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Children's and parents' perspectives of health-related quality of life in newly diagnosed adolescent idiopathic scoliosis

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ABSTRACT

The aim of this study is to compare child and parent perceptions of health-related quality of life in Adolescent Idiopathic Scoliosis. The scoliosis-specific SRS-22 and the generic KIDSCREEN-52 were administered to newly diagnosed patients and the latter also to a parent. Strong correlations ($r > 0.5$, $p < 0.001$) were revealed between conceptually similar dimensions of the instruments. Parents' assessments of their child's HRQoL were generally higher than the children/adolescents; however score differences were small and insignificant. The significance of parents' perceptions was also confirmed with OLS regressions. In conclusion, HRQoL is thoroughly investigated when both generic and disease-specific instruments are used.

1. Introduction

Adolescent idiopathic scoliosis (AIS) is the most common type of scoliosis, affecting mostly children and adolescents between ages 10–18, although it affects adults as well.[1] The condition has no identifiable causes, as implied by the term "idiopathic", but significant research is ongoing, including the genetic basis for AIS.[2] It accounts for more than 80% of scoliosis cases[3] and AIS prevalence rates range from 0.47% in Turkey,[4] to 3.26% in South Korea[5] and 5.2% in Germany.[6] The female to male ratio ranges from 1.5:1 to 3:1 and increases substantially with increasing age.[7] Almost 10% of patients with AIS will require some form of treatment, and up to 0.1% will eventually require surgery.[8]

With early detection and proper treatment, people diagnosed with scoliosis can lead healthy, active lives.[9] However, when left untreated the condition can get worse and cause chronic back pain, impact heart and lung function, affect self-esteem and lead to increasing physical, psychological, and social problems such as limited physical activities, musculoskeletal pain, poor body image, self-depreciation, maladjustment at school, and difficulty in peer relationships.[10,11] Moreover, there are social, familial, and treatment-related factors which might lead patients to develop mental disorders.[12] or even attempt suicide.[13] Even without severe progression, the deformity may interfere with daily life and, therefore, provokes an increasing interest in measuring health-related quality of life (HRQoL) in AIS patients in order to evaluate the burden of disease and the effectiveness of different treatment strategies.

The development of the Scoliosis Research Society (SRS) patient questionnaire enabled a comprehensive evaluation of the HRQoL of AIS patients and the latest revised version, the SRS-22r,[14] is the most widely used disease-specific instrument to assess quality of life in patients with AIS. Generic HRQoL instruments, on the other hand, can be equally useful in identifying groups with health problems or disabilities.[15] From an epidemiological perspective it is desirable to have valid HRQoL instruments to aid with public policy decisions and public health promotion strategies and, consequently, the improvement of population health. One such instrument, the KIDSCREEN-52 which was funded by the European Commission, measures HRQoL of life of children and adolescents aged 8–18 years on ten dimensions covering physical, psychological and social domains of quality of life.[16]

Optimal assessment and proper care of patients with AIS can be achieved if, apart from common clinical indicators such as mortality and morbidity, physicians have access to personal health status perceptions of children and adolescents. Furthermore, as parents play a fundamental role in the treatment of AIS patients, it seems appropriate to take into account their assessment of their child's HRQoL.[17,18] There are only limited studies investigating and comparing child and parent perceptions in AIS and, in this respect, the present study is seen as a contribution to the literature. This work also aims to cover a literature gap in studies having used both a disease-specific and a generic HRQoL instrument in this patient group. In light of this, the investigation of the relationship between the SRS-22 and the KIDSCREEN-52 is another important research objective in this study.

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2. Materials and methods

2.1. Instruments

The SRS-22 instrument includes four dimensions with five questions each: function/activity, pain, self-image/appearance and mental health, and one more dimension with two questions measuring satisfaction with AIS management. The scoring scale ranges from 1 to 5, with higher scores reflecting better health status. Each dimension has a total sum score ranging from 5 to 25, except for satisfaction, which ranges from 2 to 10. Results are usually expressed as the mean (total sum of the dimension score divided by the number of items answered) for each dimension. The Greek version of the instrument has been translated following standard translation procedures and its reliability and validity have been demonstrated in a sample of patients who had been surgically treated for idiopathic scoliosis and had a minimum follow-up of 2 years,[19] as well as in a sample of conservatively treated patients.[20]

The KIDSCREEN-52 questionnaire is made up of 52 questions which are categorized into ten dimensions, including physical wellbeing, psychological well-being, moods and emotions, self-perception, autonomy, parental relations and home life, financial resources, peers and social support, school environment and bullying. For each dimension, scores are usually expressed as T-values with scale means of 50 and a standard deviation of 10 with higher values indicating higher HRQoL. Alternatively, the relevant items can be summed and scaled to yield a score ranging from 0 to 100, with higher scores indicating better HRQoL. The latter was chosen in this study. The KIDSCREEN is a well validated measurement tool that allows comparisons with the Greek general population. Reference data are available for gender and two age groups, namely 8–11 and 12–18 years.[21]

2.2. Sample and data

This cross-sectional study was conducted from November 2014 to March 2015 in the scoliosis and spine outpatient department of KAT hospital, an Athens-based tertiary general hospital specializing in trauma restoration. The sample comprised of newly diagnosed children and adolescents between the ages of 10 and 17 with moderate spine deformity (Cobb angle 20°–40°). Patients receiving or having previously received any therapy for AIS such as physiotherapy, bracing or surgery were excluded from the study. A trained interviewer administered the SRS-22 to the patients, and the KIDSCREEN-52 to patients and to a parent who provided his/her perception of the child/adolescent's quality of life. The instruments were administered in the same order. Standard demographic data were collected from both groups. All parents provided informed consent for their child, and for themselves to participate in the study.

2.3. Analysis

Descriptive statistics were used for the overall sample and subgroups. Scoring of SRS-22 and KIDSCREEN-52 questions and dimensions was performed according to their corresponding scoring guidelines. Questions with a negative meaning were recoded in both instruments so that higher values correspond to better HRQoL. Normality of dimension distributions was examined and confirmed with the Kolmogorov-Smirnov test (results not shown for parsimony). Score differences were examined with student's *t*-test for independent samples, and an effect was considered statistically significant at $p < 0.05$. Interrelationships between the two instruments' dimensions were examined with Pearson's correlation coefficient. Multiple stepwise linear regressions were used to identify KIDSCREEN-52 dimensions that were significant predictors of SRS-22 dimensions. The models included only those variables with a statistical significance of at least $P < 0.05$. Data recording, management and statistical analysis were conducted using SPSS (version 21.0) software (IBM Corp., Armonk, NY).

Table 1
Demographics of the study sample ($n = 50$).

Child/Adolescent	n (%)	Participating Parent	n (%)
Age years (mean ± SD)	13.22 ± 1.68	Mother	35 (70)
Age 10–13 years	32 (64)	Father	15 (30)
Age 14–17 years	18 (36)		
Gender		Family status	
Boy	15 (30)	Married/cohabitation	41 (82)
Girl	35 (70)	Single/divorced/ widowed	9 (18)
		Number of children	
Height cm (mean ± SD)	159.46 ± 9.68	One	9 (18)
Weight (mean ± SD)	56.77 ± 10.36	Two	28 (56)
		Three or more	13 (26)
Residence		Education	
Urban	31 (62)	≤ 9 years	5 (10)
Rural	19 (38)	9–12 years	26 (52)
		12+ years	19 (38)
Nationality			
Greek	45 (90)		
Other	5 (10)		

3. Results

In total, 55 newly diagnosed children and adolescents were recruited for the study and 50 (with parental consent) agreed to participate, giving a response rate of 90.9%. The demographic characteristics of patients and parents are presented in Table 1. The mean age for the entire sample is 13.2 years. The majority of patient participants were girls (70%), lived in urban areas (62%), Greek nationals (90%), accompanied by their mother (70%), lived with both parents (82%) and had at least one sibling (82%). As for the accompanying parent, 52% were high school graduates and 38% had a higher education.

Results from the assessment, analysis and comparison of the patients' responses to the KIDSCREEN-52 questionnaire and data available from the general Greek population for ages 11–17 are presented in Table 2. Significantly higher scores from the AIS sample are observed in four dimensions: *moods and emotions* ($p < 0.001$), *self-perception* ($p < 0.001$), *parent relation and home life* ($p < 0.01$) and *social acceptance* ($p < 0.01$). On the other hand, children and adolescents from the general population had higher scores in *financial resources* ($p < 0.001$). The parents' assessments of their child's HRQoL were higher than that of the child/adolescents in most dimensions; however score differences were small and insignificant. The only noteworthy score difference was recorded in the *social support and peers* dimension in which children had higher scores than their parents ($p < 0.001$).

In our study sample, mean SRS-22 dimension scores were between 3.9 for *self image/appearance* and 4.4 for *pain* (Table 3). On the other hand, the scores from one Greek validation study involving 51 patients who had been surgically treated for AIS were between 3.5 for *mental health* and 4.2 for *function/activity*. 19

Correlations between the dimensions of two instruments are presented in Table 4. It is noteworthy that every KIDSCREEN-52 dimension correlates significantly ($p < 0.05$ or better) with at least one SRS-22 domain, implying an association between the two instruments. This association is further demonstrated by the significant correlations between KIDSCREEN-52's *physical well-being* and *self-perception* dimensions and all SRS-22 domains. Moreover, three others: *moods and emotions, financial resources* and *school environment* correlate significantly ($p < 0.05$ or better) with three SRS-22 domains. Finally, it is interesting to note that all KIDSCREEN-52 dimensions correlate significantly ($p < 0.05$ or better) with the SRS-22 *mental health* dimension.