

# Relation between functional ability and health-related quality of life of children with juvenile rheumatoid arthritis

HYO-JEONG KWON, PT, MS<sup>1)</sup>, YOU LIM KIM, PT, MS<sup>1)</sup>, SUK MIN LEE, PT, PhD<sup>1)\*</sup>

<sup>1)</sup> Department of Physical Therapy, Sahmyook University: 26-21 Gongneung2-dong, Nowon-gu, Seoul 139-742, Republic of Korea

**Abstract.** [Purpose] The aim of this study was to assess patients' health-related quality of life, compare it with a healthy age-matched population, and examine associations between functional ability and quality of life among juvenile rheumatoid arthritis (JRA) patients. [Subjects and Methods] The study participants were 26 JRA patients and 25 controls. The Childhood Health Assessment Questionnaire and the Pediatric Quality of Life Inventory 4.0 Generic Core Scales were used to evaluate functional ability and health-related quality of life, respectively. [Results] Functional ability scores averaged 0.37 in the JRA group and 0.08 in the control group. There were significant between-group differences in functional ability scores in the overall cohort and in the subgroup of participants aged 14–16 years. Health-related quality of life scores were significantly lower in the JRA group than in the control group (68.39 vs. 85.17). In the JRA group, functional ability was statistically positively correlated with health-related quality of life. [Conclusion] We conclude that the mental state of adolescents with JRA affects their particular functional abilities. Subjects in the 14–16 age group who had a longer disease duration and higher difficulty scores showed a lower health-related quality of life than children in the other age groups.

**Key words:** Juvenile rheumatoid arthritis, Functional ability, Health-related quality of life

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## INTRODUCTION

The estimated prevalence of juvenile rheumatoid arthritis ranges from 16 to 150 persons per 100,000<sup>1)</sup>. Juvenile rheumatoid arthritis (JRA) is diagnosed in children aged less than 16 years who have arthritis for at least 6 weeks. Though the etiology is unknown, Ravelli and Martini reported that genetic and environmental factors are associated with juvenile rheumatoid arthritis<sup>2)</sup>.

JRA often results in significant impairments such as persistent pain, limited range of joint motion, joint stiffness, growth disturbance and poor physical fitness<sup>3, 4)</sup>. This is of concern because physical condition through childhood and adolescence results in numerous short- and long-term health problems.

In addition, the aerobic, anaerobic, and functional abilities of juvenile rheumatoid arthritis patients have been reported to be lower than those of normal children<sup>5)</sup>. Functional ability is therefore a critical consideration in the treatment of juvenile rheumatoid arthritis, and its evaluation determines a patient's current state as well as the efficacy of treatment.

A functional ability assessment is also a quick method of evaluating the disease stage and prognosis<sup>6)</sup>.

Many studies have reported that the health-related quality of life of children with juvenile rheumatoid arthritis is poor compared to that of healthy children<sup>7)</sup>. Nearly 20% of juvenile rheumatoid arthritis patients manifest behavioral problems, social isolation, depression, and anger<sup>7)</sup>. Melancholia also affects the health-related quality of life of juvenile rheumatoid arthritis patients<sup>8)</sup>. Many studies have found that pain is associated with health-related quality of life<sup>9–11)</sup>. Disease progression was also associated with health-related quality of life<sup>12)</sup>. However, while the association between pain and health-related quality of life has been the subject of many studies, few studies have focused on the association between functional ability and quality of life in juvenile rheumatoid arthritis.

The aim of this study was to assess patients' health-related quality of life and compare it with a healthy age-matched population, and to examine associations between functional ability and quality of life among juvenile rheumatoid arthritis patients.

## SUBJECTS AND METHODS

We studied 51 subjects including 26 children with juvenile rheumatoid arthritis and 25 normal children visiting a hospital in Gyunggido, Korea. The inclusion criteria were an age of 8 to 16 years; a diagnosis of JRA; the ability to move independently, communicate, and follow instructions

\*Corresponding author. Suk Min Lee (E-mail: leesm@syu.ac.kr)

in research tests; and voluntary consent to participation in the experiment after being given an explanation of content and told about its purposes. All experimental protocols and procedures were explained to each subject, and they were approved by the Institutional Review Board of Sahmyook University, Korea. All subjects provided their written informed consent prior to study enrollment.

Functional ability was assessed using a modified Korean version of the CHAQ-DI. The CHAQ assesses subjects' performance across 8 activity areas: dressing, grooming, standing up, eating, walking, hygiene, reaching with the hands, and holding ability. Each of the 30 CHAQ items is scored on a 3\_ point scale: 'not difficult' (0 points), 'a little difficult' (1 point), 'very difficult' (2 points), and 'can't do' (3 points). The highest score determines the functional level of each corresponding area. If any help or assistive devices are necessary to achieve perfect performance, at least 2 points are recorded for the corresponding area. Point averages for each of the 8 functional areas range from 0–3 points, with 0 representing no difficulty and 3 representing serious difficulty. The participants children were instructed to read the survey explanation and questions and to handwrite answers together with their parents within approximately 10 minutes. A therapist provided additional explanations when requested by the respondents. The measurement tool's reliability has been reported to have a Cronbach's alpha = 0.88–0.97<sup>13</sup>).

Health-related quality of life was assessed using a modified Korean version of the PedsQL<sup>14</sup>. The PedsQL comprises 23 questions: 8 physical items, 5 mental items, 5 social items, and 5 school-life indications. The period to recall of the survey was 1 month. Items are scored as 0 points for 'no problem at all', 1 point for 'almost no problem', 2 points for 'problem sometimes', 3 points for 'problems often', and 4 points for 'problems almost always'. Each question's point value is converted to a corresponding score on a 0–100 point scale, with scores of 1, 2, 3, and 4 points corresponding to scores of 75, 50, 25, and 0 points, respectively. The final score ranges from 0 to 2,300, with higher scores indicating better quality of life. The participants children were instructed to read the survey explanation and questions and to handwrite answers together with their parents within approximately 5 minutes. A therapist provided additional explanations when requested by the respondents. The measurement tool's reliability has been reported to have a Cronbach's alpha = 0.93<sup>15</sup>).

All of the analytical and statistical processing performed in this study was conducted using SPSS ver. 21.0. The Kolmogorov-Smirnov test was used to determine the normality of the general subject characteristics and the measured variable values. The independent sample t-test was used to evaluate differences in health-related quality of life between the juvenile rheumatoid arthritis patients and normal children, and the Mann-Whitney U test was used to examine group differences in functional ability. One-way ANOVA was used to compare age-specific differences in health-related quality of life and the Kruskal-Wallis test was performed to compare age-specific differences in functional ability. A Spearman correlation analysis was conducted to identify correlations between functional abilities and health-related quality of life. The Scheffe test was used for post hoc

analysis. For all analyses, the significance level was chosen as 0.05.

## RESULTS

The general characteristics of the subjects shown in Table 1.

Differences in functional ability between the children with juvenile rheumatoid arthritis and normal children are shown in Table 2. The functional ability scores of males and females were 0.46 and 0.22 respectively in the juvenile rheumatoid arthritis group, and 0.04 and 0.12 respectively in the control group. The functional ability scores of age averaged 0.37 in the juvenile rheumatoid arthritis group and 0.08 in the control group. There were significant group differences in functional ability scores categorized by gender, overall cohort and the subgroup of participants aged 14–16 years ( $p < 0.05$ ).

Differences in health-related quality of life between children with juvenile rheumatoid arthritis and normal children are shown in Table 3. The health-related quality of life scores of males and females were 67.46 and 69.67 respectively in the juvenile rheumatoid arthritis group, and 85.43 and 84.78 respectively in the control group. There were significant group differences in health-related quality of life scores categorized by gender ( $p < 0.05$ ). Average health-related quality of life scores were significantly lower in the juvenile rheumatoid arthritis group than in the control group (68.39 vs. 85.17,  $p < 0.001$ ).

Correlations between functional ability and health-related quality of life children with juvenile rheumatoid arthritis are presented in Table 4. Negative correlations were found between functional ability scores and each dimension of health-related quality of life. CHAQ-DI scores decreased as

**Table 1.** General characteristics of the subjects

	JRA children (n = 26)	Normal children (n = 25)
Gender (male/female)	15/11	15/10
Height (cm)	141.66±17.25*	151.61±14.25
Weight (kg)	40.05±10.73	40.30±11.91

\* $p < 0.05$

**Table 2.** Comparison of functional ability scores (CHAQ-DI) (N=51)

	JRA children (n = 26)	Normal children (n = 25)
Gender	Male	0.46±0.72*
	Female	0.22±0.26*
Age	8–10 years (A)	0.20 ±0.26 <sup>a</sup>
	11–13 years (B)	0.25±0.45
	14–16 years (C)	0.61±0.80*
	All	0.37±0.58*

\* $p < 0.05$

<sup>a</sup>: mean ± SD

JRA children: juvenile rheumatoid arthritis children, CHAQ-DI: Childhood Health Assessment Questionnaire-Disability Index

scores of the physical ( $r = -0.709$ ,  $p < 0.01$ ), emotional ( $r = -0.519$ ,  $p < 0.01$ ), social ( $r = -0.623$ ,  $p < 0.01$ ), and school ( $r = -0.466$ ,  $p < 0.05$ ) subscales as well as the overall health-related quality of life score ( $r = -0.736$ ,  $p < 0.01$ ) increased.

Higher physical health-related quality of life scores were associated with higher emotional ( $r = 0.522$ ,  $p < 0.01$ ), social ( $r = 0.640$ ,  $p < 0.01$ ), and school ( $r = 0.655$ ,  $p < 0.01$ ) subscale scores as well as with the higher overall health-related quality of life score ( $r = 0.904$ ,  $p < 0.01$ ). Emotional health-related quality of life was higher when social ( $r = 0.711$ ,  $p < 0.01$ ), school ( $r = 0.513$ ,  $p < 0.01$ ), and overall health-related quality of life ( $r = 0.770$ ,  $p < 0.01$ ) scores were higher. Higher school ( $r = 0.465$ ,  $p < 0.01$ ) and overall health-related quality of life ( $r = 0.838$ ,  $p < 0.01$ ) scores were associated with better social health-related quality of life. Higher overall health-related quality of life scores were associated with better school health-related quality of life ( $r = 0.748$ ,  $p < 0.01$ ).

### DISCUSSION

In the study of Shaw et al., 17 year-old juveniles with rheumatoid arthritis were found to have the poorest functional abilities on the CHAQ<sup>15</sup>). In particular, at least 10% of the adolescent respondents answered that they could not ride a bicycle or enjoy a preferred sport. This was said to be indicative of increased pain levels, reduced overall happi-

ness, and difficulties in the adolescent period. In this study, the average CHAQ-DI score among children with juvenile rheumatoid arthritis aged 14–16 years was 0.61, representing a slightly serious level of difficulty. Functional abilities were reported to be the strongest factor determining mental state<sup>16</sup>). Therefore, we consider that the mental state of adolescents with juvenile rheumatoid arthritis affects their functional abilities. Follow-up studies are expected to investigate the mental state of children aged 14–16 years with poorer than normal functional abilities.

Children with juvenile rheumatoid arthritis have been reported to have a lower health-related quality of life than normal children<sup>16</sup>) or children with other chronic diseases<sup>17</sup>). Consistent with these reports, we found significant differences in health-related quality of life across all age groups. The health-related quality of life of juveniles with rheumatoid arthritis exhibited age-specific differences. Arthritis patients in the 14–16 year age group showed lower back strength, body fat percentage, and functional abilities than normal children. The study of Amine et al. reported that the health-related quality of life decreased during the adolescent period and worsened with a later diagnosis. Key variables indicative of a degrading health-related quality of life have been reported to be disease duration, difficulty scores, and pain<sup>10</sup>). In the present study, subjects in the 14–16 year age group who had longer disease durations and higher difficulty scores showed a lower health-related quality of life than children in other age groups.

In the early stage of juvenile rheumatoid arthritis, pain leads parents, school staff, and medical experts to aggressively limit patients' exercise for their protection. Out of the fear of damaging weak joints, patients' participation in normal childhood activities tends to be limited, and patients take greater precautions when outdoors<sup>18</sup>). This reduction in physical activity from the ages of 8 through 16, a key period for normal development, delays the optimization of large-scale movements that require speed, power, and coordination. As childhood development proceeds through the interaction of physical, emotional, social, and school dimensions, limited development would ultimately have an impact on health-related quality of life<sup>15</sup>). An initial reduction in physical activity because of pain will subsequently affect physical strength and the quality of life of children with juvenile rheumatoid arthritis, and, in turn, further diminish physical activity forming a vicious cycle. Through

**Table 3.** Comparison of health-related quality of life (N=51)

	Age	JRA children (n = 25)	Normal children (n = 26)
Sex	Male	67.46±17.94*	85.43±14.80
	Female	69.67±16.71*	84.78±10.26
Age	8–10 years (A)	72.17±14.76 <sup>a*</sup>	89.13 ±7.10
	11–13 years (B)	76.81±14.01*	88.53± 10.43
	14–16 years (C)	55.07±14.93*	78.74± 16.82
	All	68.39± 17.13 <sup>***</sup>	85.17± 12.94
	Post hoc analysis	A B   C*	

\* $p < 0.05$ , \*\*\* $p < 0.001$

<sup>a</sup>: mean ± SD

JRA children: juvenile rheumatoid arthritis children, CHAQ-DI: Childhood Health Assessment Questionnaire-Disability Index

**Table 4.** Correlations among physical fitness, functional ability, and health-related quality of life

	C-DI	PedsQL	PedsQLP	PedsQLE	PedsQLS	PedsQLSC
C-DI	1					
PedsQL	-0.736**	1				
PedsQLP	-0.709**	0.904**	1			
PedsQLE	-0.519**	0.770**	0.522**	1		
PedsQLS	-0.623**	0.838**	0.640**	0.711**	1	
PedsQLSC	-0.466*	0.748**	0.655**	0.513**	0.465*	1

\* $p < 0.05$ , \*\* $p < 0.01$

C-DI: Childhood Health Assessment Questionnaire-Disability Index, PedsQL: Pediatric Quality of Life Inventory 4.0 Generic Core Scales, PedsQLP: Physical PedsQL, PedsQLE: emotional PedsQL, PedsQLS: social PedsQL, PedsQLSC: school PedsQL

the assessment of functional ability, children's status can be accurately identified and exercise interventions that would enable participation in daily activities should be presented in order to break the vicious cycle of decreasing activity leading decreasing functional ability in juvenile rheumatoid arthritis and improve patients' quality of life.

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