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The psychological impact of children spinal deformities on their parents: How to measure with a Rasch consistent unidimensional questionnaire

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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 due to their children's condition. They are also more likely than parents of healthy children to experience higher stress levels and a poorer quality of life. The experience of parents of children suffering from asthma, diabetes or other chronic pathologies is well documented. Still, little attention has been paid to the parents of children and young people with scoliosis who undergo conservative treatment. In reality, careful assessment of the parents' psychosocial status, psychological well-being and functioning is essential given the level of involvement of the latter in treatment management. Currently, there are no questionnaires aimed at assessing the quality of life of this population. This study aims to develop a new Rasch consistent questionnaire for measuring the impact of pathology and treatment on parents of patients with spinal deformities.
Methods: The current ongoing study consists of several stages: a conventional approach content analysis (Phase 1), an opinion poll among clinicians trained in spine deformities (Phase 2), and the Rasch analysis (partial credit model) (Phase 3).
Results: In phase 1, we used a conventional approach content analysis to identify on an online blog addressed to patients with scoliosis and their families the parents' self-reported problems affecting their QoL. According to the content analysis, we arranged a pool of 55 items. In Phase 2, a group of 24 scoliosis experts rated the items' appropriateness for measuring the parents' QoL, and we selected 48 items to create the first version of the questionnaire. In phase 3, we ran a Rasch analysis on the first version of the questionnaire administered to 300 parents. According to the analysis, 21 items did not fit the model of Rasch and were thus excluded. As a result, we created nine new items, and a new questionnaire collection is currently ongoing.
Conclusions: The analysis of the preliminary questionnaire version identified a pool of 27 items that fit the Rasch model, thus providing proper quality-of-life measures in the parents of young persons with spine deformities. In the following study's stages, we will refine the item's pool, and test additional questionnaire features, such as dimensionality.