However, although the SRS-7 performed better, its metric properties were still not satisfactory for large-scale investigations. Thus, Caronni et al. designed the Italian Spine Youth Quality of Life (ISYQOL) questionnaire using the Rasch analysis. The ISYQOL is a self-reported measure for adolescents with AIS and SK that has been shown to better delineate the quality of life (QoL) of adolescents with spinal deformities across a broader spectrum and to further discriminate patient characteristics in finer detail.

Improvements in health care and health technology, as well as advances in the development of patient-reported outcome measures in children and adolescents with spinal deformities, indicate the necessity to review HRQoL measures and their psychometric properties to assist researchers and clinicians in selecting the optimal questionnaire for their needs. Thus, the objectives of this literature review are i) to present disease-specific questionnaires for children and adolescents with spinal deformities and ii) to provide their psychometric characteristics across different languages.

Materials and Methods

We utilized several literature review methodologies to identify studies on the development and application of instruments for children and adolescents with spinal deformities. We also sought to evaluate their validity and reliability in different languages. To carry out this research, we performed a computer-based literature search in the Medline (PubMed), Scopus, EMBASE, and Google Scholar databases using the following keywords: “scoliosis” [Title/Abstract] AND “Scheuermann’s kyphosis” [Title/Abstract] OR “Scheuermann’s disease” [Title/Abstract] AND “questionnaire” [Title/Abstract] OR “tool” [Title/Abstract] OR “scale” [Title/Abstract] OR “Outcome measure” [Title/Abstract] AND “validity” [Title/Abstract] AND “reliability” [Title/Abstract] AND (Responsive* [Title/Abstract]). We also searched the reference lists of the eligible articles. Additionally, we checked the key journals related to the topic. We only included articles written in English. This search was performed up to July 2021.

Two reviewers (VM and TB) independently checked the eligibility of the articles on the basis of the title and abstract. Review articles and congress abstracts were excluded. Furthermore, studies that examined the effect of a particular treatment for SK or AIS on HRQoL of children or adolescents with spinal deformities were excluded.

Results

A total of 10 disease-specific questionnaires were identified in our literature survey. Four of them were developed in the United States, six in Europe, and one in Asia. The SRS-22 was the most widely culturally adapted questionnaire, having been translated and modified for use in 19 different languages. Except for the EOSQ-24, a proxy-reported measure, the other questionnaires were self-reported. The number of domains of included questionnaires ranged from three to nine, and the number of items ranged from three to 34. One questionnaire had illustrated items, one had both illustrated and textual items, and the remaining questionnaires had textual items.

Instruments

The QoL profile for spine deformity (QLPSD)

General description

The QLPSD is the first specific questionnaire evaluated by Climent et al. that is used to assess the effects of bracing or surgery on the HRQoL of adolescents with scoliosis or hyperkyphosis aged 10-20 years. The QLPSD has 21 items, and its questions are distributed across five domains:
Calculation

The items of the QLPSD were rated on a five-point Likert scale, ranging from 1 to 5. Total scores, therefore, fall within a range of 21-105, with higher scores showing fewer QoL impairments, and lower scores indicating more QoL impairments.

Table 1 shows the results of validity and reliability of the original Spanish, French, Persian, German, and Greek versions of QLPSD.

**The SRS-22**

*General description*

This is a disease-specific tool developed to evaluate the HRQoL of surgery patients in AIS. The questionnaire in its original form contained 24 questions. Following some changes and refinement by Asher et al., the SRS-22 was developed and found to have better psychometric properties than the original 24-item SRS. It comprises 22 items, each of which is in a five-point Likert scale format. The questions are distributed across five domains, namely, Function/activity (questions 5, 9, 12, 15, and 18), Pain (questions 1, 2, 8, 11, and 17), Self-image/appearance (questions 4, 6, 10, 14, and 19), Mental health (questions 3, 7, 13, 16, and 20), and Satisfaction with management (questions 21 and 22).

**Calculation**

Scores for each question range from 1 (worst condition) to 5 (best condition) and in each domain from 5 to 25 (except for satisfaction with management domain, where the score varies from 2 to 10). Therefore, the total score of this questionnaire varies from 22 to 110.

The Spanish, Dutch, Japanese, Chinese, German, Polish, Turkish, French Canadian, Danish, Greek, Hebrew, Italian, Swedish, Korean, Arabic, French, Thai, and Persian versions of this questionnaire include the following: General (items 9, 10, and 19), Curve (item 1), Prominence (items 2 and 3), Trunk shift (items 4 and 5), Waist (items 11, 12, and 13), Shoulders (items 6 and 16), Kyphosis (item 7), Chest (items 14 and 15), and Surgical scar (item 17). Lastly, there are three open-ended questions (items 8, 18, and 20) included in the questionnaire.

**The brace questionnaire (BrQ)**

*General description*

The BrQ is a self-reported tool aimed at assessment of the QoL of adolescents with AIS treated with a brace. The original version of this questionnaire was designed and validated in Greece by Vasiliadis et al. The BrQ comprises 34 items and eight domains that assess the HRQoL adolescents aged between 9 and 18 years who have AIS. The domains of this questionnaire include the following: General health perception (items 1 and 2), Physical functioning (items 3-9), Emotional functioning (items 10-14), Self-esteem and esthetics (items 15 and 16), Vitality (items 17 and 18), School activity (items 19-21), Bodily pain (items 22-27), and Social functioning (items 28-34).

**Calculation**

The scoring system of BrQ is as follows: for items 4, 5, 6, 12, 14, 15, 16, and 17, “always” receives a score of 5, “most of the time” receives a score of 4, “sometimes” receives a score of 3, “almost never” receives a score of 2, and “never” receives a score of 1. For other items, “always” is rated 1, “most of the time” is rated 2, “sometimes” is rated 3, “almost never” is rated 4, and “never” is rated 5. To calculate the overall QoL score, the score for each item is multiplied by 20, and finally, the total score is divided by 34. Thus, after final tabulation, the lowest possible QoL score is 20, and the highest possible is 100.

The BrQ has been validated in Persian, Italian, Chinese, Korean, Turkish, Polish, and French versions (Table 3).

**The spinal appearance questionnaire (SAQ)**

*General description*

The SAQ is one of the specific tools designed to assess the self-image of patients with scoliosis. This questionnaire was designed by Sanders et al. in the English language. It has two versions including a version aimed at the patient and an additional form that is filled out by the parent or guardian of the patient. Both of the SAQ questionnaires have two sections and nine subsections. The first section consists of drawing-based items that assess the perception of the severity of trunk deformity. The individual’s expectations regarding the symmetry of the shoulders, chest, and pelvis are assessed in the second section through textual-based questions. The answers to these questions are tabulated across the five-point Likert scale format. Subsections of this questionnaire include the following: General (items 9, 10, and 19), Curve (item 1), Prominence (items 2 and 3), Trunk shift (items 4 and 5), Waist (items 11, 12, and 13), Shoulders (items 6 and 16), Kyphosis (item 7), Chest (items 14 and 15), and Surgical scar (item 17). Lastly, there are three open-ended questions (items 8, 18, and 20) included in the questionnaire.

**Calculation**

The score range of each question of the SAQ form is from 1 to 5, with a score of 1 indicating the optimal situation and a score of 5 indicating the worst situation. In computing the total score, the three open-ended items are omitted and do not factor into the final tabulation. The lowest total score for the SAQ is 17, and the highest is 85.

Table 4 shows the results of validity and reliability of the original English, Polish, French-Canadian, simplified Chinese, traditional Chinese, Korean, Danish, and Turkish versions of the SAQ.
Table 1. Results of Validity and Reliability of the QLPSD in Different Studies.

| References                     | No. of patients | Age (years) | Intervention | Internal consistency | Test–retest reliability | Test time intervals | Convergent validity | Discriminate validity | Responsiveness | Floor effect (%) | Ceiling effect (%) | Missing answer (%) |
|--------------------------------|-----------------|-------------|--------------|----------------------|-------------------------|----------------------|---------------------|-----------------------|-----------------|------------------|------------------|-------------------|
| Rezaei et al. (Persian version)| 105             | 10–19       | Brace        | Psychosocial Functioning: 0.75 Sleep disturbances: 0.76 Back pain: 0.72 Body image: 0.76 Back flexibility: 0.82 | Psychosocial Functioning: 0.81 Sleep disturbances: 0.84 Back pain: 0.89 Body image: 0.78 Back flexibility: 0.91 | 2 weeks | Pearson r=0.30–0.62 with SRS-22 | Able to discriminate between participants who differed regarding the type of deformity, gender, Cobb angle, and duration of bracing | Not provided | Not provided | Not provided | Not provided |
| Climent et al. (Original Spanish version) | 174             | 15          | Not provided | Psychosocial Functioning: 0.81 Sleep disturbances: 0.84 Back pain: 0.75 Body image: 0.70 Back flexibility: 0.70 | Psychosocial Functioning: 0.89 Sleep disturbances: 0.78 Back pain: 0.91 Body image: 0.66 Back flexibility: 0.67 | 10 days | Pearson r=0.22–0.38 with SRS-22 | Able to discriminate between participants regarding the type of curve, back pain, and type of treatment. | Not provided | Not provided | Not provided | Not provided |
| Korovessis et al. (Greece version) | 79              | 12.7        | Brace        | Not provided | | 4 weeks | | Able to discriminate between participants regarding the type of deformity. | Not provided | Not provided | Not provided | Not provided |
| Schulte et al. (German version)  | 255             | 16          | Brace surgery | Psychosocial Functioning: 0.86 Sleep disturbances: 0.85 Back pain: 0.87 Body image: 0.88 Back flexibility: 0.89 | Psychosocial Functioning: 0.63 Sleep disturbances: 0.84 Back pain: 0.83 Body image: 0.73 Back flexibility: 0.81 | 8 weeks | Pearson r=0.32–0.59 with SRS-22 | Able to distinguish between patients with scoliosis and individuals in a healthy control group and patients with different curve magnitude. | Not provided | Not provided | Not provided | Not provided |
| References                        | No. of patients | Age (years) | Intervention | Internal consistency | Test–retest reliability | Test time intervals | Convergent validity | Discriminate validity | Responsiveness | Floor effect (%) | Ceiling effect (%) | Missing answer (%) |
|----------------------------------|----------------|-------------|--------------|----------------------|-------------------------|---------------------|---------------------|----------------------|----------------|----------------|-------------------|-------------------|
| Asher et al. (Original English version) | 58             | 14.6        | Surgery      | Function: 0.86       | Function: 0.90          | 28                  | Pearson r=0.68–0.90 | Not provided           | Not provided | <2%            | 15.5%             | 15.5%             |
|                                  |                |             |              | Pain: 0.92           | Pain: 0.96              |                     | with SF-36           |                      |                |                |                   |                   |
|                                  |                |             |              | Self-image: 0.75     | Self-image: 0.90        |                     |                     |                      |                |                |                   |                   |
|                                  |                |             |              | Mental health:       | Mental health:          |                     |                     |                      |                |                |                   |                   |
|                                  |                |             |              | 0.90                | 0.87                    |                     |                     |                      |                |                |                   |                   |
|                                  |                |             |              | Satisfaction: 0.88   | Satisfaction: 0.85      |                     |                     |                      |                |                |                   |                   |
| Asher et al. (Original English version) | 100            | 13–14       | Untreated    | Not provided         | Not provided            | Not provided        | Not provided        | Able to discriminate | Not provided | Not provided | Not provided | Not provided |
|                                  |                |             | Braced       |                      |                         |                     |                     | between individuals  | Not provided | Not provided | Not provided | Not provided |
|                                  |                |             | Pre-surgical |                      |                         |                     |                     | with no scoliosis or | Not provided | Not provided | Not provided | Not provided |
|                                  |                |             |              |                      |                         |                     |                     | moderate curves and  | Not provided | Not provided | Not provided | Not provided |
|                                  |                |             |              |                      |                         |                     |                     | large curves. It     | Not provided | Not provided | Not provided | Not provided |
|                                  |                |             |              |                      |                         |                     |                     | cannot discriminate  | Not provided | Not provided | Not provided | Not provided |
|                                  |                |             |              |                      |                         |                     |                     | patients regarding    | Not provided | Not provided | Not provided | Not provided |
|                                  |                |             |              |                      |                         |                     |                     | curve type. Severity  | Not provided | Not provided | Not provided | Not provided |
|                                  |                |             |              |                      |                         |                     |                     | of trunk asymmetry    | Not provided | Not provided | Not provided | Not provided |
|                                  |                |             |              |                      |                         |                     |                     | was significantly     | Not provided | Not provided | Not provided | Not provided |
|                                  |                |             |              |                      |                         |                     |                     | correlated with self- | Not provided | Not provided | Not provided | Not provided |
|                                  |                |             |              |                      |                         |                     |                     | image, function, and  | Not provided | Not provided | Not provided | Not provided |
|                                  |                |             |              |                      |                         |                     |                     | pain scores.         | Not provided | Not provided | Not provided | Not provided |
| Asher et al. (Original English version) | 58             | 16          | Surgery      | Not provided         | Not provided            | Preoperatively, at 3 | Not provided        | Self-image was made   | Not provided | Not provided | Not provided | Not provided |
|                                  |                |             |              |                      |                         | 6, 12, and 24        |                     | better after 3 months | Not provided | Not provided | Not provided | Not provided |
|                                  |                |             |              |                      |                         | month intervals      |                     | ($P<0.0001$) and      | Not provided | Not provided | Not provided | Not provided |
|                                  |                |             |              |                      |                         | postoperatively      |                     | continued to be      | Not provided | Not provided | Not provided | Not provided |
|                                  |                |             |              |                      |                         |                     |                     | better until final    | Not provided | Not provided | Not provided | Not provided |
|                                  |                |             |              |                      |                         |                     |                     | follow-up. Function   | Not provided | Not provided | Not provided | Not provided |
|                                  |                |             |              |                      |                         |                     |                     | was decreased at 3  | Not provided | Not provided | Not provided | Not provided |
|                                  |                |             |              |                      |                         |                     |                     | months ($P<0.0001$)   | Not provided | Not provided | Not provided | Not provided |
|                                  |                |             |              |                      |                         |                     |                     | and returned to pre-  | Not provided | Not provided | Not provided | Not provided |
|                                  |                |             |              |                      |                         |                     |                     | surgery condition by  | Not provided | Not provided | Not provided | Not provided |
|                                  |                |             |              |                      |                         |                     |                     | 6 months. Pain        | Not provided | Not provided | Not provided | Not provided |
|                                  |                |             |              |                      |                         |                     |                     | severity was increased | Not provided | Not provided | Not provided | Not provided |
|                                  |                |             |              |                      |                         |                     |                     | at 3 months ($P=0.0099$) | Not provided | Not provided | Not provided | Not provided |
|                                  |                |             |              |                      |                         |                     |                     | and decreased at 6 ($P=0.0011$), | Not provided | Not provided | Not provided | Not provided |
|                                  |                |             |              |                      |                         |                     |                     | and 12 ($P<0.0001$),  | Not provided | Not provided | Not provided | Not provided |
|                                  |                |             |              |                      |                         |                     |                     | 24 ($P=0.0037$) months. | Not provided | Not provided | Not provided | Not provided |
| Alanay et al. (Turkish version)  | 54             | 19.8        | Surgery      | Function: 0.81       | Function: 0.76          | 35 days             | Pearson r=0.27–0.81 | Not provided           | Not provided | <7%            | 17%               | 17%               |
|                                  |                |             |              | Pain: 0.84           | Pain: 0.63             |                     | with SF-36           |                      |                |                |                   |                   |
|                                  |                |             |              | Self-image: 0.78     | Self-image: 0.82        |                     |                     |                      |                |                |                   |                   |
|                                  |                |             |              | Mental health:       | Mental health:          |                     |                     |                      |                |                |                   |                   |
|                                  |                |             |              | 0.90                | 0.78                   |                     |                     |                      |                |                |                   |                   |
|                                  |                |             |              | Satisfaction: 0.82   | Satisfaction: 0.81      |                     |                     |                      |                |                |                   |                   |
| References | No. of patients | Age (years) | Intervention | Internal consistency | Test–retest reliability | Test time intervals | Convergent validity | Discriminate validity | Responsiveness | Floor effect (%) | Ceiling effect (%) | Missing answer (%) |
|------------|----------------|-------------|--------------|---------------------|------------------------|-------------------|-------------------|-------------------|----------------|----------------|-----------------|------------------|
| Lonjon et al. (French–Canadian version in France) | 145 | 14.2 | Surgery | Function: 0.68 | Not provided | Not provided | Pearson r=0.54–0.79 with SF-12 | Able to discriminate AIS cases regarding sex, age, BMI, curve magnitude, and treatment types. | Not provided | <1% | 22.1% for pain and satisfaction domains | Not provided |
| Sathira-Angkura et al. (Thai version) | 58 | 18.7 | Surgery | Function: 0.70 | 14 days | Pearson r=0.73 with SF-36 | Not provided | Not provided | <2% | 6.9% for mental health, 13.8% for pain, and 43.1% for satisfaction domains | Not provided |
| Lee et al. (Korean version) | 64 | 18.3 | Surgery | Function: 0.85 | Not provided | Pearson r=0.19–0.81 with SF-36 | Not provided | Not provided | Function: 1.2 | 11.1% for mental health, 22.8% for pain, and 17.1% for satisfaction domains | Not provided |
| Théroux et al. (French version) | 352 | 13.5 | Brace | Pain: 0.79 | Not provided | Pearson r=0.36–1.00 with SF-12 | Not provided | Not provided | Function: 1.2 | <7% | 18% for mental health, 30% for pain, and 44% for function | Not provided |
| Cheung et al. (Chinese version) | 48 | 16.5 | Not provided | Function: 0.86 | 7 days | Pearson r=0.18–0.77 with SF-36 | Not provided | Not provided | <7% | | | Not provided |
| Climent et al. (Spanish version) | 175 | 19 | Brace | Function: 0.86 | Not provided | Pearson r=0.84 with QLPSD | Able to discriminate AIS cases regarding age, curve magnitude, and treatment types. | Not provided | Not provided | Not provided | Not provided | Not provided |
| References | No. of patients | Age (years) | Intervention | Internal consistency | Test–retest reliability | Test time intervals | Convergent validity | Discriminate validity | Responsiveness | Floor effect (%) | Ceiling effect (%) | Missing answer (%) |
|------------|----------------|-------------|--------------|----------------------|--------------------------|---------------------|---------------------|---------------------|-----------------|----------------|------------------|------------------|
| Simony et al. (Danish version) | 169 | Not provided | Brace Surgery | Function: 0.89 Pain: 0.88 Self-image: 0.87 Mental health: 0.90 Satisfaction: 0.93 | Not provided | Not provided | Pearson r=0.62 with SF-36 | Not provided | Not provided | 25.45% for function 9.09% for pain, and 26.42 for satisfaction domains | Not provided |
| Danielsson et al. (Swedish version) | 141 | 23.3 | Brace Surgery | Function: 0.72 Pain: 0.78 Self-image: 0.84 Mental health: 0.87 Satisfaction: 0.81 | Function: 0.87 Pain: 0.93 Self-image: 0.78 Mental health: 0.80 Satisfaction: 0.84 | 2 weeks | Pearson r=0.08–0.88 with SF-36 | Able to discriminate AIS cases regarding age, curve magnitude, and treatment types. | Not provided | <3% | 22.8% for function 28.3% for pain, and 17.7% for satisfaction domains | Not provided |
| Mousavi et al. (Persian version) | 84 | 12–18 | Brace Surgery | Function: 0.70 Pain: 0.73 Self-image: 0.68 Mental health: 0.78 Satisfaction: 0.76 | Function: 0.87 Pain: 0.82 Self-image: 0.85 Mental health: 0.79 Satisfaction: 0.79 | 1–2 weeks | Pearson r=0.35–0.85 with SF-36 | Able to discriminate cases regarding curve magnitude, and function. | Not provided | <3% | 16.1% for pain and 19.4% for satisfaction domains | Not provided |
| Schlösser et al. (Dutch version) | 135 | 15.1 | Brace Surgery Under Observation | Function: 0.74 Pain: 0.85 Self-image: 0.71 Mental health: 0.77 Satisfaction: 0.71 | Function: 0.86 Pain: 0.92 Self-image: 0.87 Mental health: 0.85 Satisfaction: 0.79 | 2 weeks | Pearson r=0.38–0.88 with SF-36 | Able to discriminate between scoliosis patients with different levels of disease-specific quality of life | Not provided | <2% | 33% for function 20% for pain and 22% for satisfaction domains | Not provided |
| Haidar et al. (Arabic version) | 81 | 10–18 | Brace Surgery | Function: 0.58 Pain: 0.82 Self-image: 0.85 Mental health: 0.77 Satisfaction: 0.44 | Function: 0.87 Pain: 0.90 Self-image: 0.84 Mental health: 0.88 Satisfaction: 0.82 | 1 week | Not provided | Not provided | Not provided | <5% | 14.6% for pain and 26.8% for satisfaction domains | Not provided |
| Glowacki et al. (Polish version) | 60 | 16.6 | Surgery | Function: 0.81 Pain: 0.81 Self-image: 0.77 Mental health: 0.80 Satisfaction: 0.69 | Function: 0.58 Pain: 0.82 Self-image: 0.85 Mental health: 0.77 Satisfaction: 0.44 | 1 day | Not provided | Not provided | Not provided | <2% | 36% for pain and 15% for mental health and 38% for function domains | Not provided |
| References                  | No. of patients | Age (years) | Intervention    | Internal consistency | Test-retest reliability | Test time intervals | Convergent validity | Discriminate validity                                                                 | Responsiveness | Floor effect (%) | Ceiling effect (%) | Missing answer (%) |
|-----------------------------|-----------------|-------------|-----------------|----------------------|-------------------------|---------------------|---------------------|----------------------------------------------------------------------------------------|----------------|------------------|-------------------|-------------------|
| Hashimoto et al. (Japanese version) | 114             | 10–18       | Not provided    | Function: 0.75       | Pain: 0.88              | Not provided         | Pearson r=0.18–0.80 with SF-36              | Able to discriminate cases regarding curve magnitude, and pattern plus treatment. | Not provided | Not provided | 38% for function, 36% for pain and 15% for mental health domains | Not provided |
| Monticone et al. (Italian version) | 35              | 8.5–19      | Brace Exercise  | Not provided         | Not provided for each domain | 1 week              | Not provided         | Not provided                                                                                      | Not provided | <2%                            | Not provided | Not provided |
| Niemeyer et al. (German version) | 222             | 19          | Brace Exercise  | Function: 0.67       | Pain: 0.75              | 30 days             | Spearman rho 0.14–0.60 | Not provided                                                                                   | Not provided | 0.0%                           | 11.5% for mental health domains | Not provided |
| Zhao et al. (Chinese version)  | 86              | 13.9        | Brace           | Function: 0.70       | Pain: 0.80              | 3-4 days            | Function: 0.66–0.74 | Not provided                                                                                   | Not provided | Pain: 7.0                         | Mental health: 17.9% for pain and 26.9% for satisfaction domains | Not provided |
| Li et al. (simplified Chinese (mainland) version) | 87              | 15.6        | Surgery         | Function: 0.81       | Pain: 0.88              | 21 day              | Pearson r=−0.25–1.0 with SF-36 | Not provided                                                                                   | Not provided | 1.6%–3.2%                       | 1.6% for self-image to 22.2% for pain. | Not provided |
| References                          | No. of patients | Age (years) | Intervention   | Internal consistency | Test–retest reliability | Test time intervals | Convergent validity | Discriminate validity | Responsiveness          | Floor effect (%) | Ceiling effect (%) | Missing answer (%) |
|------------------------------------|-----------------|-------------|----------------|----------------------|--------------------------|----------------------|---------------------|----------------------|------------------------|--------------------|---------------------|---------------------|
| Bezale et al. (Hebrew version)      | 45              | 17.3        | Brace Surgery  | Function: 0.63       | Function: 0.88           | Not provided          | Pearson r=0.22–0.54 with SF-36 | Not provided          | Not provided          | 15.0% for function, 18.3% for pain and 26.7% for satisfaction domains | <4%                | Not provided         |
| Beausejour et al. (French–Canadian versions) | 145             | 9.8–21.2    | Brace Surgery  | Function: 0.67       | Not provided             | Not provided          | Pearson r=0.54–0.79 with SF-12 | Not provided          | 0.0%–0.7%             | Pain: 22.1% Mental health: 51.6% Satisfaction: 22.1% | Not provided         |
| Antonarakos et al. (Greek version)  | 51              | 21.2        | Surgery        | Function: 0.67       | >0.70 for all domains   | Not provided          | Pearson r=0.38–0.89 with SF-36 | Not provided          | 2.00%                  | Satisfaction: 37.3% | Not provided         |
| References                     | No. of patients | Age (years) | Intervention | Internal consistency | Test–retest reliability | Test time intervals | Convergent validity | Discriminant validity | Responsiveness | Floor effect (%) | Ceiling effect (%) | Missing answer (%) |
|-------------------------------|----------------|-------------|--------------|----------------------|-------------------------|---------------------|---------------------|-----------------------|----------------|----------------|-----------------|------------------|
| Rezaee et al. (Persian version) | 51             | 13.88±2.14  | Brace        | General health perception: 0.72  
Physical functioning: 0.78  
Emotional functioning: 0.76  
Self-esteem and esthetics: 0.76  
Vitality: 0.80  
School activity: 0.81  
Bodily pain: 0.84  
Social functioning: 0.86  
| General health perception: 0.96  
Physical functioning: 0.96  
Emotional functioning: 0.98  
Self-esteem and esthetics: 0.80  
Vitality: 0.97  
School activity: 0.98  
Bodily pain: 0.97  
Social functioning: 0.98  
| 7 days                         | Pearson r=0.17–0.71 with SRS-22 | Not provided | Not provided | 0% | 0% | Not provided |
| Vasiliadis et al. (Greek version) | 28             | 13.5        | Brace        | General health perception: 0.72  
Physical functioning: 0.80  
Emotional functioning: 0.77  
Self-esteem and esthetics: 0.88  
Vitality: 0.84  
School activity: 0.82  
Bodily pain: 0.85  
Social functioning: 0.88  
| Not provided                  | Not provided | Not provided | The correlation between BrQ overall scores for mild (18°–29°) and moderate (30°–38°) scoliosis was statistically significant | 0% | 0.0%–10.7% | 0.0%–3.57% |
| Chan et al. (Chinese version)  | 120            | 9–18        | Brace        | General health perception: 0.70  
Physical functioning: 0.52  
Emotional functioning: 0.66  
Self-esteem and esthetics: 0.87  
Vitality: 0.42  
School activity: 0.56  
Bodily pain: 0.83  
Social functioning: 0.79  
| 0.83                         | 1–2 weeks     | Pearson r=0.07–0.18 with SRS-22 | Able to discriminate cases regarding the time of wearing and age | Not provided | 0.0%–12.1% | 17.2% | 0% |
| Deceuninck et al. (French version) | 40             | 9–17        | Brace        | General health perception: 0.51  
Physical functioning: 0.74  
Emotional functioning: 0.82  
Self-esteem and esthetics: 0.91  
Vitality: 0.52  
School activity: 0.71  
Bodily pain: 0.82  
Social functioning: 0.77  
| 0.85                         | 7 days        | Not provided | Not provided | Not provided | 0.0%–2.5% | 0.0%–15% | Not provided |
| Kinel et al. (Polish version)  | 35             | 10–16       | Brace        | General health perception: 0.51  
Physical functioning: 0.74  
Emotional functioning: 0.82  
Self-esteem and esthetics: 0.91  
Vitality: 0.52  
School activity: 0.71  
Bodily pain: 0.82  
Social functioning: 0.77  
| 0.82                         | 7 days        | Not provided | Not provided | Not provided | 0% | 17% for item 21 to 33% for item 6. | Not provided |
| References | No. of patients | Age (years) | Intervention | Internal consistency | Test-retest reliability | Test time intervals | Convergent validity | Discriminate validity | Responsiveness | Floor effect (%) | Ceiling effect (%) | Missing answer (%) |
|------------|----------------|-------------|--------------|----------------------|------------------------|---------------------|---------------------|---------------------|----------------|----------------|-----------------|------------------|
| Aulisa et al. (Italian version) | 34 | 14 | Brace | Not provided | 0.94 | 3–7 days | Pearson r=0.38–0.82 with SRS-22 | Able to discriminate cases regarding Cobb angle age | Not provided | Not provided | No floor effects | Not provided |
| Gür et al. (Turkish version) | 28 | 14.6 | Brace | 0.94 | General health: 0.72 Physical functioning: 0.93 Emotional functioning: 0.83 Self-esteem esthetics: 0.79 Vitality: 0.82 School activity: 0.73 Bodily pain: 0.91 Social functioning: 0.95 Total: 0.95 | 5 days | Pearson r=0.67 and 0.64 with BSSQ-Brace and SRS-22, respectively. | Not provided | Not provided | Not provided | Not provided |
| Lim et al. (Korean version) | 120 | 12.1 | Brace | General health: 0.88 Physical functioning: 0.86 Emotional functioning: 0.87 Self-esteem esthetics: 0.90 Vitality: 0.86 School activity: 0.89 Bodily pain: 0.87 Social functioning: 0.90 Total: 0.87 | General health: 0.90 Physical functioning: 0.87 Emotional functioning: 0.88 Self-esteem esthetics: 0.92 Vitality: 0.85 School activity: 0.93 Bodily pain: 0.88 Social functioning: 0.90 Total: 0.91 | 1 or 2 weeks | Pearson r=0.71 with SRS-22 | Able to discriminate patients according to curve magnitude | Not provided | No floor effects | No ceiling effects | Not provided |
Table 4. Results of Validity and Reliability of the SAQ in Different Studies.

| References                        | No. of patients | Age (years) | Intervention | Internal consistency | Test-retest reliability | Test time intervals | Convergent validity | Discriminate validity | Responsiveness | Floor effect (%) | Ceiling effect (%) | Missing answer |
|-----------------------------------|-----------------|-------------|--------------|----------------------|-------------------------|---------------------|---------------------|----------------------|----------------|------------------|-------------------|----------------|
| Roy–Beaudry et al. (French–Canadian version) | 182             | Not provided | Brace surgery | General: 0.33–0.660 | Not provided            | Not provided        | Pearson r=0.35–0.53 with SRS-22 | Not provided | Not provided | 15.4% for chest domain | 34.6% for mental health | Not provided |
| Guo et al. (traditional Chinese version) | 112             | 13          | Brace surgery | General: 0.66 | 2 weeks | Pearson r=0.15–0.44 with SRS-22 | TC-SAQ total score was significantly positively correlated to major curve magnitude. | Not provided | Not provided | 0.0% | 0.0% | Not provided |
| Carreon et al. (Original English version) | 1802            | 14.8        | Brace surgery | Appearance: 0.89 | 2 weeks | 0.16–0.50 | It discriminates between patients who require surgery from those who do not. | Not provided | Not provided | 14.2 for curve and 15.2 for kyphosis | 10.7 for curve and 17.9 for waist and 18.8 for chest | Not provided |
| Lee et al. (Korean version)        | 160             | 12.3        | Brace surgery | General: 0.892 | 2 weeks | Pearson r=0.35–0.53 with SRS-22 | It discriminates among patients requiring observation, bracing, or surgery. | Not provided | Not provided | 0.0% | 0.0% | Not provided |
| Sanders et al. (Original English version) | 127             | Not provided | Brace surgery | General: 0.892 | 1–47 days | Not provided | Not provided | The SAQ demonstrates excellent responsiveness to surgical curve correction and excellent responsiveness to surgical correction. | Not provided | Not provided | 0.0% | 0.0% | Not provided |
| References                          | No. of patients | Age (years) | Interven- | Internal consistency | Test–retest reliability | Test time intervals | Convergent validity | Discriminate validity | Responsiveness | Floor effect (%) | Ceiling effect (%) | Missing answer (%) |
|------------------------------------|----------------|-------------|------------|----------------------|--------------------------|---------------------|---------------------|----------------------|-----------------|--------------------|---------------------|---------------------|
| Simony et al. (Danish version)     | 51             | 16          | Brace      | Appearance: 0.93     | Appearance: 086          | 2 weeks             | Pearson r=−0.24 to −0.60 with SRS-22 | It can discriminate between the patients who require surgery from those who do not have surgery and significantly correlated with curve magnitude. | Not provided | 7.84% for Expectations | 17.65% for Expectations | Not provided |
| Yapar et al. (Turkish version)     | 75             | 15.5        | Brace      | Appearance: 0.94     | Appearance: 0.97         | 14–28 days          | Spearman rho 0.92–0.94 with SRS-22 | There were strong positive correlations between the patient’s major curve magnitude and appearance score and total score in Tr-SAQ. | Not provided | 0.0%               | 37.3% for Expectations | Not provided |
| de Albuquerque Rosendo et al. (Brazilian Portuguese) | 20 | 14.8 | Surgery | 0.79 for patients and 0.75 for their relatives | Not provided | Not provided | Not provided | Not provided | Not provided | Not provided | Not provided | Not provided |
| Wei et al. (Simplified Chinese)    | 223            | 14.58       | Brace      | General: 0.55–0.75   | 0.90–0.95                | 4–7 days            | Pearson r=−0.35 to −0.53 with SRS-22 | Able to discriminate cases regarding curve magnitude and pattern plus treatment. | Not provided | 15.3% for curve and 16.7% for kyphosis | 19.5% for waist and 20.5% for chest | Not provided |
The early onset scoliosis questionnaire-24 (EOSQ-24)

General description

This questionnaire is a parent-reported tool designed by Matsumoto et al.\(^{10}\) to assess HRQoL of patients aged 0-18 years with EOS. The EOSQ-24 comprises 24 items distributed across four domains and 11 subdomains. The HRQoL domain collects data regarding general health (two items), pain/discomfort (two items), pulmonary function (two items), ease of transfer (one item), physical function (three items), daily living (two items), fatigue/energy level (two items), and emotion (two items) of patients with EOS. Parental burden (five items) and financial burden (one item) are additional domains that evaluate the strain placed on parents of their child’s condition, and the satisfaction (two items) domain evaluates the satisfaction level of the EOS patient and their parents.

Calculation

The scores given to each of the items vary from 1 to 5, with a score of 1 indicating the worst situation possible and a score of 5 indicating the best. To obtain an average score in each domain, the score of each question is summed, and after subtracting one from the tabulated number, the result is then divided by 4. Finally, the number is multiplied by 100. Hence, the score range of general health, pain, pulmonary function, daily living, fatigue, and emotion domains varies from 2 to 10. The score range for the domains of mobility, physical performance, parental burden, and financial burden varies from 1 to 5, 3 to 15, 5 to 25, and 1 to 5, respectively. The total score of the EOSQ-24 varies from 24 to 120\(^{10}\).

Psychometric characteristics of this questionnaire have been evaluated in Spanish\(^{67}\), Turkish\(^{68}\), traditional Chinese\(^{69}\), Norwegian\(^{70}\), German\(^{71}\), Arabic\(^{72}\), Dutch\(^{73}\), Brazilian Portuguese\(^{74}\), and Persian\(^{75}\) (Table 5).

The bad sobernheim stress questionnaire (BSSQ)

General description

The BSSQ is a specific unidimensional questionnaire used to examine the stress levels of adolescents with idiopathic scoliosis. This tool is available in two versions: BSSQ-Brace (mit corset) and BSSQ-Deformity, designed by Weiss et al.\(^{10}\) in Germany. Each version of this questionnaire has eight items.

Calculation

The answer to each item in this questionnaire is gauged on a four-point Likert scale format. Each item comprises four options, including completely true (score 0), nearly true (score 1), hardly true (score 2), and not true at all (score 3). Based on the scores from this questionnaire, each patient is categorized into one of the following groups: high-stress level (with a score from 0 to 8), moderate stress level (from 9 to 16), and minimum stress level (from 17 to 24)\(^{10}\). The validity and reliability of the Polish\(^{76}\), Italian\(^{77}\), Spanish\(^{78}\), Turkish\(^{79}\), Persian\(^{80}\), Japanese\(^{81}\), and Chinese\(^{82}\) versions of BSSQ have been examined (Table 6).

The body image disturbance questionnaire-scoliosis (BIDQ-S)

General description

The BIDQ-S\(^{12}\) is a self-administered, seven-item questionnaire that evaluates an AIS patient’s concerns regarding body image. This measure is aimed at evaluating whether the scoliosis patient’s back shape causes a feeling of unattractiveness or induces uncomfortability at social activities such as while at school or work or with friends and family. The form then looks to assess whether or not these feelings ultimately lead to a decrease in interest in participating in specific activities.

Calculation

The scoring system of this questionnaire is based on a five-point Likert scale from 1 to 5, with a score of 1 indicating “not at all concerned” and a number 5 indicating “extremely concerned.” Thus, the total score varies from 7 to 35. A higher score indicates more severe body image disturbance\(^{12}\).

The validity and reliability of this questionnaire were evaluated by Auerbach et al.\(^{12}\) for adolescents with AIS. The Korean\(^{49}\), simplified Chinese\(^{50}\), Turkish\(^{56}\), and German\(^{77}\) versions of this questionnaire are also available (Table 7).

The ISYQOL

General description

The ISYQOL questionnaire\(^{10}\) was designed using the Rasch analysis to assess the QoL of adolescents with AIS and SK between ages 10 to 18 years. The ISYQOL is a specific self-reported tool comprising 20 items. These items are distributed across two domains: “spinal health” and “brace status.” Items 1-13 are related to the spinal health domain, and items 14-20 are regarding the patient’s condition while using the brace. Thus, if the patient is being treated with a brace, they optimally need to complete the full questionnaire items. Conversely, a patient who is not currently utilizing a brace should only complete the spine health domain or items 1-13. The ISYQOL can then be used to compare the conditions of patients who wear a brace with those who do not.

Calculation

The answers to each item of the ISYQOL are based on a three-point Likert scale (0-2) in three options (never, sometimes, and often). Therefore, the total range of numerical scores will be from 0 to 40 (for the full version including the portion on brace condition) or 0 to 26 (for the spinal health domain only). The number 0 is considered to be the highest possible QoL, whereas the number 40 denotes the
Table 5. Results of Validity and Reliability of the EOSQ-24 in Different Studies.

| References                          | No. of patients | Age (years) | Intervention | Internal consistency | Test–retest reliability | Test time intervals | Convergent validity | Discriminate validity | Responsiveness | Floor effect (%) | Ceiling effect (%) | Missing answer (%) |
|-------------------------------------|-----------------|-------------|--------------|----------------------|-------------------------|---------------------|---------------------|----------------------|----------------|----------------|-------------------|-----------------|
| Matsumoto et al. (Original English version) | 90              | 6.4         | Surgery      | General Health, Pain/Discomfort, Pulmonary Function, Transfer, Physical Function, Daily Living Fatigue/Energy Level, and Emotion=0.92; Satisfaction=0.87; Family Burden=0.64 | General Health (0.84), Pain/Discomfort (0.85), Pulmonary Function (0.90), Transfer (0.84), Physical Function (0.97), Daily Living (0.98), Fatigue/Energy Level (0.92), Financial Burden (0.94), Child Satisfaction (0.93), and Parent Satisfaction (0.89), Emotion (0.68) and Parental Burden (0.80) | 7–29 days | The EOSQ-24 domain scores of General Health, Pain/Discomfort, Pulmonary Function, Daily Living, Fatigue/Energy Level, and Emotion were positively correlated with % predicted values of forced expiratory volume in 1 second and forced vital capacity. | The EOSQ-24 scores could discriminate patients with different etiology. | Not provided | Not provided | Not provided |
| del Mar Pozo-Balado et al. (Spanish version) | 44              | <10         | Observation Bracing Casting Surgery | General health: 0.82 Pain: 0.81 Pulmonary: 0.82 Function Mobility: 0.82 Physical function: 0.80 Daily living: 0.81 Fatigue: 0.81 Emotion: 0.81 Parental burden: 0.80 Financial burden: 0.83 Satisfaction: 0.82 | Not provided | Not provided | It can discriminate between EOS patients regarding Cobb angle, diagnosis, and ambulatory status. | Not provided | The floor effect ranged from 22.7% for item 11 to 29.5% for item 12. The ceiling effect ranged from 19.7% for item 21 to 74.4% for item 5. | 0%–6.8% |
| Molland et al. (Norwegian version) | 100             | 8.9         | Surgery graduated Bracing Observation Growing instrumentation | General health: 0.78 Pain: 0.88 Pulmonary: 0.65 Function Physical function: 0.87 Daily living: 0.70 Fatigue: 0.79 Emotion: 0.79 Parental burden: 0.86 Satisfaction: 0.88 | General health: 0.84 Pain: 0.88 Pulmonary: 0.86 Function Mobility: 0.76 Physical function: 0.90 Daily living: 0.93 Fatigue: 0.82 Emotion: 0.84 Parental burden: 0.88 Financial burden: 0.82 Satisfaction: 0.86 | 2 weeks | High correlations were found between the EOSQ-24 total score and NRS general health (r=0.66), NRS pain (r=0.63), and NRS physical function (r=0.78) (P<0.001). The subdomain scores of general health, pain, and physical function were strongly correlated with their corresponding NRS scores (r=0.78, r=0.78, r=0.70, P<0.001). | It has discriminate capabilities among patients with different etiology, treatment status, and severity of deformity. | Not provided | The floor effect ranged from 17% for item 9 to 26% for item 12. The ceiling effect ranged from 19% for item 9 to 63% for item 5. | 0%–3% |
| References                          | No. of patients | Age (years) | Intervention            | Internal consistency | Test–retest reliability | Test time intervals | Convergent validity | Discriminate validity | Responsiveness | Floor effect (%) | Ceiling effect (%) | Missing answer (%) | Floor effect (%) | Ceiling effect (%) | Missing answer (%) |
|------------------------------------|-----------------|-------------|-------------------------|----------------------|-------------------------|----------------------|---------------------|-----------------------|-----------------|-----------------|-------------------|--------------------|-----------------|-------------------|--------------------|
| Demirkiran et al. (Turkish version) | 61              | 9.1         | Surgery                 | General Health: 0.42 | Not provided            | Not provided         | Pearson r=0.051–0.523| Not provided          | Not provided      | The floor effect | ranged from 16.4% | for items 19 and 22 to 21.7% for item 10. | The ceiling effect | ranged from 18.6% | for item 2 to 68.3% | for item 6. |
|                                    |                 |             |                         | Pain: 0.90           |                         |                      |                     |                       |                 | Parental burden: | 1.6               | Fatigue: 1.6       |                   |                 |                   | 1%                 |
|                                    |                 |             |                         | Pulmonary: 0.61      |                         |                      |                     |                       |                 | Financial burden:| 0.91              | Satisfaction: 0.80 |                   |                 |                   |                    |
|                                    |                 |             |                         | Function             |                         |                      |                     |                       |                 |                 |                   |                    |                 |                   |                    |
|                                    |                 |             |                         | Mobility: 0.90       |                         |                      |                     |                       |                 |                 |                   |                    |                 |                   |                    |
|                                    |                 |             |                         | Physical function: 0.81 |                      |                      |                     |                       |                 |                 |                   |                    |                 |                   |                    |
|                                    |                 |             |                         | Daily living: 0.68   |                         |                      |                     |                       |                 |                 |                   |                    |                 |                   |                    |
|                                    |                 |             |                         | Fatigue: 0.80        |                         |                      |                     |                       |                 |                 |                   |                    |                 |                   |                    |
|                                    |                 |             |                         | Emotion: 0.67        |                         |                      |                     |                       |                 |                 |                   |                    |                 |                   |                    |
|                                    |                 |             |                         | Parental burden: 0.77 |                      |                      |                     |                       |                 |                 |                   |                    |                 |                   |                    |
|                                    |                 |             |                         | Financial burden: 0.91 |                     |                      |                     |                       |                 |                 |                   |                    |                 |                   |                    |
|                                    |                 |             |                         | Satisfaction: 0.80   |                         |                      |                     |                       |                 |                 |                   |                    |                 |                   |                    |
| Wijdicks et al. (Dutch version)    | 103             | 9.1         | Brace Mehta casting     | General health: 0.59 | General health: 0.89   | 4 months             | Pearson r=−0.35 to −0.76 with SRS-22 | able to discriminate between scoliosis type, curve severity, and ambulatory status | Not provided | The floor effect | ranged from 17.5% for item 11 to 28.2% for item 12. | The ceiling effect | ranged from 16.5% for item 1 to 72.8% for item 5. | 1%               |
|                                    |                 |             | Observation             | Pain: 0.87           | Pain: 0.89             |                      |                     |                       |                 | Parental burden:| 1.6               | Fatigue: 1.6       |                   |                 |                   |                    |
|                                    |                 |             |                         | Pulmonary: 0.52      | Pulmonary: 0.89        |                      |                     |                       |                 | Financial burden:| 0.87              | Satisfaction: 0.91 |                   |                 |                   |                    |
|                                    |                 |             |                         | Function             | Function: 0.83         |                      |                     |                       |                 |                 |                   |                    |                 |                   |                    |
|                                    |                 |             |                         | Mobility: 0.83       | Mobility: 0.91         |                      |                     |                       |                 |                 |                   |                    |                 |                   |                    |
|                                    |                 |             |                         | Physical function: 0.83 | Physical function: 0.91 |                      |                     |                       |                 |                 |                   |                    |                 |                   |                    |
|                                    |                 |             |                         | Daily living: 0.71   | Daily living: 0.92     |                      |                     |                       |                 |                 |                   |                    |                 |                   |                    |
|                                    |                 |             |                         | Fatigue: 0.85        | Fatigue: 0.89          |                      |                     |                       |                 |                 |                   |                    |                 |                   |                    |
|                                    |                 |             |                         | Emotion: 0.80        | Emotion: 0.85          |                      |                     |                       |                 |                 |                   |                    |                 |                   |                    |
|                                    |                 |             |                         | Parental burden: 0.89 | Parental burden: 0.93 |                      |                     |                       |                 |                 |                   |                    |                 |                   |                    |
|                                    |                 |             |                         | Financial burden: 0.83 | Financial burden: 0.93 |                      |                     |                       |                 |                 |                   |                    |                 |                   |                    |
|                                    |                 |             |                         | Satisfaction: 0.95   | Satisfaction: 0.91     |                      |                     |                       |                 |                 |                   |                    |                 |                   |                    |
| References                                      | No. of patients | Age (years) | Intervention | Internal consistency | Test–retest reliability | Test time intervals | Convergent validity | Discriminate validity | Responsiveness | Floor effect (%) | Ceiling effect (%) | Missing answer (%) |
|------------------------------------------------|----------------|-------------|--------------|----------------------|-------------------------|---------------------|---------------------|----------------------|----------------|------------------|-------------------|--------------------|
| Cheung et al. (Traditional Chinese)            | 100            | 12.1        | Observation only | General health: 0.91  | Not provided            | Not provided         | Not provided        | The total score of EOSQ-24 had significant correlations ($P<0.001$) with all domains of CHQ-PF50. | Not provided | Item 8: 16%     | Item 9: 18%        | 0%                 |
|                                             |                |             | Under bracing  | Pain: 0.89            |                         |                     |                     |                      |                 |                  |                   |                    |
|                                             |                |             | Completed bracing | Pulmonary: 0.58       |                         |                     |                     |                      |                 |                  |                   |                    |
|                                             |                |             | Postoperative  | Function: 0.93        |                         |                     |                     |                      |                 |                  |                   |                    |
|                                             |                |             | Planned operation | Physical function: 0.93 |                     |                     |                     |                      |                 |                  |                   |                    |
|                                             |                |             | Growing rod undergoing distractions | Fatigue: 0.80 | Not provided |                     |                     |                      |                 |                  |                   |                    |
|                                             |                |             |                | Emotion: 0.87         |                         |                     |                     |                      |                 |                  |                   |                    |
|                                             |                |             |                | Parental burden: 0.87 | Not provided |                     |                     |                      |                 |                  |                   |                    |
|                                             |                |             |                | Satisfaction: 0.82    | Not provided |                     |                     |                      |                 |                  |                   |                    |
| De Mendonc et al. (Brazilian Portuguese)      | 76             | 11.88       | Not provided   | General health: 0.81  | Not provided            | Not provided         | Not provided        | Items correlation presented good discriminatory validity for all domains. | Not provided | Item 9: 28.9%  | Item 10: 43.4%    | 0%                 |
|                                             |                |             |                | Pain: 0.86            |                         |                     |                     |                      |                 |                  |                   |                    |
|                                             |                |             |                | Pulmonary: 0.47       |                         |                     |                     |                      |                 |                  |                   |                    |
|                                             |                |             |                | Function: 0.76        |                         |                     |                     |                      |                 |                  |                   |                    |
|                                             |                |             |                | Physical function: 0.76 |                     |                     |                     |                      |                 |                  |                   |                    |
|                                             |                |             |                | Daily living: 0.56    | Not provided            |                     |                     |                      |                 |                  |                   |                    |
|                                             |                |             |                | Fatigue: 0.68         |                         |                     |                     |                      |                 |                  |                   |                    |
|                                             |                |             |                | Emotion: 0.69         |                         |                     |                     |                      |                 |                  |                   |                    |
|                                             |                |             |                | Parental burden: 0.80 | Not provided            |                     |                     |                      |                 |                  |                   |                    |
|                                             |                |             |                | Satisfaction: 0.93    | Not provided            |                     |                     |                      |                 |                  |                   |                    |
### Table 5. continued.

| References | No. of patients | Age (years) | Intervention | Internal consistency | Test–retest reliability | Test time intervals | Convergent validity | Discriminate validity | Responsiveness | Floor effect (%) | Ceiling effect (%) | Missing answer (%) |
|------------|-----------------|-------------|--------------|----------------------|-------------------------|---------------------|----------------------|----------------------|----------------|----------------|--------------------|--------------------|
| Hanbali et al. (Arabic version) | 58 | <10 | Surgery | General health: 91  
Pain: 0.90  
Pulmonary: 0.90  
Function transfer: 0.91  
Physical function: 0.90  
Daily living: 0.91  
Fatigue: 0.90  
Emotion: 0.91  
Parental impact: 0.91  
Financial impact: 0.91  
Satisfaction: 0.91 | Not provided | Not provided | Not provided | Able to discriminate patients according to severity of curves, complications after surgery, and ambulatory status. | Not provided | Item 17: 36.2%  
Item 22: 20.7% | 0.0% for item 21 and 46.6% for item 5. | 1.7% |
| Esfandiari et al. (Persian version) | 100 | 6.30 | Brace | General health: 0.69  
Pain: 0.85  
Pulmonary function: 0.85  
Physical function: 0.85  
Daily living: 0.49  
Fatigue: 0.75  
Emotion: 0.87  
Parental impact: 0.84  
Satisfaction: 0.67 | Not provided | Not provided | Pearson r=0.44–0.67 with SRS-22 | Able to discriminate cases regarding curve magnitude | Not provided | No significant floor effect was observed. | The ceiling effect ranged from 8% for item 23 to 52% for item 2. | <1% |

EOSQ-24=Early-Onset Scoliosis 24-item Questionnaire, NRS=numeric rating scale
Table 6. Results of Validity and Reliability of the BSSQ in Different Studies.

| References                                      | No. of patients | Age (years) | Intervention | Internal consistency | Test–retest reliability | Test time intervals | Convergent validity | Discriminate validity | Responsiveness | Floor effect (%) | Ceiling effect (%) | Missing answer (%) |
|------------------------------------------------|-----------------|-------------|--------------|----------------------|--------------------------|---------------------|----------------------|-----------------------|-----------------|-------------------|--------------------|---------------------|
| Botens-Helmus et al. (BSSQ-brace, original German version) | 62              | 14.5        | Brace        | 0.97                 | 0.88                     | 1–3 days            | Not provided         | Not provided          | Not provided   | 2.3%              | 27%                | Not provided        |
| D'Agata et al. (Spanish version)                  | 35              | 13          | Brace        | 0.80                 | 0.90                     | 4–7 days            | Pearson r=0.65 with SRS-22 | Not provided          | Not provided   | 0%                | 0%                 | Not provided        |
| Misterska et al. (Polish version)                 | 35              | 14.8        | Brace        | BSSQ-Deformity: 0.87; BSSQ-Brace: 0.80 | BSSQ-Deformity: 0.95; BSSQ-Brace: 0.88 | 2 days | Not provided | Significant correlation was identified between BSSQ-Brace and the angle of rotation (r=0.395). | Not provided | 2.9%              | 17.1%              | Not provided        |
| Asada et al. (Japanese version)                   | 71              | 14          | Brace        | 0.84-0.87            | 0.75                     | 7 days              | Not provided         | Not provided          | Not provided   | 0%                | 6.8%–13.6%         | Not provided        |
| Xu et al. (Chinese version)                       | 50              | 13          | Brace        | BSSQ-Brace: 0.90; BSSQ-Deformity: 0.85 | BSSQ-Brace: 0.88; BSSQ-Deformity: 0.97 | 3–7 days            | Pearson r=0.29–0.79 | Not provided          | Not provided   | <5%               | <5%                | Not provided        |
| Rezaei Motlagh et al. (Persian version)           | 53              | 13.47       | Brace        | BSSQ-Brace: 0.72; BSSQ-Deformity: 0.72 | BSSQ-Brace: 0.88; BSSQ-Deformity: 0.97 | 2 weeks            | Spearman r=0.34–0.63 with SRS-22 | Not provided          | Not provided   | Not provided      | Not provided        | Not provided        |
| Aulisa et al. (Italian version)                   | 108             | 15.4        | Brace        | 0.91                 | Pearson r=0.92          | 5–7 days            | Pearson r=0.39 with SRS-22 | Not provided          | Not provided   | Not provided      | Not provided        | Not provided        |
Table 7. Results of Validity and Reliability of the BIDQ, the SRS-7, the ISYQOL, and the TAPS in Different Studies.

| Questionnaire | References | No. of patients | Age (years) | Intervention | Internal consistency | Test–retest reliability | Test time intervals | Convergent validity | Discriminate validity | Responsiveness | Floor effect (%) | Ceiling effect (%) | Missing answer (%) |
|---------------|------------|-----------------|-------------|--------------|----------------------|------------------------|----------------------|---------------------|----------------------|----------------|-----------------|-----------------|------------------|
| The BIDQ      | Auerbach et al. (Original English version) | 98              | 15.7        | Surgery      | 0.82                 | Not provided           | Not provided         | Pearson r=−0.50 to −0.72 with SRS-22 | BIDQ-S scores differed significantly between patients and controls, establishing discriminant validity. | Not provided | Not provided | Not provided | Not provided |
|               | Wetterkamp et al. (German version)     | 259             | 30.2        | Brace Surgery | 0.87                 | 0.79                   | 8 weeks              | Pearson r=−0.30 to −0.72 with SRS-22 | The German-BIDQ showed discriminant validity, with a strong difference between the scoliosis group and the control group. | Not provided | Not provided | Not provided | Not provided |
|               | Bae et al. (Korean version)             | 152             | 12.5        | Brace Surgery |                      |                        | 2 weeks              | Pearson r=0.617 with Spinal Appearance Questionnaire | Discriminant validity was confirmed by significant differences in K-BIDQ scores among patients requiring observation, bracing, or surgery. | Not provided | 0%             | 0%             | Not provided |
|               | Bao et al. (Simplified Chinese version) | 100             | 10.5        | Brace Surgery |                      |                        |                     | Pearson r=−0.32 to −0.65 with SRS-22 | Discriminant validity was confirmed by significant differences in BIDQ scores among patients with different Cobb angles. | Not provided | Not provided | Not provided | Not provided |
|               | Kuzu et al. (Turkish version)           | 83              | 14–69       | Observation   | 0.88                 | Not provided           | Not provided         | Pearson r=0.69 with total score of the SRS-22 | Not provided | Not provided | Not provided | Not provided |
|               | The SRS-7     | 685             | 14.7        | Surgery      | 0.64 for preoperative patients and 0.67 for postoperative patients | Not provided           | Not provided         | Pearson r=0.17 with SRS-22 (r=0.78; P<0.001) | There was a strong correlation between preoperative SRS-7 and SRS-22 scores (r=0.78; P<0.001) and between postoperative SRS-7 and SRS-22 scores (r=0.78; P<0.001) | Not provided | Not provided | Not provided | Not provided |
|               | Jain et al.  | 685             | 14.7        | Surgery      |                      |                        |                     | Pearson r=0.78 with SRS-22 (P<0.001) | Discriminant validity was confirmed by significant differences in SRS-7 scores among patients with different Cobb angles. | Not provided | Not provided | Not provided | Not provided |
|               |                                                |                 |             |                                           |                        |                     |                     | The SRS-7 was very effective in terms of detecting a change in HRQOL measures with surgical treatment in children with AIS. | Not provided | Not provided | Not provided | Not provided |
| Questionnaire                          | References                                      | No. of patients | Age (years) | Intervention | Internal consistency | Test–retest reliability | Test time intervals | Convergent validity | Discriminate validity | Responsiveness | Floor effect (%) | Ceiling effect (%) | Missing answer (%) |
|---------------------------------------|------------------------------------------------|-----------------|-------------|--------------|----------------------|------------------------|---------------------|---------------------|----------------------|----------------|------------------|--------------------|------------------|
| The ISYQOL (Original Italian version) | Caroni et al.                                   | 1000            | 16          | Observation Brace | Not provided         | Not provided           | Not provided       | Satisfactory correlations were found between ISYQOL and SRS22 (scoliosis, rho=0.71; kyphosis, rho=0.56). | The ISYQOL can discriminate across groups of patients regarding diagnosis, sex, age, curve magnitude, and treatment types. | Not provided | Not provided | Not provided | Not provided |
| Kinel et al. (Polish version)         |                                                   | 58              | 13.8        | Brace         | Spine health: 0.79  | 0.90                  | 7 days              | Not provided       | Not provided       | Not provided | 0%               | 0.0%–1.7%          | Not provided      |
| Liu et al. (simplified Chinese)       |                                                   | 138             | 13.7        | Observation Brace | Spine health: 0.85  | 0.72–0.80             | 14 days            | Spearman rho=0.62 with SRS-22 | Not provided | Not provided | 0%               | 0%               | 0.6              |
| Scoliosis Japanese Questionnaire-27  | Doi et al. (Original Japanese version)           | 384             | 143         | Brace         | Observation Surgery | 0.91                  | Not provided       | Not provided       | Spearman rho=0.69 with SRS-22 | Not provided | 0.5%             | 0%               | 0.1%             |
| Bazancir et al. (Turkish version)     |                                                   | 139             |             | Surgery       | 0.99               | 0.99                  |                   | Pearson r=0.61 with SRS-22 | Not provided | 1.6%             | 3.8%              | 0%               |
| Trunk Appearance Perception Scale (TAPS) | Bago et al. (Original version)                     | 186             | 17.8        | Observation Brace | 0.89               | 0.92                  | 7 days             | Spearman rho=0.47–0.52 | The TAPS can discriminate across groups of patients regarding curve type and curve magnitude. | The TAPS instrument shows adequate responsiveness to surgical treatment of idiopathic scoliosis. | Not provided | 0.0%             | 2.7%              | Not provided |
| Misterska et al. (Polish version)     |                                                   | 36              | 13.4        | Brace         | 0.50–0.84           | Not provided         | Not provided       | Spearman rho=−0.44 with Cobb angle | Not provided | 1.6%             | 3.8%              | 0%               |
lowest level of QoL. The validity and reliability of the Polish and simplified Chinese versions of ISYQOL have been evaluated (Table 7).

The scoliosis Japanese questionnaire-27 (SJ-27)

General description

The SJ-27 is a self-reported, scoliosis-specific questionnaire that was developed by Doi et al. This questionnaire is aimed at the evaluation of HRQoL variables in female patients aged 10-18 years with AIS. This gender-specific form is composed of 27 items across five domains. In items 1-4, the patient is asked about their upper/lower back pain while lying down, following sitting or standing movement, or regarding neck/shoulder stiffness or soreness. In items 5-10 and 27, the questions are about patient discomfort while wearing clothes or lifting/holding bags. In items 11, 15, 16, and 19, the patients are then asked about any difficulties that they may have when participating in exercise, sport, and standing in front of a group of people. Items 12-14, 22, 25, and 26 are related to appearance-related self-consciousness during public situations. There are six items (items 17, 18, 20, 21, 23, and 24) regarding feelings of anxiety or depression resulting from the patient’s spinal deformity.

Calculation

The 27 items of the SJ-27 are scored on a five-point Likert scale from 0 (best condition) to 4 (worst condition). Thus, the total score ranges from 0 to 108. The original Japanese version of the SJ-27 has an acceptable internal consistency and discriminant validity. The Turkish version of this questionnaire is also available (Table 7).

The trunk appearance perception scale (TAPS)

General description

The TAPS is a specific self-administered drawing-based tool aimed at the evaluation of a scoliosis patient’s perception of their trunk deformity. The TAPS was introduced by Bagó et al. and comprises three sets of drawings that show the patient’s trunk from three viewpoints: (1) looking toward the back (SET 1), (2) looking toward the head when the patient is in an Adams forward bending test (SET 2), and (3) looking toward the front (SET 3). The front viewpoint comprises two sets of figures, that is, one for males and one for females. The instruction section of the TAPS contains a brief description: “which of these drawings do you think best represents the appearance of your body?”

Calculation

Each set of drawings is scored from 1 (maximum deformity) to 5 (minimum deformity). The average total score can be calculated by summing the scores of three drawings and dividing them by 3. Thus, the maximum score will be 5, and the minimum score will be 1. This questionnaire has acceptable reliability and validity for scoliosis patients aged from 10 to 42 years (Table 7).

Discussion

The increasing number of questionnaires designed to measure HRQoL in children and adolescents with spinal deformity substantiates the importance of this issue in this cohort. Previous studies have shown that attention to HRQoL is as crucial as radiological variables and pulmonary conditions in the management of AIS or SK, many of whom fall within the most vulnerable periods of life regarding peer perceptions. Considering the preponderance of testing for HRQoL in this cohort, it follows that practitioners looking to implement these tools should have sufficient knowledge and awareness of the existing questionnaires to optimize selection for specific patient applications. To address this concern, the present study was conducted to investigate all the disease-specific questionnaires evaluating HRQoL of children and adolescents with spinal deformity.

The results of this review of the literature mandate the importance of selecting appropriate tools for assessing the outcomes of patients with spinal deformities on the basis of specific deformity patterns and planned therapeutic intervention. There does not appear to be a “one size fits all” approach, but rather, practitioners should aim to carefully choose a test on the basis of the specific question they are looking to answer or research.

Our analysis of the available testing options as they relate to the specific type of deformity showed that there is only one existing questionnaire to assess the HRQoL of EOS patients. Although the SRS-22 has also been used to assess the HRQoL of patients with congenital scoliosis, this questionnaire has several limitations and poorly reflects other important aspects of a patient’s life. In EOS, factors such as pulmonary function, fatigue, and parental burden are arguably more essential factors to evaluate than for other types of adolescent or adult scoliosis. Thus, the SRS-22 questionnaire, which does not address any of these specific areas, may not be a suitable tool for measuring HRQoL in patients with EOS. Additionally, most patients with EOS are under the age of 10 years and therefore may not have the independence and understanding to self-report their condition. Hence, in these circumstances, questionnaires such as EOSQ-24, which is parentally reported, are preferable to the SRS-22.

There are five disease-specific questionnaires for evaluating HRQoL of adolescents with spinal deformities, most of which are designed based on the classical test theory framework and are multidimensional. These questionnaires are used for all patients, regardless of whether they are treated with bracing, surgery, or medical observation. It can be easily surmised, however, that the health and wellness condition of a patient treated with a brace can vary substantially from the condition of the patient treated with an extensive posterior fusion construct or even the patient under exclusively medical observation. Hence, two patients...
who have the same total score on a multidimensional questionnaire may wildly differ regarding their current well-being and functional/emotional status.

Another important factor that practitioners must carefully consider regarding HRQoL tools for spinal deformity is the presence of pain-related items in a multidimensional tool, such as SRS-22. Although pain can certainly arise in late-stage deformity in certain patients, pain is typically not the chief concern for the adolescent or child with spinal deformity (in sharp contrast to adult forms of spinal pathology). For this reason, the pain domain of the SRS-22 has a ceiling effect in the original and most translated versions. Recently, researchers have developed unidimensional or two-dimensional questionnaires such as SRS-7 and ISYQOL using the Rasch-consistent analysis. In reviewing the literature, we found that the trend of designing unidimensional questionnaires is also observed in other areas of HRQoL of patients with spinal deformities such as stress-related deformity and body image.

Practitioners and researchers evaluating HRQoL of AIS and SK patients must also carefully consider the emotional ramifications that may result from an abnormal appearance of the patient’s spine. Regardless of functional status, cosmetic disfigurement is a primary concern of adolescents with spinal deformities and their parents and is often cited as the chief reason they elect to seek medical intervention. With spinal deformities and their parents and is often cited as the chief concern for the adolescent or child with spinal deformity (in sharp contrast to adult forms of spinal pathology). For this reason, the pain domain of the SRS-22 has a ceiling effect in the original and most translated versions. Recently, researchers have developed unidimensional or two-dimensional questionnaires such as SRS-7 and ISYQOL using the Rasch-consistent analysis. In reviewing the literature, we found that the trend of designing unidimensional questionnaires is also observed in other areas of HRQoL of patients with spinal deformities such as stress-related deformity and body image.

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Scholars have debated the impact of bracing or surgical intervention on the HRQoL of patients with AIS and SK. Some researchers found that these interventions may have negative consequences on HRQoL parameters in patients with AIS and SK. Nevertheless, other work has indicated that bracing or surgery has no significant impact on HRQoL in these cohorts. This inconsistency may be due to the use of differing questionnaires across investigations. According to the presented literature review, clinicians and researchers should consider the following suggestions before selecting a questionnaire to use in evaluating HRQoL of children and adolescents with AIS and SK:

1. For children with EOS, the ideal questionnaire to evaluate their HRQoL parameters is the EOSQ-24.
2. To evaluate HRQoL of adolescents with AIS and SK who are potential candidates for surgical intervention, the use of SRS-22, SJ-27, and QLPSD is appropriate.
3. Considering the high ceiling effects of the pain and satisfaction domains of SRS-22, it may be optimal to use this questionnaire to evaluate function/activity, self-image, and mental health of patients with AIS and SK.
4. To evaluate the HRQoL of those patients who are under nonsurgical treatment, the BrQ and ISYQOL questionnaires can be used. However, the BrQ is specifically designed for AIS patients who are currently undergoing brace treatment, and the ISYQOL is designed for AIS and SK patients who are currently undergoing either medical observation or brace treatment.
5. When the specific intent of a study is to evaluate the self-image perception of patients with AIS and SK, the use of drawing-based questionnaires such as SAQ and TAPS may be the optimal choice.

Conclusion

The present study demonstrates that when choosing an
HRQoL assessment tool for the patient with AIS or SK, the type of questionnaire must be consistent with the therapist or researcher’s goal and should be tailored as best as possible to the specific patient situation. Specific domains of the questionnaires should be considered in choosing the appropriate metric as well as other integral factors such as sensitivity to change, desired outcome, and careful consideration of the type of treatment planned and the patient’s age.

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