

## ORIGINAL ARTICLE

# Comparison of adolescent and parental perception of health-related quality of life of adolescents with idiopathic scoliosis

*İdiyopatik skolyozlu adölesanların sağlıkla ilgili yaşam kalitesine ilişkin adölesan ve ebeveyn algılarının karşılaştırılması*

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**Abstract** *Purpose:* Evaluation of the health-related quality of life (HRQoL) of individuals with idiopathic scoliosis (IS) is important because of the physical and psychosocial problems caused by IS. In general, children interact closely with their parents and are thus influenced by their parents' opinions. It is thus useful to examine adolescent and parental perceptions of the adolescent's HRQoL for the rehabilitation of individuals with IS.

*Methods:* This study compared the adolescents' and their parents' perceptions of the adolescent's HRQoL including 65 individuals with IS (10–18 years). It was used the pediatric quality of life inventory (PedsQL) to assess the adolescents' HRQoL and to examine the domains of physical health, emotional functioning, social functioning, school functioning, and psychosocial health.

*Results:* The results showed that the scores of the adolescents were higher than their parents' in social functioning. Scores of social functioning and HRQoL were higher in girls than in their parents.

*Conclusion:* This discrepancy between the adolescents and their parents may have a negative effect on their rehabilitation, healthy social integration, and adaptation of individuals with IS. Shedding light on the reasons for this discrepancy would be beneficial for raising the awareness of parents with children with IS about this issue.

*Keywords:* Scoliosis, Health-related quality of life, Parent-child relations, Social participation, Social desirability.

## Öz

**Amaç:** İdiyopatik skolyozlu (İS) bireylerin sağlıkla ilişkili yaşam kalitesinin (SİYK) değerlendirilmesi, İS'nin neden olduğu fiziksel ve psikososyal sorunlar nedeniyle önemlidir. Genel olarak, çocuklar ebeveynleriyle yakın etkileşim içindedir ve ebeveynlerinin görüşlerinden etkilenirler. Bu nedenle, İS'li bireylerin rehabilitasyonu için adölesanın SİYK'sine ilişkin adölesan ve ebeveyn algılarını incelemek yararlı olacaktır.

**Yöntem:** Bu çalışma 65 İS'li bireyi (10-18 yaş) dahil ederek, adölesanların ve ebeveynlerinin adölesanın SİYK'sine ilişkin algılarını karşılaştırdı. Adölesanların SİYK'sini değerlendirmek ve fiziksel sağlık, emosyonel işlevsellik, sosyal işlevsellik, okul işlevselliği ve psikososyal sağlık alanlarını incelemek için Çocuklar için Yaşam Kalitesi Envanteri (ÇİYKÖ) kullanıldı.

**Bulgular:** Sonuçlar, adölesanların sosyal işlevsellik puanlarının ebeveynlerin verdiği puandan daha yüksek olduğunu göstermiştir. Sosyal işlevsellik ve SİYK puanları kızlarda ebeveynlerinden daha yüksekti.

**Sonuç:** Adölesanlar ve ebeveynleri arasındaki bu uyumsuzluk, İS'li bireylerin rehabilitasyonlarını, sağlıklı sosyal entegrasyonlarını ve uyumlarını olumsuz yönde etkileyebilir. Bu farklılığın nedenlerinin aydınlatılması, İS'li çocuğa sahip ebeveynlerin bu konuda bilinçlendirilmesi açısından faydalı olacaktır.

**Anahtar kelimeler:** Skolyoz, Sağlıkla ilgili yaşam kalitesi, Ebeveyn-çocuk ilişkileri, Sosyal katılım, Sosyal istenirlik.

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## INTRODUCTION

Health-related quality of life (HRQoL) is a concept that includes mental, physical and social well-being. Also, HRQoL domains are associated with well-being and functioning of physical, emotional, social, psychosocial, and school.<sup>1</sup> Idiopathic scoliosis (IS) is a complex deformity involving three planes of the vertebral column. This deformity affects the physical and psychosocial functioning of the individual.<sup>2</sup> In IS, body dysmorphism has a negative effect on the development of the body image. In addition, low self-esteem, low social adaptation ability, mood disturbances, and worry over peer relations have been reported in individuals with IS. Thus, IS might occur unfavorable effects on HRQoL due to physical and psychosocial problems.<sup>3</sup> Previous studies have strongly underlined the fundamental role of family in the development of the behavior and attitudes of children and adolescents.<sup>4,5</sup> IS research has indicated that mothers' attitudes have a significant effect on their child's attitudes.<sup>6</sup> Some studies have detected similar perceptions between children and their parents about HRQoL and spinal appearance,<sup>7,8</sup> while others have reported a difference in the perceptions of trunk deformity and HRQoL.<sup>9,10</sup> Furthermore, it has been shown that discrepancies in the perception of trunk deformity between adolescent girls and their parents influenced HRQoL scores.<sup>11</sup> However, past researches regarding the discrepancy between adolescents with IS and their parents did not examine psychosocial, social, emotional, and school functioning of the adolescents. Ultimately, the interaction between parents and individuals in terms of HRQoL perception in IS remains controversial.

HRQoL can be evaluated with disease-specific instruments or general instruments. Specific instruments to assess HRQoL are specifically designed for a specific disease, such as spinal deformity,<sup>6</sup> foot-related disorders,<sup>12</sup> knee injuries,<sup>13</sup> or musculoskeletal diseases.<sup>14</sup> Specific instruments enable comprehensive assessment of the HRQoL of the patients and also aim to understand the perceptions of the patient regarding their current condition and measure their satisfaction with IS management.<sup>9,15</sup> However, as general

instruments are designed to capture all aspects of HRQoL, they provide a wider context in which to construe information about the change in HRQoL.<sup>15</sup> Scoliosis-specific questionnaires, such as Scoliosis Research Society-22, Bad Sobernheim Stress Questionnaire, and Brace Questionnaire,<sup>16-18</sup> have been developed specifically for individuals with scoliosis. However, these instruments are inadequate for examining psychosocial functioning, peer relations, and detailed social functioning.

Several studies have investigated the HRQoL of individuals with IS using scoliosis-specific instruments.<sup>9,19</sup> However, few existing IS literature has investigated individuals' HRQoL using general questionnaires. The most common questionnaires used to assess general health are the Short Form-36 Health Survey (SF-36) and Nottingham Health Profile; however, as these are designed for use with adults, they are less appropriate for pediatric and adolescent scoliosis individuals.<sup>20,21</sup> Pediatric quality of life inventory (PedsQL) is the widely used general instrument for evaluating HRQoL among children and adolescents.<sup>22</sup> Compared to other disease-specific instruments, the PedsQL has the advantage because it questions relationships with peers, difficulties at school, social problems, and emotional problems in children and adolescents. Knowing the general HRQoL perception of the individual is important for following the health status of individuals and their level of satisfaction with their lives in several ways.<sup>6</sup>

There is a gap in the literature, the lack of study investigating the discrepancy of perception of parents and adolescents about adolescents' HRQoL using the PedsQL. This study investigates (a) whether a difference exists between the parents' and adolescents' perceptions of the general HRQoL of the adolescent with IS, (b) whether the perceived HRQoL of the adolescent relates to the adolescent's gender, and (c) whether the perceived HRQoL depends on the adolescent's age.

## METHODS

### Participants

The study included 65 adolescents with IS

who has been diagnosed for their scoliosis in different centers and their parents. The participants' mean age was  $14.1 \pm 2.0$  years (range: 10–18 years), and the participants consisted of 52 girls and 13 boys. While composing the PedsQL, it was created forms for different age groups, considering that children and adolescents may have different concerns about health and disease.<sup>23</sup> Fourteen (21%) of the participants were assigned to the 10-12 age group, and 51 (79%) were assigned to the 13-18 age group. The inclusion criteria were as follows: aged 10–18 years; a Cobb angle for the main curve of least 10 degrees; no prior history of scoliosis treatment; and a double curve, a single thoracic curve, or a single lumbar curve. We excluded participants partaking in regular sports activities or with other patterns of scoliosis from the analysis.

The University of Hasan Kalyoncu Research Ethics Committee (2019/08 on 5 February 2019) approved the study protocol. After ethics committee approval, patients who agreed to participate in the study between February 2019 and May 2019 were included. Participants and their parents were informed about the study, and signed informed consent forms were obtained prior to participation from both the participants and their parents.

#### Measures and procedures

It was recorded demographic data and participant characteristics, including age, weight, height, and body mass index. Also, it was recorded clinical data regarding scoliosis using assessments of the curve pattern, Cobb angle, and axial trunk rotation and calculated the PedsQL scores. The curve pattern expression is used to express the number of curvatures (such as single, double) and its region (such as thoracic, lumbar) in the spine. The Cobb angle is expressed the magnitude of the curve, and axial trunk rotation is the amount of the turning (rotation) of the trunk because of deformity.

The curve pattern was classified as either a single (thoracic or lumbar) or double (right thoracic and left lumbar) curve. The Cobb angles were calculated using a postero–anterior standing radiograph to determine the magnitude of the spinal curve.<sup>24</sup> We measured the axial trunk rotation via the forward bending test and placed a Bunnell scoliometer on the convex side apex of the curve.<sup>25</sup>

We used the PedsQL to assess the general HRQoL of the participants in the study, which was designed for application in healthy and patient children/adolescents.<sup>23</sup> The PedsQL consists of 23 items in the following four domains: physical functioning (8 items), emotional functioning (5 items), social functioning (5 items), and school functioning (5 items). The scores for each item range from 0 to 100 and are calculated as follows: never a problem: 100 point, almost never a problem: 75 point, sometimes a problem: 50 point, often a problem: 25 point and almost always a problem: 0 point.<sup>23</sup> We recorded scores for physical functioning, emotional functioning, social functioning, and school functioning. We also obtained a psychosocial health summary and total score for all participants. The total scale score was derived by the mean of all items, and the psychosocial health summary score comprised the means of the items in the emotional functioning, social functioning, and school functioning subscales. Higher PedsQL scores indicate better HRQoL.<sup>23, 26</sup> The PedsQL comprised the child/adolescent self-report and the parent proxy report that assessed parents' perceptions of their child's HRQoL. This instrument has different versions for children aged 2–4, 5–7, 8–12, and 13–18 years. The scale for the 2–4 age group has only a parent proxy report.<sup>23</sup> When composing the PedsQL, Varni et al. considered that children and adolescents may have different concerns about health and illness and enounced that the contents of items were kept as similar as possible across different age forms, allowing for developmental differences in cognitive ability.<sup>23</sup> Therefore, this study investigated the scores of the 10- to 12-year-old age group and 13- to 18-year-old age group participants separately and in total in this study.

Previous studies have confirmed the validity and reliability of the PedsQL for evaluating the life quality of 8-12-year-old Turkish children and 13-18-year-old Turkish adolescents. The internal consistency of the PedsQL was calculated with the Cronbach's alpha method and the level of significance was determined to be  $p < 0.05$  within a 95% CI. Cronbach's alpha value was found ranged between 0.60 and 0.87 in the 13-18-year-old form and ranged between 0.84 and 0.86 in the 8-12-year-old form.<sup>27, 28</sup>

### Statistical analysis

We performed a statistical analysis using SPSS software version 23 (SPSS Inc., Armonk, New York, USA). Data were expressed as mean (standard deviation) and minimum-maximum values. The alpha level was 0.05 for all tests of statistical significance. Because the data were not normally distributed, we conducted the Wilcoxon Signed Ranks Test to compare the results of the adolescents and parents, the girls and the boys, and the two age groups (10–12 and 13–18).

## RESULTS

Table 1 shows the descriptive characteristics of the adolescents in the study, and Table 2 shows a comparison of the parents' and adolescents' report scores in the PedsQL subscales. The only significant difference among the parents and adolescents report scores was in the social functioning summary score ( $p < .05$ ), where the score of the adolescents' reports was higher than that of their parents.

**Table 1. Descriptive and clinical characteristics of the participants.**

	Mean±SD
Age (years)	14.1±2.0
Body weight (kg)	49.2±11.6
Height (cm)	160.7±10.2
Body mass index (kg/m <sup>2</sup> )	18.8±3.0
Thoracic Cobb angle (°)	26.1±9.2
Lumbar Cobb angle (°)	21.8±6.7
Thoracic rotation angle (°)	7.2±3.3
Lumbar rotation angle (°)	6.2±2.6

As shown in Table 3, no significant difference existed between parents' and adolescents' report scores among the boys ( $p > .05$ ). However, among the girls, a significant difference was observed between parents' and adolescents' report scores in the social functioning summary score and total scale score ( $p < .05$ ). The scores of the adolescents' were

higher than their parents' in the social functioning summary score and total scale score. Additionally, there was no significant difference in the physical health summary score, emotional functioning summary score, school functioning score, and psychosocial health summary score between the parents' and adolescents' report scores for the girls.

As depicted in Table 4, significant differences existed between the parents' and adolescents' social functioning summary scores for both age groups ( $p < .05$ ). In both groups, the score of the adolescents' reports was higher than that of the parents in the social functioning score.

## DISCUSSION

This study investigated the differences between the perceptions of adolescents' and parents' toward the general HRQoL of the individual with IS and explored whether their perceptions related to the adolescent's gender and age group. The findings of this study demonstrated that the opinions of the adolescents and their parents in the study about the adolescent's HRQoL conflicted in relation to social functioning. However, the perceptions relating to the parameters of physical health, emotional functioning, school functioning, psychosocial health, and total score were similar between the adolescents and their parents. Although the results related to adolescent gender seem to reveal that this discrepancy was specific to the girls, we cannot state that directly because the number of boys in the study was not insufficient. The results relating to age group showed no differences between children (10–12-year-old) or adolescents (13–18-year-old) in terms of the perceptions obtained from the adolescents and their parents. These results can indicate that adolescents with IS tended to overestimate their level of social functioning or that their parents underestimated it.

Our study found that the social functioning scores of individuals with IS were higher than those reported by their parents. Several previous studies have also shown that children with chronic diseases reported higher social functioning scores than did their parents.<sup>29,30</sup> Bridwell et al. found that parents showed greater concern about the disease than their

children in their study about adolescents with IS.<sup>31</sup> Thus, the parents may have negatively exaggerated the level of social functioning of their children in our study due to the scoliosis condition and concern. In addition, Sawyer et al. suggested that children may have difficulty communicating with others about their disease.<sup>30</sup> Similarly children may be bashful when explaining their responses in connection with their perceptions of social functioning in our study. However, in their study of 3,195 healthy children, Gaspar et al. reported that parents tend to perceive the HRQoL of their children as higher than do their children.<sup>32</sup> Silva et al. found no significant differences in the HRQoL perceived by the individuals and their parents and claimed that the disease has an impact on the perception of HRQoL.<sup>33</sup> The results of another systematic review about social functioning and peer relations in children with chronic pain specify that the pain resulted in reduced opportunities to interact with friends and increased peer victimization, which affected their social functioning.<sup>34</sup> In our study, the parameters of the social functioning assessment included such issues as get along with peers, make friends, peer victimization, rejection by peers, and activity participation with peers. Adolescents may have problems with social functioning due to psychosocial problems caused by scoliosis, such as body image disturbance, low self-image, low social adaptation ability, and worry over peer relations. While parents may have realized these problems, the adolescents may not have admitted these effects to themselves, thus leading to a discrepancy in the social functioning score between the adolescents

and their parents. However, since our study does not evaluate these parameters that not included in PedsQL, it is not possible to make certain inferences about them. Further, Arabiat et al. investigated social desirability in children with chronic illnesses and found that the chronically ill group had higher social desirability than the control group.<sup>35</sup> We also consider that adolescents with IS may not have been realistic in expressing their social functionality due to social desirability. However, future research is needed to question the social desirability of adolescents with IS. In addition, the findings of this study showed that physical, emotional, school functioning, psychosocial health and total score were similar between participants and their parents. Varni et al. reported a high correlation between pediatric cancer patients (8-18 ages) and their parents for physical functioning in their study.<sup>23</sup> According to the results of a systematic review, there was a great agreement for observable functioning such as physical HRQoL, less agreement for non-observable functioning such as emotional or social HRQoL between children and their parents.<sup>36</sup> Consistent with these studies, parents may have the chance to observe their children's physical and school functions more easily and therefore they may have similar scores on subscales in our study.

The present study found that no significant difference existed between the adolescents' and parents' scores among the boys. However, the scores for the girls' reports were higher than those of their parents in the social functioning summary score and the total HRQoL score. Abbott et al. collected data from 1,342

Table 2. Comparison of the parents' and adolescents' report scores in the Pediatric Quality Of Life Inventory (PedsQL) subscales.

Pediatric Quality Of Life Inventory (PedsQL)	Parent report	Child/Adolescent report	z	p
	Mean±SD	Mean±SD		
Physical health summary score	70.0±23.1	75.2±13.8	-1.314	0.189
Emotional functioning summary score	71.1±24.1	74.5±18.3	-0.891	0.373
Social functioning summary score	85.5±18.3	92.4±11.3	-3.065	0.002*
School functioning scores	76.9±19.0	73.3±17.0	-1.268	0.205
Psychosocial health summary score	77.8±17.3	80.1±13.3	-0.925	0.355
Total scale score	74.5±17.2	78.2±12.0	-1.616	0.106

\*p<0.05. z: Wilcoxon Signed Ranks Test.



Table 3. Comparison of the Parents' and Adolescents' Report Scores within the girls and the boys.

Pediatric Quality Of Life Inventory (PedsQL)	Parent report	Child/Adolescent report	z	p
	Mean±SD	Mean±SD		
<b>Girls (N=52)</b>				
Physical health summary score	68.9±23.9	75.7±13.4	-1.668	0.095
Emotional functioning summary score	69.2±24.7	75.2±18.8	-1.579	0.114
Social functioning summary score	84.2±17.8	93.4±10.3	-3.725	<0.001
School functioning scores	77.3±18.8	75.3±16.3	-0.568	0.570
Psychosocial health summary score	76.7±17.4	81.3±12.7	-1.671	0.095
Total scale score	74.5±17.2	78.2±12.0	-1.616	0.106
<b>Boys (N=13)</b>				
Physical health summary score	74.2±19.2	73.0±15.4	-0.356	0.722
Emotional functioning summary score	78.4±20.0	71.5±16.5	-1.848	0.065
Social functioning summary score	90.7±19.5	88.0±14.2	-0.423	0.672
School functioning scores	75.0±20.4	64.1±17.5	-1.589	0.112
Psychosocial health summary score	81.7±17.1	75.1±14.5	-1.483	0.138
Total scale score				

\*p<0.05. z: Wilcoxon Signed Ranks Test.

Table 4. Comparison of the parents' and within the different age groups adolescents' report scores.

Pediatric Quality Of Life Inventory (PedsQL)	Parent report	Child/Adolescent report	z	p
	Mean±SD	Mean±SD		
<b>10-to 12-year-old age group (N=14)</b>				
Physical health summary score	62.7±22.8	73.7±14.0	-1.195	0.232
Emotional functioning summary score	66.1±26.0	76.4±19.7	-0.981	0.327
Social functioning summary score	77.5±19.7	89.6±12.0	-2.105	0.035*
School functioning scores	77.3±18.3	76.1±13.3	-0.585	0.558
Psychosocial health summary score	73.2±19.0	80.7±12.9	-0.945	0.345
Total scale score	67.0±16.4	77.3±11.2	-1.712	0.087
<b>13-to 18-year-old age group (N=51)</b>				
Physical health summary score	71.9±22.9	75.6±13.9	-0.678	0.498
Emotional functioning summary score	72.4±23.5	74.0±18.1	-0.423	0.673
Social functioning summary score	87.7±17.4	93.1±11.0	-2.314	0.021*
School functioning scores	76.7±19.4	72.5±17.9	-1.131	0.258
Psychosocial health summary score	79.0±16.8	79.9±13.4	-0.415	0.678
Total scale score	76.4±17.0	78.4±12.2	-0.886	0.376

\*p<0.05. z: Wilcoxon Signed Ranks Test.

Australian adolescents and reported that girls had lower functional and aesthetic body satisfaction than boys.<sup>37</sup> Additionally, in their

study investigating the social functioning quality of life and self-esteem in girls and boys with disabilities taking part in adapted

competitive sport, Dinomais et al. found that girls had significantly reduced self-esteem and 'attractive body' scores.<sup>38</sup> When considering the social status and functions seen according to gender difference, girls tend to have more problems with self-esteem and sociality than boys. The lack of self-confidence can result in anxiety and may lead to isolation in social functioning.<sup>2</sup> The girls' parents may have noticed these social problems, or the girls responded with inaccurate answers due to social desirability. Future studies should include larger sample size, for can generalize the results regarding gender difference. In addition, there was a trend toward changes in the physical and psychosocial health summary scores between the girls and their parents. Bisegger et al. assessed the HRQoL of 3,710 children and adolescents and found that the physical and psychological dimensions decrease more with increasing age for girls than for boys.<sup>39</sup> According to these mentioned studies, whether girls are healthy or have different pathologies, they seem to have more disadvantages than boys. Future studies should examine whether these disadvantages or other factors cause the different perceptions of HRQoL parameters between girls and their parents.

When examining the results relating to the individuals' age group, the results did not differ. Both groups obtained higher social functioning scores than their parents. Bisegger et al. found that scores decreased with increasing age, especially after age 12, for the physical and psychological dimensions of HRQoL in 3,710 children and adolescents.<sup>39</sup> Gaspar et al. reported that children had higher HRQoL scores than adolescents.<sup>32</sup> The findings of this study showed that a difference exists between the perceptions of girls and their parents about the social functioning of the adolescent with IS. These results suggest that either the adolescents overestimate their perceived HRQoL or their parents underestimate it. However, parents consider their child's HRQoL to be worse than do their children. Since this discrepancy between the adolescents and their parents may have negative effects on the healthy social integration and adaptation of the adolescent with IS. More studies are needed that shed light on the factors that cause this discrepancy. In addition, social functioning and the HRQoL of the adolescent may also affect

participation in treatment by the adolescent with IS. Also, it is needed future studies investigated results of this discrepancy between adolescents and their parents for shed light on how health professionals and parents should approach adolescents during the treatment process regarding their developmental stages and functioning. We consider that, regardless of age group, the social functioning, social issues, and social desirability of adolescents with IS should be comprehensively examined.

#### **Limitations**

A limitation of the study is that there was no control group that included healthy individuals and their parents for comparison purposes. Therefore, the comparison could not be made between in the perceptions of scoliosis individuals and their parents and differences in the perceptions of healthy individuals and their parents. In addition, the questionnaires did not include open questions about the factors that caused the parents to perceive the HRQoL of their child as worse than their children in the study. The future studies that will be planned by considering the limitations of this study and included a larger sample for gender comparison are needed.

#### **Conclusion**

To our knowledge, this is the first study to explore the comparison of adolescent and parental perception of general HRQoL of individuals with IS using the PedsQL. The perception of physical health, emotional functioning, school functioning, and psychosocial health regarding the girls were similar between girls and their parents. Girls with IS perceived their level of social functioning and HRQoL higher than their parents. The perceptions relating to the parameters of HRQoL were similar between boys with IS and their parents. Implications from this study include the discrepancy between the individuals and their parents about individuals' HRQoL may have a negative effect on their rehabilitation, healthy social integration, and adaptation of individuals with IS to the social environment. This subject should be taken into account during the rehabilitation process.

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**Conflicts of Interest:** *None*

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