Comparison of the Test-Retest Reliability of the English Translation of the ISYQOL Scale (Italian Spine Youth Quality-of-Life) to other Self-Image Questionnaires in Adolescents with Idiopathic Scoliosis

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Introduction: Existing QOL tools for adolescent idiopathic scoliosis (AIS) present limitations. The Scoliosis Research Society-22 (SRS-22r) was developed for surgical candidates and presents high ceiling effects in conservative care. The Spinal Appearance questionnaire (SAQ) asks patients to express how they look from behind which they cannot see. Three questionnaires have been proposed recently to address these limitations. We recently translated into English, the Italian Spine Youth Quality-of-Life Scale (SYQOL), which was developed based on concerns expressed by patients and was shown appropriate in patients with AIS treated non-surgically. The Trunk Anterior Asymmetry Scoliosis Questionnaire (TAASQ) was proposed to appraise anterior appearance. The Body Image Disturbance Questionnaire measures body image disturbance in general and was recently adapted for scoliosis (BIDQS).

Objective: Our objective was to determine the test-retest reliability of the new QOL tools (ISYQOL, BIDQS, TAASQ) and compare to established tools (SRS22r, SAQ).

Methods: Thirty-five consecutive volunteer females with AIS aged 10 to 18 years were recruited from a scoliosis clinic. Five tools were computer-administered by email invitation using REDCAP one and two weeks after a specialist consult. Up to two reminders were sent. New tools included the English ISYQOL (one continuous scale), the BIDQS (one domain), and the TAASQ (8 domains). Established tools were used for comparison: SRS-22r (5 domains), and SAQ20 (9 domains) and SAQ20+3 (2 domains). Participants were blinded to their first responses. Intraclass correlation coefficient (ICC3,1) with 95% confidence interval (95%CI) were used to estimate reliability. The standard error of measurement (SEM) was also estimated. ICCs over 0.70 and over 0.90 were deemed adequate for research and clinical use with individuals, respectively.

Results: The mean age was 13 ± 2 years. The mean largest Cobb angle was 26 ± 8°. The largest curve for 60% of patients was thoracic, 23% lumbar, 14% thoracolumbar and 3% upper thoracic. Treatments received included: observation 49%, exercise 29%, and bracing (night 17%, part-time 3%, and full-time 26%). The test-retest reliability of all the scores was adequate for research with two exceptions: the SAQ items selected as the most bothersome and most important expectations. The test-retest reliability of the English ISYQOL was also adequate for individual use using the brace-relevant items or not. The test-retest reliability of the BIDQS and the following TAASQ scores also met the standard for individual use: Breast, Appearance, Clothing, and Clothing General. In patients treated conservatively, the following established comparison questionnaire scores did not meet the standard for individual use in this population: SRS22 (Function, Pain, Satisfaction), SAQ20 (Curve, Prominence, Waist, Shoulders, Kyphosis) and SAQ20+3 (expectations). The minimal detectable change for new questionnaires was ≤ 10, 6 or 11% of the total score for domains of the ISYQOL, BIDQS and TAASQ, respectively. The SRS22r and SAQ20+3 domains had similar MDC but the SAQ20 had higher MDC.

Conclusion: The test-retest reliability of the ISYQOL, BIDQS and TAASQ, newly proposed for the follow-up of patients with AIS treated conservatively, was adequate for research. The English ISYQOL, the BIDQS and part of the TAASQ also had adequate reliability for clinical use monitoring individual patients.