

Review of Patient Reported Outcome Measures used in Pediatric Spinal Deformity Surgery

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Introduction

Healthcare interventions are under increasing scrutiny regarding cost-effectiveness.¹ Patient reported outcome measures (PROM) have revolutionized clinical research facilitating objective interpretation and comparison across different healthcare systems. The objectives of our study were to identify all available PROM instruments and questionnaires designed for pediatric spinal deformity to evaluate and compare their respective clinimetric domains.

Materials and Methods

A comprehensive search for all available PROM and published review articles for spinal deformity surgery was undertaken on PubMed up to December 2012. Twenty disease-specific spinal deformity questionnaires were identified (10 for ankylosing spondylitis alone and 10 for adult, adolescent and early-onset spinal deformities). The questionnaires specific to ankylosing spondylitis were excluded from analysis. The remaining 10 questionnaires were evaluated and the following clinimetric domains were each scored on a scale of 0-6 points:

- 1. Validity (content, construct and criterion validity)
- 2. Reliability (internal consistency and reproducibility)
- 3. Responsiveness to change

All published full-text articles reporting evaluation, validation, surgical outcomes of these spinal deformities PROM were retrieved and independently analyzed by two investigators (NSH and JPD).

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Results

Only 3 of 10 PROM had satisfied all six clinimetric domains in methodological evaluation (score 6/6). These included:

 Pediatric Outcomes Data Collection Instrument (PODCI) - designed by the AAOS and POSNA²

- SRS-22 questionnaire (Scoliosis Research Society) designed by Asher *et al*³
- Spinal Appearance Questionnaire (SAQ) designed by Sanders *et al*⁴

Four of 10 PROM were not evaluated (either by designers of PROM or other investigators) for at least 50% of the six clinimetric domains (scores of less than or equal to 3 of 6). The SRS-22 is the most popular PROM used globally and has been translated into at least 9 languages (Chinese, French-Canadian, German, Japanese, Korean, Persian, Spanish, Turkish and Thai) with independent validation studies in each of those languages. Though PODCI is a generic questionnaire designed for pediatric musculoskeletal pathologies, at least one study has used it to report results following scoliosis surgery.

Discussion

Clinicians should be cautious in the choice of the appropriate validated outcome measures for reporting of their surgical results. Recommendations from governing bodies (NIH, FDA) and specialist societies (AAOS, SRS) should be considered. The SAQ is less popular than SRS-22/SRS-22r despite demonstrating excellent psychometric behavior and better responsiveness to change following surgical intervention. Early-onset scoliosis (EOS) presents unique challenges and the sole questionnaire has only recently been developed in 2011.

Conclusions

SRS-22/22r is the most widely used PROM amongst scoliosis surgeons. Validated translations of SRS-22 have facilitated cross-cultural adaptation and global comparison of surgical results. Incorporation of SAQ elements into SRS-22/22r to make the existing questionnaire more robust constitutes ground for further research. Validation studies of other clinimetric domains for EOS questionnaire are desired.

Table 1. Summary of Patient Reported Outcome Measures used in Pediatric Spinal Deformity Surgery

No.	Questionnaire / Outcome measure	Content Validity	Construct Validity	Criterion Validity	Internal Reliability	Reproducibility	Responsive to change	Total Score
1	Quality of Life Instrument for adolescent idiopathic scoliosis ⁶	V	V		V	V		4/6
2	PODCI - AAOS & POSNA ^{2,3}	$\sqrt{}$	$\sqrt{}$	$\sqrt{}$	$\sqrt{}$	$\sqrt{}$	$\sqrt{}$	6/6
3	SRS – 24 ⁷	$\sqrt{}$	$\sqrt{}$				$\sqrt{}$	3/6
4	Spina Bifida questionnaire ⁸	$\sqrt{}$	$\sqrt{}$			$\sqrt{}$		3/6
5	Modified SRS – 24 & SRS-239	$\sqrt{}$	$\sqrt{}$		$\sqrt{}$	$\sqrt{*}$		4/6
6	SRS – 22 & SRS-22r ⁴	$\sqrt{}$	$\sqrt{}$	$\sqrt{}$	$\sqrt{}$	$\sqrt{}$	$\sqrt{}$	6/6
7	Walter Reed Visual Assessment Scale (WRVAS) ¹⁰		$\sqrt{}$	$\sqrt{}$	$\sqrt{}$	$\sqrt{}$		4/6
8	Scoliosis Quality of Life Index Questionnaire (SQLI) ¹¹		$\sqrt{}$		$\sqrt{}$	V		3/6
9	Spinal Appearance Questionnaire (SAQ) ⁵	$\sqrt{}$	$\sqrt{}$	$\sqrt{}$	$\sqrt{}$	$\sqrt{}$	$\sqrt{}$	6/6
10	EOS Questionnaire ¹²		$\sqrt{}$		*			2/6

^{*}Uncertain if evaluated in the original paper - we have given authors the benefit of the doubt

References

- **1. Suk M, Norvell DC, Hanson B et al.** Evidence-based orthopaedic surgery: what is evidence without the outcomes? *J Am Acad Orthop Surg* 2008;16:123-9.
- **2. Daltroy LH, Liang MH, Fossel AH, et al.** The POSNA pediatric musculoskeletal functional health questionnaire: report on reliability, validity, and sensitivity to change. Pediatric Outcomes Instrument Development Group. Pediatric Orthopaedic Society of North America. *J Pediatr Orthop* 1998;18:561-71.
- **3. Lerman JA, Sullivan E, Haynes RJ.** The Pediatric Outcomes Data Collection Instrument (PODCI) and functional assessment in patients with adolescent or juvenile idiopathic scoliosis and congenital scoliosis or kyphosis. *Spine* 2002;27:2052-7.
- **4. Asher M, Min Lai S, Burton D.** The reliability and concurrent validity of the Scoliosis Research Society-22 patient questionnaire for idiopathic scoliosis. *Spine* 2003;28:63-9.
- **5. Sanders JO, Harrast JJ, Kuklo TR, et al.** The Spinal Appearance Questionnaire: results of reliability, validity, and responsiveness testing in patients with idiopathic scoliosis. *Spine* 2007;32:2719-22.
- **6. Climent JM, Reig A, Sánchez J, et al.** Construction and validation of a specific quality of life instrument for adolescents with spine deformities. *Spine* 1995;20:2006-11.

- **7. Haher TR, Gorup JM, Shin TM, et al.** Results of the Scoliosis Research Society instrument for evaluation of surgical outcome in adolescent idiopathic scoliosis. A multicenter study of 244 patients. *Spine* 1999;24:1435-40.
- **8. Wai EK, Owen J, Fehlings D, et al.** Assessing physical disability in children with spina bifida and scoliosis. *J Pediatr Orthop* 2000;20:765-70.
- **9. Asher MA, Min Lai S, Burton DC.** Further development and validation of the Scoliosis Research Society (SRS) outcomes instrument. *Spine* 2000;25:2381-6.
- **10. Sanders JO, Polly DW Jr, Cats-Baril W, et al.** Analysis of patient and parent assessment of deformity in idiopathic scoliosis using the Walter Reed Visual Assessment Scale. *Spine* 2003;28:2158-63.
- **11. Feise RJ, Donaldson S, Crowther ER, et al.** Construction and validation of the scoliosis quality of life index in adolescent idiopathic scoliosis. *Spine* 2005;30:1310-5.
- **12. Corona J, Matsumoto H, Roye DP, et al.** Measuring quality of life in children with early onset scoliosis: development and initial validation of the early onset scoliosis questionnaire. *J Pediatr Orthop* 2011;31:180-5.