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 cases³ and AIS prevalence rates range from 0.47% in Turkey,⁴ to 3.26% in South Korea⁵ 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

Table 1

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

Child/Adolescent	n (%)	Participating Parent	n (%)
Age years (mean $\pm$ SD)	13.22 $\pm$ 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 $\pm$ SD)	159.46 $\pm$ 9.68	One	9 (18)
Weight (mean $\pm$ SD)	56.77 $\pm$ 10.36	Two	28 (56)
		Three or more	13 (26)
Residence		Education	
Urban	31 (62)	$\leq$ 9 years	5 (10)
Rural	19 (38)	9–12 years	26 (52)
		12+ years	19 (38)
Nationality			
Greek	45 (90)		
Other	5 (10)		

SPSS (version 21.0) software (IBM Corp., Armonk, NY).

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.

Table 2
KIDSCREEN-52 child/adolescent self-reports, parent reports and Greek population scores.

KIDSCREEN-52 dimension	Present study			Validation sample ^c (n = 1193)	p-sig ^b
	Child/Adolescent (n = 50)	Parent (n = 50)	p-sig ^a		
Physical well-being	65.10 ± 15.40	68.40 ± 12.38	0.249	66.1 ± 19.2	0.648
Psychological well-being	67.75 ± 18.48	72.75 ± 10.89	0.103	70.0 ± 19.3	0.393
Moods and emotions	87.00 ± 16.31	88.93 ± 9.05	0.467	72.6 ± 18.2	< 0.001
Self-perception	74.60 ± 15.01	75.30 ± 10.12	0.785	66.4 ± 21.0	< 0.001
Autonomy	63.40 ± 17.27	60.20 ± 16.72	0.349	58.7 ± 23.5	0.060
Parent relation and home life	75.92 ± 12.49	77.08 ± 11.73	0.631	70.5 ± 20.2	0.004
Financial resources	58.50 ± 20.52	62.83 ± 17.91	0.263	69.5 ± 24.3	< 0.001
Social support and peers	67.00 ± 17.02	59.33 ± 13.67	0.015	70.4 ± 21.3	0.164
School environment	67.00 ± 15.03	69.83 ± 12.86	0.314	64.2 ± 18.7	0.194
Social acceptance (bullying)	95.67 ± 8.29	93.54 ± 11.69	0.298	91.9 ± 14.0	0.002

^a According to independent samples *t*-test between child/adolescent and parent scores.

^b According to one sample *t*-test between present study and validation study child/adolescent scores.

^c Tzavara et al, 2012.

Table 3
SRS-22 child/adolescent self-reports and Greek population sample scores.

SRS-22 domain	Child/Adolescent (n = 50)	Validation sample ^b (n = 51)	p-sig ^a	Validation sample ^c (n = 87)	p-sig ^a
Function/activity	4.36 ± 0.54	4.2 ± 0.7	0.019	4.8 ± 0.3	< 0.001
Pain	4.37 ± 0.48	4.1 ± 0.8	< 0.001	4.5 ± 0.4	0.070
Mental health	4.00 ± 0.68	3.5 ± 0.8	< 0.001	3.9 ± 0.8	0.311
Self image/appearance	3.88 ± 0.52	4.1 ± 0.8	0.011	3.9 ± 0.8	0.746

^a According to one sample *t*-test between present study and validation study child/adolescent scores.

^b Antonarakos et al, 2009.

^c Poutoupnis et al, 2012.

Table 4
Correlation coefficients between instrument dimensions.

KIDSCREEN-52 dimension	SRS-22 dimension			
	Function	Pain	Mental health	Self image
Physical well-being	0.56***	0.48**	0.74***	0.46**
Psychological well-being	0.29*	0.13	0.70***	0.22
Moods and emotions	0.35*	0.05	0.65***	0.29*
Self-perception	0.29*	0.31*	0.47***	0.29*
Autonomy	0.16	0.25	0.40**	0.13
Parent relation and home life	0.21	0.33*	0.56***	0.17
Financial resources	0.41**	0.15	0.45***	0.34*
Social support and peers	0.12	0.22	0.35*	0.19
School environment	0.41**	0.27	0.66***	0.37**
Social acceptance (bullying)	0.22	0.16	0.30*	0.33*

* *P* < 0.05.

** *P* < 0.01.

*** *P* < 0.001.

The significance of the above-mentioned relationships between KIDSCREEN-52 and SRS-22 dimension scores was confirmed with multivariate OLS regressions (Table 5). The resulting models with KIDSCREEN-52 child and parent scores used as independent variables, explained large portions of SRS-22 dimension variance, ranging from 40.9% for *self image* to 82.9% for *mental health*. The child's perception of *physical well-being* is a significant (*p* < 0.01 or better) predictor of all SRS-22 dimension scores. Parent perceptions of their child's HRQoL proved to be important, since at least one parent dimension score is a significant (*p* < 0.05 or better) in each model, which implies that parent perceptions are important predictors of their child's HRQoL. It is also worth noting that the coefficient of determination (*R*²) is much

lower (0.193–0.672) when parent dimension scores were excluded as potential explanatory variables from the models.

4. Discussion

The World Health Organization conceptualizes HRQoL as a multi-dimensional and comprehensive model associated with the individual's perception of their position in life, and covers dimensions encompassing physical, emotional and social well-being, and not just the absence of illness.²² Over the years, the measurement of HRQoL in children and adolescents has received increasing attention in pediatrics and adolescent care and several instruments are now available for use in these groups.²³ In the case of children/adolescents with AIS, this is particularly important because the condition is often associated with specific treatments that dramatically affect lifestyle. In this cross-sectional study, we evaluated the HRQoL of newly diagnosed children/adolescents with AIS using a generic multidimensional questionnaire and a scoliosis-specific instrument, which have been validated for the Greek population. When the interest is in measuring the HRQoL of patients, disease-specific instruments are often preferred to generic ones since they focus on particular health problems and tend to be more sensitive to clinically important differences. On the other hand, generic instruments are preferable in general population surveys, and across a variety of diseases and conditions.²⁴

With the KIDSCREEN-52, our sample of patients with AIS had higher scores in *moods and emotions*, *self-perception*, *parent relation and home life* and *social acceptance* than their age-adjusted peers from the general Greek population.²¹ This implies that they experience fewer depressive moods, emotions and stressful feelings such as loneliness, sadness, insufficiency and resignation. They view their body image more positively and are more satisfied with looks and clothes. They perceive a higher quality interaction with their parents, as well as love and support from their family, than their general population counterparts. The AIS children/adolescents do not feel intimidated or rejected in school, and enjoy social acceptance and feel treated with respect. On the other hand, they are less convinced that they have enough financial resources to allow them to live a lifestyle which is comparable to other children/adolescents, as implied by the lower score in the *financial resources* dimension than the general population.

Our findings highlight that the HRQoL of newly diagnosed children/adolescents with AIS compared to the general Greek population is not severely impaired and, interestingly, they had higher scores in half of the KIDSCREEN-52 dimensions. This is consistent and comparable to the results of other studies conducted on pediatric patients/adolescents versus healthy controls from the general population. We are not aware of any previous study having used the KIDSCREEN-52 on patients with AIS, which would allow for a direct comparison of the results. However

Table 5
Multiple stepwise linear regression models.

SRS-22	Predictors	B	SE	t	P-sig	Adjusted R2
Function	(Constant)	2.563	0.665	3.853	< 0.001***	0.414 (0.371)^a
	Physical well-being	0.029	0.006	4.880	< 0.001***	
	Parent relation and home life	−0.019	0.007	−2.635	0.012**	
	Moods and emotions (parent)	0.015	0.007	2.209	0.033*	
Pain	(Constant)	3.214	0.332	9.690	< 0.001***	0.544 (0.347)
	Physical well-being	0.030	0.005	6.038	< 0.001***	
	Psychological well-being	−0.018	0.005	−3.570	0.001***	
	School environment (parent)	0.018	0.005	3.952	< 0.001***	
	Moods and emotions	−0.009	0.004	−2.143	0.038*	
Mental Health	(Constant)	−0.285	0.495	−0.576	0.568	0.829 (0.672)
	Physical well-being	0.026	0.004	6.384	< 0.001***	
	Moods and emotions	0.014	0.004	3.408	0.002***	
	Moods and emotions (parent)	0.031	0.006	5.486	< 0.001***	
	School environment	0.023	0.005	4.904	< 0.001***	
	Self-perception	−0.013	0.004	−3.237	0.003***	
	Physical well-being (parent)	−0.013	0.004	−2.996	0.005**	
	Social acceptance (bullying) (parent)	−0.012	0.005	−2.310	0.027*	
Self Image	(Constant)	2.833	0.296	9.562	< 0.001***	0.409 (0.193)
	Financial resources (parent)	0.016	0.004	3.967	< 0.001***	
	Physical well-being	0.013	0.004	3.153	0.003**	
	Autonomy (parent)	−0.012	0.004	−2.873	0.006**	

* $P < 0.05$.

** $P < 0.01$.

*** $P < 0.001$.

^a Values in the parentheses correspond to adjusted R2 from models without parent scores.

the instrument, has been used many times in other patient groups and again higher scores have been recorded in some dimensions from patients, compared to healthy children/adolescents of the general population, although the differences were not always significant.^{25–27}

Another interesting result of the present study is the comparison of the HRQoL assessment carried out by the patient and the parent. The assessments did not differ in most dimensions and the most obvious exception was noted in the case of *social support & peers* in which the quality of life assessed by the parent was lower than that assessed by the child ($p < 0.05$). This dimension examines the nature of the child/adolescent's social relations with their peers and explores the quality of these interactions as well as their perceived support. Our results imply that the child/adolescent feels more accepted and supported by friends than his/her parent perceives. This particular discrepancy was also observed in the Greek validation study of the KIDSCREEN-52.²¹

Discrepancies between assessments carried out by the child/adolescent and by the parent is an important issue because the parent usually participates in the therapeutic process. Some authors incline towards greater consideration of the child's assessment due to the subjectivity of HRQoL assessment.^{28,29} However, parameters such as pain or mood are by definition subjective. As there is no tool allowing for the objective validation of the accuracy of particular assessments and, as mentioned above, parents play a fundamental role in the treatment of AIS patients, it seems appropriate to take into account both assessments. Discrepancies between the child's and parent's assessment are not a methodological mistake, but the perception of the same issue from two, equally important, perspectives.^{17,18}

Compared to the sample of surgically treated AIS children/adolescents from a Greek SRS-22 validation study,¹⁹ our sample had higher scores in *function/activity* ($p < 0.05$), *pain* ($p < 0.001$) and *mental health* ($p < 0.001$), and lower scores ($p < 0.05$) in *self image/appearance*, which was the lowest scored dimension in our study. In this respect, the present results are consistent with another Greek validation study involving 87 conservatively treated AIS patients, in which scores ranged from 3.9 for *self image/appearance* and *mental health* to 4.8 for *function/activity*.²⁰ Our patients' scores were closer to those from the second study, and the only significant difference was observed in *function/activity*. Contrastingly, all SRS-22 dimension scores were

significantly different than the respective ones from the first study involving surgically treated patients. It should be noted that *satisfaction with management* is not applicable in our study (no previous or current treatment in effect), and therefore the respective SRS-22 questions were not answered.

It is noteworthy that *self image/appearance* was also the lowest scored dimension in many SRS-22 validation studies.^{30–32} This is important since a better understanding of the child/adolescents' body perceptions can contribute to improving care. The outcomes of treatments could be improved by identifying the emotions and feelings that this deformity induces in young people with AIS and by improving therapeutic communication based on active listening, feedback and empathy.³³

Strong correlations ($r > 0.50$) were found in comparisons of the *mental health* dimension of SRS-22 with five dimensions of the KIDSCREEN-52, i.e. 0.74 with *physical well-being*, 0.70 with *psychological well-being*, 0.66 with *school environment*, 0.65 with *moods and emotion*, and 0.56 with *parent relation and home life*. Another strong correlation ($r = 0.56$) was recorded between SRS-22's *function* and KIDSCREEN-52's *physical well-being* dimensions. Apart from these, other moderate correlations ($r > 0.30$) were observed as well. As mentioned previously, there is no previous study in which these two particular instruments have been used, and therefore direct comparisons are not possible. However our results, which indicate moderate and strong correlations between conceptually similar instrument dimensions, are consistent with comparisons between SRS-22 and dimensions of the widely used SF-36 generic instrument which are reported in many previous studies.^{14,19,32,34–37} Although not a direct research objective in this study, strong correlations between dimensions hypothesized to be strongly correlated is also an indication of convergent construct validity of both instruments.

Each SRS-22 dimension was separately regressed against the KIDSCREEN-52 dimension scores to identify aspects of general HRQoL that might be more closely linked to AIS-specific parameters. Four regression models resulted which explained high proportions of SRS-22 variance. The KIDSCREEN-52 *physical well-being* dimension of patients was a significant predictor of all four SRS-22 dimensions, and most KIDSCREEN-52 dimensions were significant predictors of at least one AIS-

specific domain. This provides evidence that the generic instrument is indeed measuring disease-specific HRQoL aspects.

To the extent that it is possible to manipulate quality of life aspects, our results imply that a systematic approach to the improvement of these aspects may prove beneficial in terms of HRQoL for the AIS population. It is logical that portions of variability of each SRS-22 domain remained unexplained, since other demographic or health-related variables were not used in the regression models, and this could trigger further research. In accordance to other studies,^{38–40} we observed discrepancies between child/adolescent and parent assessments of HRQoL. However, the exclusion of the parent's perceptions in the OLS regressions significantly weakened all models as indicated by the much lower R^2 . This finding obviously highlights the importance of parents' perceptions of their child's HRQoL.

At first sight, the sample size in this study is relatively small and might raise issues regarding the generalizability of the results. However, taking into consideration the demographics of the country and the 1.7% prevalence of AIS in Greece (0.9% in boys and 2.6% in girls),⁴¹ along with the fact that there are many similar studies involving AIS patients in the literature with comparable samples, it is fair to claim that the present sample is fairly representative. Also, the cross-sectional might limit its potential to identify causal relationships between variables. However, the work lays the foundation for future studies to investigate both the HRQoL in this sensitive patient group and, in doing so, to exploit both generic and disease-specific HRQoL instruments in order to exploit their combined advantages.

Conflict of interest

None.

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