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RESEARCH

SCaRES – scoliosis caregiver response and emotional scale: a Rasch-validated questionnaire to measure the psychological impact of children's scoliosis on their parents

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Abstract

Purpose Having a child diagnosed with Idiopathic Scoliosis (IS) can be stressful for parents who report higher rates of mood disturbances, anxiety, and diminished quality of life (QoL). Currently, there are no questionnaires to assess the QoL of this population. This study aimed to develop a Rasch-validated questionnaire to measure the impact of their children's pathology and treatment on the QoL of parents of IS patients.

Methods We designed a cross-sectional psychometric study; we used a conventional approach for content analysis on an online blog addressed to patients and families with scoliosis to identify parents' self-reported problems affecting their QoL. Progressively refined versions of the questionnaire were administered to parents caring for a child with IS. Rasch analysis was performed.

Results The final version of the questionnaire consisted of 18 items rated on a 4-point Likert scale. The variance explained was 14.39 eigenvalue (44.4%). The variance in 1st contrast was 2.56 eigenvalue (7.9%). All the 18 items fit the Rasch model. The questionnaire targeting was satisfactory. The Person's ability spanned 6.99 logits from −5.17 to 1.82 with an ability mean measure of -1.41 logits (SD = 1.14 logits). Item difficulty spanned 2.07 logits from −1.17 to 0.90. Reliability was 0.83, allowing for the distinction of the 3.32 strata participant's mean. No DIF was noted for parents' age, sex, or the child's age and sex.

Conclusion The questionnaire reliably measures the QoL of parents of children with IS. These findings support its validity and possible implementation in clinical settings.

Keywords Caregiver burden · Adolescent idiopathic scoliosis · Quality of life

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Introduction

Having a child diagnosed with a chronic condition can be stressful for parents who report higher rates of mood disturbances, anxiety, physical and cognitive problems, and loss of control compared to parents of children without chronic health issues [1]. The experiences of parents of children with asthma or diabetes are well-documented [2, 3], however, for other chronic pathologies the picture is different. One example is Idiopathic Scoliosis (IS), a three-dimensional spinal and thoracic deformity that usually develops and progresses in children [4]. This condition is generally asymptomatic during growth, but can lead to an aesthetic impact, often a primary concern prompting families and patients to seek treatment [5], can affect the quality of life (QoL), and cause back pain in adulthood [6]. Together with the impact of the pathology itself, there is a relevant burden associated with treatment [7]. The current options are exercises, whose main pitfall is that they are time-consuming and require consistency; bracing, whose impact on more vulnerable children and families can be hard; and surgery, which leads to a permanent impairment of the spine being it an arthrodesis [4]. Children are not alone in this hard path, since their parents oversee their health, supporting and helping them. Nevertheless, parents are often under pressure due to the difficulties of the treatment experienced by their children and the fear of the negative consequences associated with treatment failure. The natural conflicts of adolescence can further exacerbate the burden on parents, especially mothers who are often the primary caregivers [8]. Adolescence is characterized by a search for autonomy, identity formation, and resistance to parental authority [9]. The need for ongoing medical supervision, brace compliance, or even surgical interventions may add more tension, as teenagers might perceive these requirements as restrictive or intrusive. Parents are in a challenging position, having to enforce medical recommendations while also striving to maintain a supportive and trusting relationship with their children. The emotional strain of managing both the demands of treatment and the struggles of adolescence can contribute to parental stress, frustration, and feelings of helplessness. These factors highlight the need for targeted psychosocial support to help parents. Nevertheless, little attention has been paid to them so far [10]. While many questionnaires have been developed to assess children's QoL and psychological well-being with IS [11, 12], none is available for parents.

For these reasons, the present study aimed to develop a new Rasch-validated questionnaire to measure the impact of the pathology and treatment on QoL of the parents of children with idiopathic scoliosis. We used Rasch Analysis (RA) instead of the Classical Test Theory because it ensures the measurement of a single underlying construct, produces interval instead of ordinal scales making statistics easier and more precise, and provides person- and item-independent measures [13].

Methods

Study design

This cross-sectional study was conducted in a tertiary-referral outpatient clinic specialised in the conservative treatment of spinal deformities from May 2021 to December 2024. All participants provided written informed consent. This study was approved by the local Ethical Committee (approval number 450_2021, April 21, 2021) and is registered on ClinicalTrials.gov (NCT04899297).

Participants and sample size

We included a convenience sample of consecutive parents of children with IS under observation or treated with brace and/or exercises. Participants were excluded if their child had a history of other comorbidities, a positive neurological examination or previous spine surgery. In the RA measurement framework, a sample size of 300 participants is usually recommended and provides robust estimates of item calibrations and person measures [12, 14].

Development of the scoliosis caregiver response and emotional scale (SCaRES) questionnaire

The development of the questionnaire followed the same steps as a similar Rasch-validated questionnaire [12]. RA is a modern psychometric approach used to develop and validate questionnaires by ensuring that items consistently measure a single underlying construct and function across different groups [13]. It transforms raw scores into interval-level measurements, thus making comparisons more precise. Unlike Classical Test Theory, which relies on total scores and assumes equal item contributions, RA provides person-independent and item-independent measures.

The questionnaire development consisted of several stages:

Phase I

We conducted a literature review to identify key issues for parents and caregivers of children with chronic conditions and to determine appropriate domains and items. Additionally, a clinical psychologist with specialized expertise in the rehabilitative treatment of scoliosis performed a conventional content analysis as described by Hsieh and Shannon

[15] to examine an online blog focused on scoliosis and its treatment, with 70,000 annual visits. The analysis began with repeated readings of the parents' and caregivers' comments on the blog to identify and open-code key concepts and patterns. Codes were then grouped into categories based on similarities and differences, allowing themes to emerge directly from the data. As a result of the content analysis, challenges and concerns affecting parents' QoL were identified, and a pool of 55 items was drafted.

Phase II

To assess content validity, 24 scoliosis experts (16 physiotherapists and 8 physicians with an average of 12.3 ± 3.7 and 10.2 ± 3.9 years of experience in IS conservative treatment) reviewed and rated the items based on their relevance and accuracy for measuring parents' QoL. As a result, 48 items were selected to create the first version of the questionnaire using a 5-point Likert scale.

Phase III

We conducted an iterative psychometric analysis using Rasch to evaluate the questionnaire's performance. We performed four rounds of analysis on progressively refined versions administered to parents of children with IS.

Data analysis

Descriptive statistics, mean, and standard deviation were computed to summarise the data, and frequencies and percentages were computed for categorical variables. The Rating Scale model was applied for data analysis using the Winsteps® software (v. 5.6.1). Details of the Rasch rating scale model can be found elsewhere [16]. RA is an iterative process consisting of different steps to assess the psychometric features of a questionnaire. In cases of unsatisfactory results, the procedure was stopped, a solution was sought, and a new analysis was performed. The following were evaluated (further details are provided in Appendix A).

Category function and threshold order

The performance of categories (i.e. Andrich thresholds) was evaluated according to the criteria described by Linacre [17].

Unidimensionality

The RA model assumes that questionnaires are one-dimensional, suggesting that a single variable influences their scores. Principal component analysis of residuals (PCAr) was conducted to verify this assumption for SCaRES items. One or more principal components (reported as first and second contrast) with an eigenvalue exceeding 2.0 indicate the presence of concealed, undesired variables that may influence item scores, in addition to the variable modelled by the Rasch model. When multidimensionality is detected, it is determined that for it to be significant, it must be both interpretable (i.e. meaningful) and detrimental to measurement. These additional criteria have been established because relying solely on eigenvalues in PCAr can yield misleading results [18]. The impact of multidimensionality on measurements is subsequently evaluated in accordance with established practices.

The goodness-of-fit

The 18 items of the SCaRES questionnaire were assessed for fit to the Rasch model by calculating Infit and Outfit Mean Square (MNSQ) and z-standardised (ZSTD) statistics. Acceptable item fit was defined as Infit/Outfit MnSq values between 0.5 and 1.5 and ZSTD > 2.0.

Item map (Wright's map)

Evidence of any floor or ceiling effects in the SCaRES responses was monitored, and the targeting of the SCaRES items to participants' abilities was assessed using Wright's map (Rasch map). Items are deemed "on target" with the sample when the person's mean ability falls within 0.5 logits of the item mean, which is conventionally set at 0 logits.

Reliability

Person and item reliability were evaluated, aiming for a person reliability of at least 0.80 and item reliability of 0.90 or higher. We also calculated separation indices to determine if the SCaRES could distinguish three QOL levels, following the guideline of person separation ≥ 2.0 and item separation ≥ 4.0.

Differential item functioning

DIF analyses were conducted to examine whether subgroups within the sample showed different item response patterns despite similar underlying trait levels. DIF was detected using two criteria: significant item calibration differences ($p < 0.01$, two-sided t-test) greater than 0.5 logits. Uniform DIF was evaluated across subgroups based on the parents' sex, age, diagnosis of scoliosis, and children's sex and age. Items with large DIF contrasts (> 0.5 logits) and significant statistical differences ($p < 0.05$) were further investigated.

Table 1 Participant's demographics

	SCaRES_ver1	SCaRES_ver2	SCaRES_ver3	SCaRES_ver4
Participants	300	164	100	300
Gender (female)	68%	63%	76%	66%
Mean Age, SD (y)	48.8 (5.79)	49.2 (6.49)	49.1 (6.28)	49 (6.41)
Unmarried	5%	5%	8%	9%
Married	84%	86%	77%	80%
Separated/divorced	5%	9%	10%	10%
Widow/er	1%	1%	2%	2%
Scoliosis diagnosis	27%	29%	24%	32%

SCaRES, Scoliosis Caregiver Response and Emotional Scale; SD, standard deviation

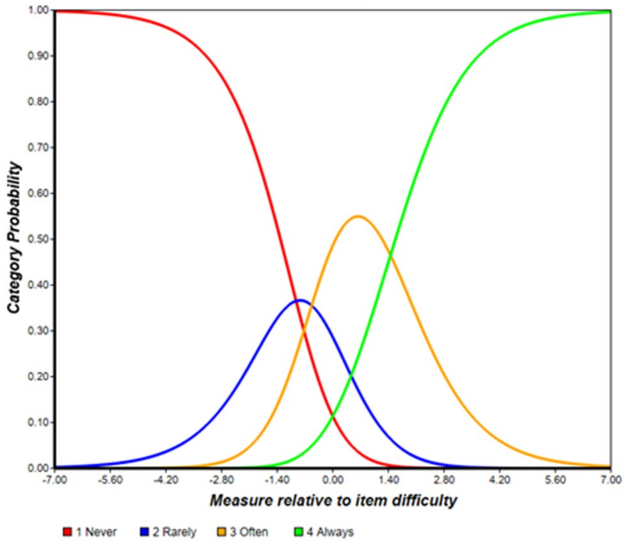


Fig. 1 Category functioning. Andrich thresholds at intersections for use of the rating scale, showing that each of the rating scale categories had distinct higher probability of being used in a logical order along the continuum of person–item difference

Results

The different versions of the questionnaire were administered to sets of consecutive parents (Table 1) during children's medical assessment. None of them refused to participate. In the first round of testing, 300 (204 women) participated, 164 (103 women) in Round 2, and 100 (76 women) in Round 3. In the fourth and final round of testing, 300 (197 women) completed the final version of the questionnaire.

Table 2 Categories and threshold order

Category Label	Observed count (%)	INFIT MNSQ	OUTFIT MNSQ	Andrich Threshold	Category Measure
1 Never	2699 (50)	1.00	1.03	NONE	-2.34
2 Rarely	1312 (24)	0.96	0.85	-0.90	-0.82
3 Often	1103 (20)	1.06	1.08	-0.55	0.63
4 Always	286 (5)	0.97	0.96	1.45	2.64

After three rounds of analysis, the number of items was reduced to 20 using a 4-point Likert scale (1 = Never, 2 = rarely, 3 = often, 4 = always).

The following are the results of the final RA:

Category function and threshold order

The 4-point Likert scale satisfied all the criteria described earlier (Fig. 1; Table 2). During the assessment of the rating scale's performance, it was observed that the category '4 Always' was utilised less frequently than anticipated. Nevertheless, this category s fulfilled the requirements for acceptable functioning.

Unidimensionality

The initial PCAr showed that the questionnaire is three-dimensional; accordingly, two items were removed, and the analysis was re-run on 18 items (Appendix B). The results of the second analysis showed that SCaRES is two-dimensional, the variance explained was 14.39 eigenvalue (44.4%), and the variance in first contrast was 2.56 eigenvalue (7.9%), meaning that the hidden dimension could impact two or three items (out of 18). However, the artefacts caused by the first contrast had a low impact on the questionnaires' measures. Further investigation revealed no substantial differences were found between the participants' mean measures from cluster 2 and cluster 1 or 3; the correlation between these measures was good. The first contrast (dimension) the Pearson correlation is high (from 0.56 to 0.62), and the deattenuated correlation, (i.e. the correlation corrected for an estimate of the measurement error), is above 0.85 is even forced to 1.00.

The goodness-of-fit

All 18 items met the set criterion for acceptable goodness-of-fit (Table 3), with a range of fit statistics between MNSQ 0.70 and 1.33.

Table 3 Goodness of fit

Items	Measure (SE)	INFIT		OUTFIT	
		MNSQ	ZSTD	MNSQ	ZSTD
1. It has been difficult for the family to adapt to my child's new needs	-0.65 (0.08)	1.14	1.78	1.16	1.74
2. It is difficult to balance my work commitments with the therapy my child needs	-0.28 (0.08)	0.87	-1.82	0.99	-0.09
3. My relationship with my child has worsened since he/she started therapy for his/her back problem	0.69 (0.10)	1.25	2.40	1.34	2.12
4. I am afraid that in the future my child's back problem will become even more noticeable	-0.77 (0.08)	1.01	0.18	0.98	-0.18
5. I am afraid that in the future my child will need medication due to back pain	-0.16 (0.08)	1.11	1.40	1.07	0.67
6. *I fear that my child will have back pain as an adult*	*-1.17 (0.08)*	*1.00*	*-0.01*	*1.04*	*0.49*
7. I am concerned that in the future my child will have difficulties at school because of his/her back problem	0.39 (0.09)	0.90	-1.08	0.81	-1.56
8. I worry that my child may feel embarrassed to show his/her body because of this problem	-0.51 (0.08)	0.83	-2.37	0.81	-2.18
9. I am worried that my child may be bullied because of his/her back	0.29 (0.09)	0.97	-0.37	0.94	-0.49
10. I sometimes cry when I think about my child's situation	0.86 (0.10)	1.09	0.90	0.90	-0.44
11. I would like help explaining to my child why he/she must consistently follow the prescriptions	-0.15 (0.08)	1.33	3.81	1.27	2.49
12. I am concerned that my child may receive ineffective treatment for his/her back problem	0.57 (0.09)	1.13	1.40	1.16	1.12
13. I am worried that my child may have problems in the future due to his/her back problem	-0.56 (0.08)	0.74	-3.86	0.70	-1.76
14. I am making sacrifices because of my child's therapy	-0.30 (0.08)	1.17	2.11	1.13	1.36
15. My child's back problem is affecting my work	*0.90 (0.10)*	*1.02*	*0.19*	*−0.92*	*-0.44*
16. I fear that my child won't be able to do everything he/she wants because of his/her back problem	-0.03 (0.08)	0.91	-1.17	0.94	-0.58
17. I think the therapy demands too much from our family	0.70 (0.10)	0.88	-1.29	0.88	-0.78
18. I am afraid that my child may suffer because of the therapy	0.17 (0.08)	0.93	-0.83	0.81	-1.17

Item map (Wright's map)

Floor effect and poor participant centring are present, as demonstrated in Fig. 2 Wright's Map. Person ability spanned 6.99 logits from −5.17 to 1.82 (mean ability −1.41 logits), whereas item difficulty (mean anchored at zero) spanned 2.07 logits from −1.17 to 0.90, and 8 participants demonstrated minimum scores (2.2%). Thus, targeting the SCaRES questionnaire to the participants' scores demonstrated a mismatch. Andrich thresholds are reported on the right of the vertical dashed line. Only two thresholds are available to measure the number of non-extreme persons measuring between −2 and −4 logits. The most difficult item to endorse was item#15 'My child's back problem is affecting my work'. Whereas the easiest item to endorse item#6' I fear that my child will have back pain as an adult.

Reliability

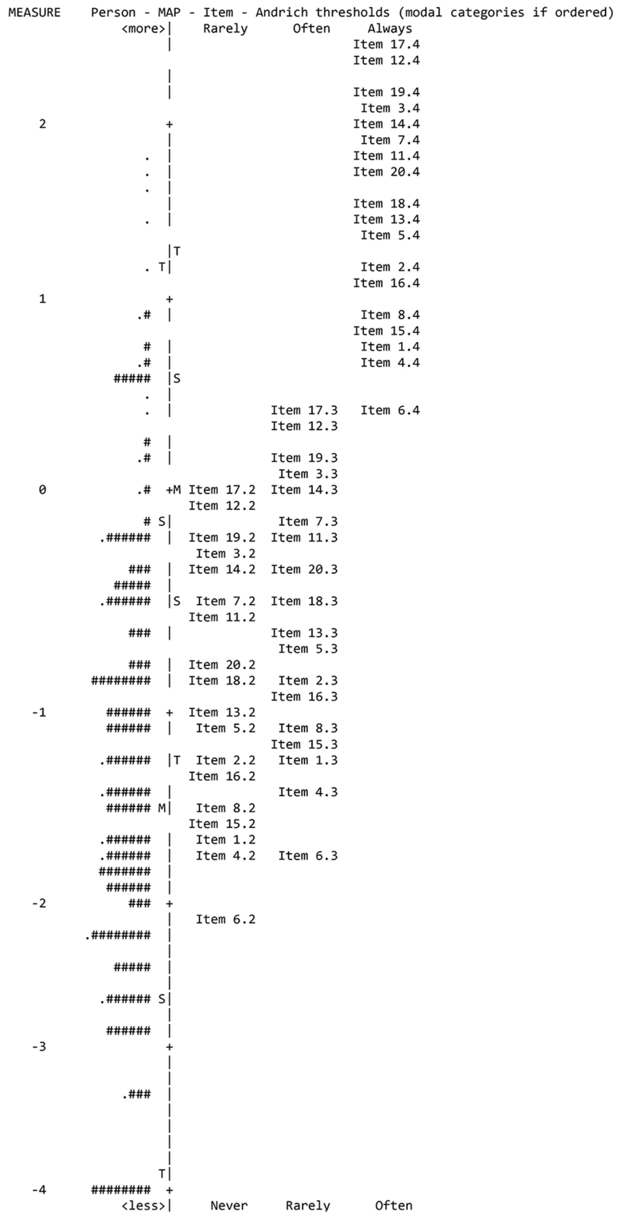
Eight participants had the minimum score (2.7%). Person separation index was 2.24 (extreme and non-extreme responses) and Person reliability of 0.83 which is interpreted similarly to Cronbach alpha (=0.91). This indicates that the scale items can distinguish individuals into three statistically distinct levels (strata) within our sample (number of strata = [4 × 2.24 + 1]/3 = 3.32) (e.g., slightly reduced, moderately reduced, and severely reduced QOL). Item separation was 6.61 and item reliability of 0.98.

Differential item functioning

No significant DIF was found across any of the subgroups: Parents' age, Parents' sex, Parents' diagnosis, Child's sex, and child's age and education.

Discussion

IS has a psychological impact on affected children and their parents [10], which has caused a growing interest in QoL assessment [19]. Many questionnaires are available to assess children's QoL and the impact of the therapies [11], and some psychological treatment attempts have been made [20]. While children are the main focus of treatment, the approach involves a multidisciplinary team of health professionals – physiotherapists, physicians, orthotists, psychologists, and surgeons – with the support of family and friends [21]. The environment in which children live plays a crucial role, forming a reciprocal relationship that influences their well-being and treatment outcomes. Parents are important actors in this scene and can have a positive or negative attitude toward the pathology and its treatment, presumably affecting their children's perspective, adherence, and overall experience [22]. Scared parents, worried that the treatment may be too tough on their children or distressing, might unintentionally project their fears onto them, potentially undermining motivation, compliance, and



```
MEASURE    Person - MAP - Item - Andrich thresholds (modal categories if ordered)
               <more>|    Rarely      Often     Always
                     |                        Item 17.4
                                              Item 12.4
                     |
                     |                        Item 19.4
                                               Item 3.4
    2                +                        Item 14.4
                     |                         Item 7.4
                  .  |                        Item 11.4
                  .  |                        Item 20.4
                  .  |
                     |                        Item 18.4
                  .  |                        Item 13.4
                                               Item 5.4
                     |T
                  . T|                         Item 2.4
                                              Item 16.4
    1                +
                 .#  |                         Item 8.4
                                              Item 15.4
                  #  |                         Item 1.4
                 .#  |                         Item 4.4
              #####  |S
                  .  |
                  .  |             Item 17.3   Item 6.4
                                   Item 12.3
                  #  |
                 .#  |             Item 19.3
                                    Item 3.3
    0            .#  +M Item 17.2  Item 14.3
                        Item 12.2
                  # S|              Item 7.3
            .######  |  Item 19.2  Item 11.3
                         Item 3.2
                ###  |  Item 14.2  Item 20.3
              #####  |
            .######  |S  Item 7.2  Item 18.3
                        Item 11.2
                ###  |             Item 13.3
                                    Item 5.3
                ###  |  Item 20.2
           ########  |  Item 18.2   Item 2.3
                                   Item 16.3
   -1        ######  +  Item 13.2
             ######  |   Item 5.2   Item 8.3
                                   Item 15.3
            .######  |T  Item 2.2   Item 1.3
                        Item 16.2
            .######  |              Item 4.3
             ###### M|   Item 8.2
                        Item 15.2
            .######  |   Item 1.2
            .######  |   Item 4.2   Item 6.3
            #######  |
             ######  |
   -2           ###  +
                     |   Item 6.2
          .########  |
                     |
              #####  |
                     |
            .###### S|
                     |
             ######  |
   -3                +
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               .###  |
                     |
                     |
                     |
                     |
                    T|
   -4      ########  +
               <less>|     Never     Rarely      Often
```

Fig. 2 Wright's Maps – Item difficulty and targeting. The Wright's Map of SCaRES. The vertical line represents the Rasch nomogram, which allows the conversion of the total raw score into a logit measure, with the mean item difficulty centred in the middle. The left-hand side the represents the distribution of persons measures. The right-hand side represents items' difficulty measures along the variable (for each item, the difficulty estimate represents the mean calibration of the threshold parameters according to the rating scale model. Quality of life (latent trait) and item difficulty increased upward in the figure. SCaRES items (listed in descending order of difficulty). The average difficulty of items in the test is set at 0 logits (and indicated with M). Accordingly, a candidate with average ability is indicated with M′. M: mean; S: 1 standard of deviation from the mean; T: tertile; # = 2 individuals;. = 1 individual

treatment outcomes. Poor information can also contribute to such feelings [23]. Some parents experience guilt related to their child's condition and their emotional difficulties [24]; some blame themselves for a delayed diagnosis because they noticed it when it was already severe [25], others feel guilty because they have scoliosis and project their personal experience onto their children. Sometimes, fostering a negative attitude due to their struggle and disappointment with their results, they can put too much pressure on kids, even those with mild scoliosis.

So far, an evaluation of this scenario has mainly been based on the experience and sensibility of the clinicians. This perspective is often limited in fully capturing the emotional and psychological dimensions of parental experiences [26]. However, recent studies highlighting mothers' narratives offer a valuable expansion of this scope, providing rich, qualitative insights that deepen our understanding of the parental journey [26]. So, a mixed methods approach could be helpful and recommended. By integrating both narrative accounts and standardized questionnaires, future research can more effectively bridge subjective experience with measurable outcomes, ensuring a more comprehensive and nuanced evaluation. The SCaRES questionnaire aims to fill a void in the support structure available to parents managing IS treatment complexities. It allows healthcare providers to tailor interventions and support strategies more effectively eventually improving adherence to treatment and overall outcomes. At this moment, when the phenomenon is not yet known and understood, we can only hypothesize some possible interventions coming from a tool that identifies specific areas of distress or burden experienced by parents. It could facilitate and drive useful conversations with physicians, or inform timely referral to psychosocial support services. By highlighting these individual challenges, the questionnaire can guide the development of targeted multidisciplinary interventions aimed at reducing parental stress, enhancing coping strategies, and ultimately supporting the family unit as a whole. The SCaRES questionnaire was statistically sound, with all items fitting well into the Rasch model. No DIF was identified concerning age or gender, meaning the questionnaire works across diverse parent demographics. The reliability score of 0.83 suggests that it can effectively distinguish between different levels of parental QoL.

Despite the study's contributions, some limitations should be discussed. First, it used a convenience sample, drawing from a single tertiary-level clinic, which may limit the generalizability of the results. Nevertheless, we developed the questionnaire from questions and real concerns raised by parents and caregivers in a dedicated online blog for scoliosis collecting questions from the general population of parents of children with AIS, ensuring that the selected items reflect genuine parental needs. Additionally, there is a possibility of reporting bias, as parents may provide answers they believe are socially acceptable or expected rather than wholly accurate. This is an inherent limitation of all questionnaires, where we could only know what the respondents wanted to tell us. Lastly, although the study implemented multiple rounds of refinement, further validation in diverse clinical environments would strengthen the applicability and robustness of the questionnaire. It is worth noting that different samples were used in the different phases, and the results of phase 3 were retested in phase 4 and led to a minor adjustment, reducing the number of items from 20 to 18. As with any validated questionnaire, further tests in different populations are needed to verify the tool's ability to adapt to continuous implementation in routine clinical practice. The main applications will be screening for parental issues that can lead to poor adherence and providing them with the needed psychological and emotional support.

Conclusion

This study provides a new Rasch-validated questionnaire to assess the QoL of parents of children with IS, addressing an unmet need in this population. The SCaRES questionnaire may enable clinicians to better understand parental challenges and tailor support strategies. Addressing the specific needs of parents with tailored psychological interventions and specific support could be valuable both for their QoL and for a more effective management of their children's treatment. Future studies should assess this questionnaire in different clinical contexts and cultures to confirm its usefulness.

Supplementary Information The online version contains supplementary material available at https://doi.org/10.1007/s00586-025-08983-x.

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Author contributions FZ, SN, and IF were responsible for the conceptualisation, methodology, and project administration. FZ, IF, and SD were involved in data collection, investigation and data curation. HRB was in responsible for the statistical analysis. All authors contributed to the interpretation of the data and critically revised it for important intellectual content. F. Z., IF, and HRB drafted the original version of the manuscript. All authors reviewed, edited, and approved the final manuscript. All the authors have read and agreed to the published version of the manuscript.

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Data availability The data that support the findings of this study are openly available in Zenodo at https://doi.org/10.5281/zenodo.15075857.

Declarations

Ethics Committee approval and trial registration The study was approved by the local Ethics Committee (Comitato Etico Milano Area 2; Parere 450_2021, April 21st/2021), and it has been registered at ClinicalTrials.gov (NCT04899297).

Patient involvement statement The study participants were not involved in the design, conduct, interpretation, or translation of the current research.

Competing interests SN owns shares of ISICO. The other authors have no conflicts of interest to declare.

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