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Quality of life and level of physical activity in primary school children with juvenile idiopathic arthritis in Primorje-Gorski Kotar County

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The aim of this cross sectional study was to assess the quality of life (QOL) and level of physical activity in primary school children with juvenile idiopathic arthritis (JIA) in the Primorje-Gorski Kotar County as compared to healthy peers, and to identify the most pronounced differences in QOL between them. The study included 13 children with JIA recruited from the paediatric rheumatology clinic and 17 healthy children from primary school. The children were aged 8-14 years. All participants, including their parents, completed questionnaires to assess the level of their physical activity (Physical Activity Questionnaire for Children; PAQ-C) and QOL (Pediatric Quality of Life Inventory (PedsQL™) Generic Core and Rheumatology Module scales). Study results showed statistically significant differences in the QOL associated with physical functioning/health (p=0.033), school activities (p=0.008) and psychosocial health (p=0.033) between JIA and control groups. Responses in the rheumatologic questionnaire revealed a statistically significant difference in the QOL associated with pain (p=0.041), daily activities (p=0.011), treatment (p=0.002), concern (p=0.0006) and communication (p=0.0002) between JIA and control groups. The JIA group showed a significantly lower level of physical activity (p=0.008). There was a statistically significant (p=0.0000) correlation between the QOL associated with pain and the QOL associated with physical functioning/health (r=0.94), emotional functioning (r=0.71), social functioning (r=0.74), school functioning (r=0.56) and psychosocial health (r=0.80). In conclusion, study results suggested JIA to affect QOL in almost all domains in the affected primary school children, with the greatest differences from their healthy peers being recorded in the QOL associated with worrying and communicating about their illness.

Key words: ARTHRITIS, JUVENILE; EXCERCISE; QUALITY OF LIFE; SCHOOLS; CHILD

INTRODUCTION

Juvenile idiopathic arthritis (JIA) is the most common rheumatic disorder in children and one of the most common causes of part-time or long-term disability (1). It has been shown that the frequency of JIA varies according to race and location. In Europe, the incidence rates *per* 100 000 range from 22.6 in Norway to 3.5 in the former East Berlin area of Germany. The prevalence rate in Sweden is 86 *per* 100 000 as compared to 31 *per* 100 000 in Costa Rica and

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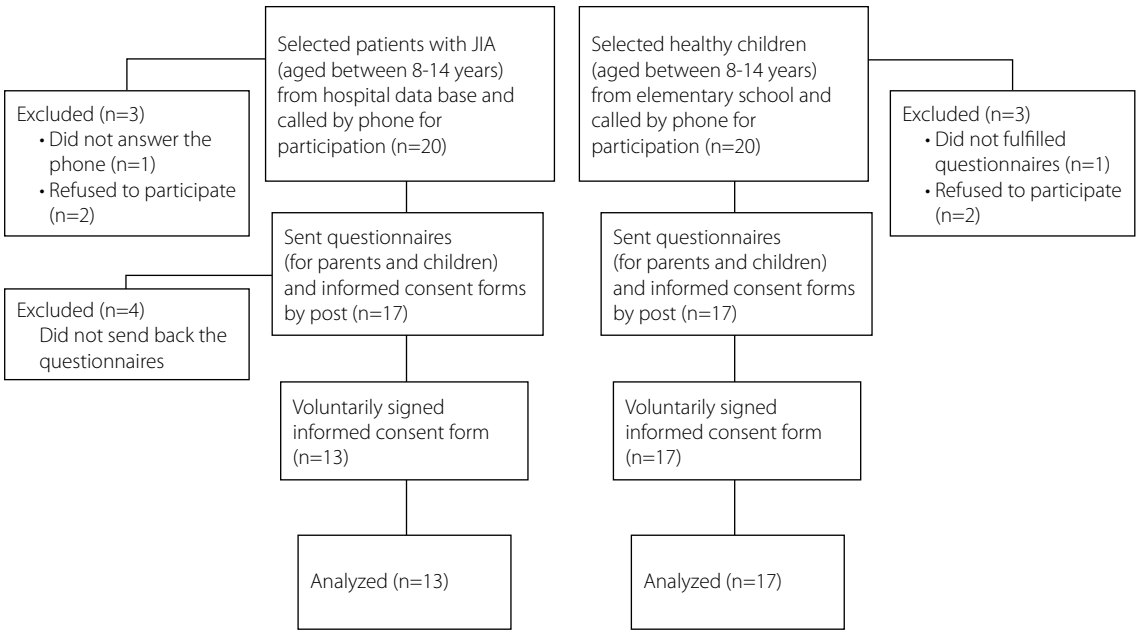

FIGURE 1. **Participants' flow chart**

0.83 *per* 100 000 in Japan (2). The diagnosis is set as the arthritis is manifested by inflammation of one or more joints, occurring before the age of 16, lasting for more than six weeks (3).

The disease is twice as common in girls as in boys although in certain subtypes (e.g., oligoarthritis) by the age of 8, the ratio of diseased girls to boys reaches up to 8:1, especially if iridocyclitis is present. JIA most commonly occurs in preschool age between the first and third year of life, with the exception of the disease incidence before the age of six months, i.e. in infants (4, 5). More than half of patients have oligoarticular type of the disease that is rarely seen in adults, whereas seropositive polyarthritis is rare in childhood.

The causative factors and pathogenesis of JIA are poorly understood, but the disease is known to arise as a result of the interaction of environmental, genetic and immune factors (6-8).

Like any other disease, JIA can greatly affect the possibility to perform physical activity and thus affect the child's quality of life (QOL) (9). The child may be ashamed of being different, which in turn leads to social isolation. Frequent school absenteeism due to medical examinations and hospital stays can make it difficult to perform schoolwork, and the presence of pain often limits them in exercise and physical activity.

Exterior differences such as growth retardation, hairiness and acne can be the result of taking medication. JIA can also influence the inability to choose the profession the child wants and the fear of not starting a family in the future. These problems can create feelings of disappointment and sadness due to the inability to achieve the desired goals; therefore, psychic support is required through all aspects of treating a child with JIA (10).

The aim of this cross sectional study was to assess the QOL and level of physical activity in primary school children with JIA in the Primorje-Gorski Kotar County as compared to their healthy peers, and to identify the most pronounced differences in QOL between them.

Given that JIA is a disease that has a chronic course and there is no therapy that can completely stop the course of the disease, the assumption was that the children suffering from JIA were concerned about their health. Therefore, all questions related to the child's physical, emotional, social and school activities were within the scope of this research.

SUBJECTS AND METHODS

Subjects, recruitment and study design

This was a cross-sectional study to assess the QOL and level of physical activity in primary school children (8-14 years old) suffering from JIA and healthy controls. All children with JIA (a total of 20 patients in the database) were selected from the Kantrida Department of Rheumatology, Rijeka University Hospital Centre database. Healthy children were randomly selected (n=20) from the Kantrida Primary School. Parents were contacted by phone and explained their and children's participation in the study.

Questionnaires for parents and children together with the informed consent forms were sent by post to those partici-

pants who accepted participation in the study. As shown in the flow chart (Figure 1), 13 parents and their children (four boys and nine girls) with JIA and 17 parents and their healthy children (six boys and eleven girls) from voluntarily signed the informed consent forms and properly filled out the questionnaires. Two trained researchers collected all demographic data (sex, age, body mass index (BMI)) and filled out the questionnaires. All participants were included in final statistical analysis. The research was approved by the Research Ethics Committee of the Rijeka University Hospital Centre (ID: 003-05/19-01/02).

Ethical approval

All procedures performed in studies involving human participants were in accordance with ethical standards set by the institutional and/or national research committee (Research Ethics Committee of the Rijeka University Hospital Centre; ID: 003-05/19-01/02) and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

Quality of life measurement

The QOL was measured using Pediatric Quality of Life Inventory™ (PedsQL™) 4.0 Generic Core and PedsQL™ 3.0 Rheumatology Module scales (Copyright © 1998 JW Varni, Ph.D.; all rights reserved; PedsQL™ contact information and permission to use: Mapi Research Trust, Lyon, France – Internet: https://eprovide.mapi-trust.org and www.pedsql.org/index.html). Both scales comprise parallel child self-report and parent proxy-report formats. The parent proxy-report forms are parallel to the child self-report forms and are designed to assess the parent's perceptions of the child's QOL. In our study, we used child self-report and parent proxy-reports for ages 8-12 (child) and 13-18 (adolescent). The instructions for both scales ask how much of a problem each item has been during the past 1 month. A 5-point Likert scale is utilized across child self-report for ages 8-18 and parent proxy-report (0 = never a problem, 1 = almost never a problem, 2 = sometimes a problem, 3 = often a problem, 4 = almost always a problem). Items are reverse scored and linearly transformed to a 0-100 scale (0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0), so that higher PedsQL scores indicate better QOL. Scale scores are computed as the sum of the items divided by the number of items answered.

The PedsQL 4.0 Generic Core Scale is a 23-item multidimensional questionnaire that encompasses the following: 1) physical functioning scale (8 items), 2) emotional functioning scale (5 items), 3) social functioning scale (5 items), and 4) school functioning scale (5 items).

The physical health summary score (8 items) is the same as the physical functioning scale. To create the psychosocial health summary score (15 items), the mean is computed as the sum of the items divided by the number of items answered in the emotional, social, and school functioning scales. The Croatian version was used with permission of Mapi Research Trust, Lyon, France – Internet: https://eprovide.mapi-trust.org and www.pedsql.org/index.html (11).

The PedsQL 3.0 Rheumatology Module is a 22-item multidimensional questionnaire that encompasses the following scales: 1) pain and hurt (4 items), 2) daily activities (5 items), 3) treatment (7 items), 4) worry (3 items), and 5) communication (3 items). The format, instructions, Likert scale, and scoring method are identical to those of the PedsQL 4.0 Generic Core Scales, with higher scores indicating better QOL. The English version was translated to Croatian version (2 forward and 2 backward translations) with permission from the authors and Mapi Research Trust, Lyon, France, according to described steps for complete translation and validation (Copyright © 1998 JW Varni, Ph.D.; all rights reserved; PedsQL™ contact information and permission to use: Mapi Research Trust, Lyon, France – Internet: https://eprovide.mapi-trust.org and www.pedsql.org/index.html). Reading, comprehension and understanding of the translated questionnaires were tested in all 13 JIA patients and their parents and 17 healthy control children and their parents, and furthermore approved by the authors and Mapi Research Trust (10, 12).

Physical activity measurement

Physical activity was measured using the Physical Activity Questionnaire for Children (PAQ-C) (13). It is a self-administered, 7-day recall instrument. It was developed to assess general levels of physical activity throughout primary school for students in grades 4 to 8 and approximately 8 to 14 years of age. The PAQ-C provides a summary of physical activity score derived from 9 items, each scored on a 5-point scale. A score of 1 indicates low physical activity, whereas a score of 5 indicates high physical activity. Each item can be calculated as a single mean score (physical activity in spare time, during physical education classes, most of the time during recess, during lunch besides eating, right after school, evenings, last weekend, last week in general and for every day last week) or, after completing all 9 items, as the final activity summary score. The item number 10 can be used to identify if anything prevented students from doing their normal physical activities but this question is not used as part of the summary activity score (13).

The original questionnaire (14) was translated to Croatian and some adjustments were made to the first item with re-

gard to the type of sports practiced in Croatia with subsequent validation. The Croatian version was used with permission from the author *Vidaković Samaržija* (15).

Data analysis

Data were analysed using the Statistica, Version 13.3 software. Descriptive statistics examined the distributions and range of scores. These data were expressed as median and range (e.g., age, BMI, mass, height, percentile) and as total numbers (e.g., number of participants, gender) (Table 1).

To compare JIA and healthy groups, Mann-Whitney U test for independent variables was used (Tables 2 and 3). For analysis of impediment frequency in physical activity during the past week, we used Fisher exact test (Table 3).

We further report the Pearson correlation coefficient (r) for the associations among the QOL associated with pain and the QOL associated with physical functioning/health, emotional functioning, social functioning, school functioning and psychosocial health. A nominal significance level of 0.05 was used in all tests.

TABLE 1. **Characteristics of study subjects**

Variable	Group	
	JIA	Control
n	13	17
Age (yrs), median (range)	10 (8-14)	10 (8-14)
Gender (N), M/F	4/9	6/11
BMI (kg/m^2), median (range)	22 (18-24)	17.5(13.6-21.5)
Mass (kg), median (range)	43 (22-80)	36 (27-62)
Height (cm), median (range)	150 (125-158)	155 (133-178)
Percentile (%), median (range)	46 (2-90)	70 (9-98)

JIA, juvenile idiopathic arthritis; F, female; M, male.

RESULTS

Thirteen children with JIA and 17 healthy ones completed the questionnaires together with their parents (Figure 1). For all 30 participants, median age was 10 (8-14) years with 69% of girls in the JIA group and 65% of girls in the control group. BMI values were in correlation with lower physical activity (data not shown). The main characteristics are displayed in Table 1.

As expected, the results of our study showed lower levels in all QOL categories in the group of children suffering from JIA (PedsQL™ Generic Core and Rheumatology Module Scales) and statistical significance was found in the QOL associated with physical functioning (p=0.033), school functioning (p=0.008), psychosocial health (p=0.033), pain (p=0.041), daily activities (p=0.011), treatment (p=0.002), and the highest in worries (p=0.0006) and communication categories (p=0.0002) (Table 2).

The results showed overall lower level of physical activity (PAQ-C) in children with JIA, with statistical significance in the time spent in physical education (p=0.012), afternoons (2.00-6.00 pm) (p=0.027), intensity of physical activities (p=0.002) and overall score for physical activity in the last week (p=0.008) (Table 3).

Five children with JIA stated they had been prevented to have physical activities in the last week, unlike the control

TABLE 2. **Quality of life (Rheumatology Module and Generic Core Scales) in juvenile idiopathic arthritis and control group**

Questionnaire	Group		
	JIA (n=13)	Control (n=17)	p values[a]
	Median (range)	Median (range)	
PedsQL™ Generic Core Scales (0-100)			
Physical Functioning/ Physical Health Summary Score	81.3 (15.6-100.0)	96.9 (68.8-100.0)	0.033*
Emotional Functioning	80.0 (20.0-100.0)	85.0 (45.0-100.0)	0.360
Social Functioning	85.0 (40.0-100.0)	95.0 (70.0-100.0)	0.196
School Functioning	75.0 (55.0-100.0)	95.0 (65.0-100.0)	0.008*
Psychosocial Health Summary Score	78.3 (45.0-100.0)	91.7 (71.7-100.0)	0.033*
Total Score	79.8 (30.3-100.0)	93.8 (75.9-100.0)	0.056
PedsQL™ Rheumatology Module Scales (0-100)	Median (range)	Median (range)	p values[a]
Pain	81.25 (12.5-100.0)	100.0 (67.5-100.0)	0.041*
Daily Activities	100.0 (45.0-100.0)	100.0 (90.0-100.0)	0.011*
Treatment	75.0 (25.0-100.0)	100.0 (67.9-100.0)	0.002*
Worries	75.0 (0.0-100.0)	100.0 (75.0-100.0)	0.0006*
Communication	66.7 (0.0-100.0)	100.0 (83.3-100.0)	0.0002*

[a]Mann-Whitney U test; *p<0.05 significant; JIA, juvenile idiopathic arthritis

TABLE 3. Physical Activity (PAQ-C) in juvenile idiopathic arthritis and control group

Questionnaire	Group		
PAQ-C	JIA (n=13)	Control (n=17)	p value[a]
	Answer score, median (range)	Answer score, median (range)	
1. question: list of activities	1.2 (1.0-1.9)	1.3 (1.0-2.0)	0.177
2. question: physical education	4.0 (1.0-5.0)	5.0 (4.0-5.0)	0.012*
3. question: break	1.0 (1.0-4.0)	2.0 (1.0-5.0)	0.720
4. question: lunch	3.0 (1.0-5.0)	4.0 (2.0-5.0)	0.063
5. question: afternoons (14-18h)	3.0 (1.0-5.0)	3.0 (1.0-5.0)	0.027*
6. question: evenings (18-22h)	2.0 (1.0-5.0)	4.0 (1.0-4.0)	0.080
7. question: weekend	2.0 (1.0-4.0)	3.0 (1.0-5.0)	0.393
8. question: weekly intensity	3.0 (1.0-4.0)	4.0 (1.0-5.0)	0.002*
9. question: daily frequency	2.9 (1.0-4.9)	3.6 (2.6-5.0)	0.082
Overall score	2.5 (1.6-3.4)	3.1 (2.2-4.4)	0.008*
10. question: impediment to performing physical activities last week	Yes/No (%)	Yes/No (%)	p value[b]
	5/8 (63%)	1/16 (6%)	0.039*

[a]Mann-Whitney U test; [b]Fisher exact test; *p<0.05 significant; JIA, juvenile idiopathic arthritis

TABLE 4. Pearson correlations (r) between PedsQL™ Rheumatology Module scale for pain and PedsQL™ Generic Core Scales

Variable	PedsQL™ Generic Core Scales									
	Physical Functioning/ Physical Health Summary Score		Emotional Functioning		Social Functioning		School Functioning		Psychosocial Health Summary Score	
PedsQL™ Rheumatology Module scale - Pain	r	p value	r	p value	r	p value	r	p value	r	p value
	0.94	0.0000*	0.71	0.0000*	0.74	0.0000*	0.56	0.0000*	0.80	0.0000*

group where only one child had been prevented to be physically active (p=0.039) (Table 3).

There was a statistically significant moderate to strong correlation between the QOL associated with pain and physical functioning/health (r=0.94), emotional functioning (r=0.71), social functioning (r=0.74), school functioning (r=0.56) and psychosocial health (r=0.80, p<0.001 all) (Table 4).

There was no statistically significant difference between the responses by children and their parents in both questionnaires (data not shown).

DISCUSSION

There is little information on the QOL and level of physical activity in primary school children with JIA in particular regions of Croatia, and with this study we wanted to explore their QOL in the Primorje-Gorski Kotar County. Furthermore, we wanted to explore differences in the mentioned parameters in comparison to their healthy peers from the same region and to identify the most pronounced differences.

Juvenile idiopathic arthritis is a great challenge to the child and the whole family, but it also poses a challenge to health care professionals who encounter them in their daily routine. Adaptation to the illness, treatment of illness, administration and side effects of medications, changing lifestyle habits are just some of the stages of the collaboration process between medical team and the child, as well as his/her parents. Common problems of a child with JIA include daily medication, painful diagnostic and therapeutic procedures, frequent doctor visits, hospital visits, school absenteeism, peer isolation due to physical limitations and diversity, lack of confidence, behavioural disorders (feelings of guilt, aggression), side effects of drugs, activity limitation or inability to play their favourite sports, growth retardation, increased hairiness, acne, joint deformities, use of aids, feelings of powerlessness ('overprotection' by family), inability to live independently, worries about the future unemployment caused by prolongation of schooling, inability to choose the desired profession, economic dependence, fear of being unable to start one's own family, shame, social isolation, fear of rejection, etc. (16).

The results of our study showed a statistically significant difference in almost all QOL categories in the group of children with JIA. The biggest difference was certainly in performing physical activities and taking medications, which healthy peers certainly did not need to take. The QOL associated with pain showed a statistically significant correlation with all other categories of life quality. However, almost the same level of severity or greater was shown by the responses related to worrying about their disease, therapy they were taking and communication or talking about their disease to other people. Accordingly, the attitude and support of the family and the environment concerning the disease is of utmost importance, including child monitoring by experts through the psychic aspect of treatment.

An interdisciplinary approach is crucial to detect and overcome unwanted complications in a timely manner, which includes paediatric rheumatologist, physiatrist, occupational therapist, psychologist, dietician and physiotherapist (17). Physical therapy is an integral part of the treatment of JIA. It should be started as early as possible, usually after the acute phase of the disease has passed. Early initiation of physiotherapy, while the disease is not yet advanced, prevents consequences of the disease, preserves functional capacity and prevents permanent disability (6, 18). Other goals of physical therapy and rehabilitation are control of pain and inflammation, prevention of contractures and maintenance of the range of motion, prevention of the onset and further progression of muscular atrophy, and stimulating the child's independence in daily living activities (6). Early beginning of physical therapy not only results in a shorter duration of physical therapy and reduced joint pain but also makes such treatment much more cost-effective for the health care system than the treatment for complications of the disease.

Due to fatigue, pain and stiffness, children suffering from JIA are less active than their peers. Poor physical activity can lead to systemic muscular atrophy and reduced cardiovascular capacity. Therefore, it is recommended that neurodevelopmental and neurosensory techniques be included in the treatment (19). Osteoporosis may develop in patients with JIA as a result of corticosteroid treatment, impaired activity, and eating disorders. Exercise with adequate load should be included in the treatment of osteoporosis.

Therapeutic exercises are certainly the most important tool of physiotherapy in the treatment of children with JIA. The therapy program should include different types of exercises, primarily those in water. Isometric exercises and passive range exercises are also used. In addition, proper positioning is very important. Sports that involve overuse of the ankles are not recommended. Moderate intensity aerobic exercises may be performed for up to half an hour a day. Stretching exercises should be carried out continuously, but only after the end of the acute phase of inflammation. Strength exercises are significant in the chronic phase, and can be performed using weights, elastic bands or resistance provided by physical therapist. It is important that all exercises be conducted under the expert supervision of a physiotherapist (6).

In addition to physical therapy itself, physiotherapists educate young patients and their parents. The physiotherapists spend more of their time with children than other medical staff, so they are best suited for this kind of education. In addition, they must explain to the parents how it will be easier to cope with this chronic illness and how the child will maintain a favourable physical status at home too (18).

Timely recognition and diagnosis of JIA and timely initiation of treatment are the main prerequisites for preventing morphological changes in the structures of the musculoskeletal system, reducing pain and improving the QOL including all domains, i.e. physical, intellectual, social, emotional and economic.

Study limitations

There were several limitations to the current investigation, which need to be mentioned. The study may have been underpowered for detecting statistical significance in particular QOL domains due to the small convenience sample involved (JIA, n=13).

Furthermore, no information on the age at diagnosis, severity/activity status, exact duration of disease or treatment, or ongoing physical therapy were taken in consideration and analysis. In addition, in this study, were enrolled only children aged 8-14 years using the registry kept at our hospital (Kantrida Department, Rijeka University Hospital Centre). The respective database has only 20 children aged 8-14 diagnosed with JIA.

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Abbreviations:

ILAR - International League of Associations for Rheumatology
JIA – Juvenile idiopathic arthritis
PAQ-C - Physical Activity Questionnaire for Children
PedsQL - Pediatric Quality of Life Inventory
QOL – Quality of life

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SAŽETAK

Kakvoća života i razina tjelesne aktivnosti djece mlađe školske dobi s juvenilnim idiopatskim artritisom u Primorsko-goranskoj županiji

Tanja Grubić Kezele, Slaven Medjimurec, Marcel Bukarica, Antonela Čorapović, Ariana Fužinac-Smojver

Cilj ovog presječnog istraživanja je utvrditi kvalitetu života (QOL) i razinu tjelesne aktivnosti djece mlađe školske dobi s juvenilnim idiopatskim artritisom (JIA) na lokaciji Primorsko-goranske županije u usporedbi sa zdravim vršnjacima te utvrditi koje su najizraženije razlike među njima vezane za kakvoću života.

Metode: Istraživanje je provedeno na 13-ero djece s JIA-om s popisa liječene na Klinici za dječju reumatologiju i 17-ero zdrave djece iz osnovne škole. Djeca su bila u dobi između 8-14 godina. Svi sudionici, uključujući njihove roditelje, ispunili su upitnike za procjenu razine svoje tjelesne aktivnosti (Physical Activity Questionnaire for Children; PAQ-C) i kvalitetu života (Quality of life Pediatric Quality of Life Inventory™ Generic Core Scale; Rheumatology Module Scale).

Rezultati su pokazali statistički značajne razlike u kakvoći života vezanoj za fizičko funkcioniranje/zdravlje (p =0,033), školske aktivnosti (p = 0,008) i psihosocijalno zdravlje (p = 0,033) između JIA i kontrolne skupine. Odgovori iz reumatološkog upitnika otkrili su statistički značajnu razliku u kakvoći života vezanoj za bol (p = 0,041), dnevne aktivnosti (p = 0,011), liječenje (p = 0,002), zabrinutost (p = 0,0006) i komunikaciju (p = 0,0002) između JIA i kontrolne skupine. JIA skupina pokazala je značajno nižu razinu tjelesne aktivnosti (p = 0,008). Otkrivena je statistički značajna (p = 0,0000) povezanost između kakvoće života vezane za bol i one vezane za fizičko funkcioniranje/zdravlje (r = 0,94), emocionalno funkcioniranje (r = 0,71), socijalno funkcioniranje (r = 0,74)), funkcioniranje u školi (r = 0,56) i psihosocijalno zdravlje (r = 0,80).

Zaključci: Rezultati istraživanja sugeriraju da JIA utječe na kakvoću života u gotovo svim područjima oboljele djece mlađe školske dobi, te da su najveće razlike prema zdravim vršnjacima prisutne u kakvoći života vezanoj za brigu o svom zdravlju i komunikaciju o njihovoj bolesti.

Ključne riječi: ARTRITIS, JUVENILNI; FIZIČKA AKTIVNOST; KAKVOĆA ŽIVOTA; ŠKOLE; DIJETE