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Investigation of the impact of COVID-19 in Children/ adolescents with Juvenile idiopathic Arthritis from a Holistic Perspective: A Controlled Trial

Sinem Yenil [1], Elif Gür Kabul [2], Bilge Başakcı Çalık [1], Gülşah Kılbaş [3] & Selçuk Yüksel [4]

[1] Pamukkale University, Faculty of Physiotherapy and Rehabilitation, Denizli, Türkiye
[2] Uşak University, Faculty of Health Sciences, Physiotherapy and Rehabilitation, Uşak, Türkiye
[3] Pamukkale University, Faculty of Medicine, Department of Pediatric Rheumatology, Denizli, Türkiye
[4] Canakkale Onsekiz Mart University, School of Medicine Department of Pediatric Rheumatology, , Canakkale, Türkiye

Abstract

Objective: The study aimed to examine the effect of coronavirus (COVID-19) exposure on the function and quality of life in children/adolescents with Juvenile Idiopathic Arthritis (JIA).

Materials and Methods: 45 children/adolescents diagnosed with JIA (29 female, 16 male) were included. The impact of coronavirus was questioned with the Numerical Analog Scale, disability level with the Childhood Health Assessment Questionnaire (CHAQ), and quality of life with the Pediatric Quality Of Life Inventory 3.0. Module Arthritis (PedsQL). Participants were divided into two groups: JIA with COVID-19 (n=21) and without COVID-19 (n=24).

Results: The mean age of children/adolescents with JIA's mean age was 13.16 ± 3.53 and disease duration was 3.58 ±2.93 years. There was no difference in impact from coronavirus, quality of life, and disability level between JIA with COVID-19 (46.7%) and without COVID-19 (53.3%)(p>0.05). General health impact from coronavirus had moderate correlation with quality of life-child (r=-0.371) and high correlation with disability level (r=0.511). Psychosocial impact from coronavirus had moderate correlation with quality of life-child (r=-0.493) and quality of life-parent (r=-0,361) and high correlation with disability level (r=0.536). Activity impact from coronavirus had a moderate correlation with quality of life-child (r=-0.371) and a moderate correlation with disability level (r=0.444).

Conclusion: According to our data results, during the pandemic period, children/adolescents with JIA were affected by the coronavirus at the same level whether they had COVID-19 or not, and their quality of life and disability levels did not change. Coronavirus has affected general health and activity, reducing the quality of life and increasing the level of disability. Psychosocially, it reduced the quality of life of both the child/adolescent with JIA and the parents.

Keywords Juvenile idiopathic arthritis · quality of life · coronavirus

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Corresponding author: Elif Gür Kabul elifgur1988@hotmail.com

INTRODUCTION

Coronavirus disease (COVID-19), caused by the SARS-CoV-2 virus, was declared a pandemic in March 2020 (1). During this period, education at school was suspended, and measures were taken to prevent the spread of COVID-19, such as banning people under the age of 20 and over the age of 65 from going out, schools giving up face-to-face education and continuing with distance education. These measures caused them to spend more time at home (2). Additionally, making the use of masks mandatory, emphasizing the importance of hand hygiene and the news reflected in the media have caused anxiety and fear in people (2). This has led to psychological effects on various populations, especially vulnerable groups such as children and older adults (3). These restrictions were found to lead to increased sleep disorders in children and adolescents (4) and a decrease in physical activity (5,6), which may also impact their quality of life.

Juvenile Idiopathic Arthritis (JIA) is the most common rheumatic disease of childhood. Patients are treated with immunosuppressant agents in most cases, as well as nonsteroidal anti-inflammatory drugs (NSAIDs) and corticosteroids. Due to the use of immunosuppressive medications, they may also have an increased susceptibility to contracting COVID-19. In addition, discontinuing the medication may lead to disease flare-ups and an increased risk of infection. (7). Consequently, the coronavirus outbreak has emerged as a significant source of concern for both families and children. Families with children with JIA have been particularly affected due to evidence of viral transmission in schools or congregate settings by children, who were referred to as “super-spreaders” due to their ability to transmit COVID-19 with remarkable efficiency and serious consequences (8,9). In this regard, a study has shown that children over the age of 13 with rheumatological diseases and their parents are psychologically affected by the coronavirus (10). Confidence in returning to school is low in JIA patients given the risk of COVID-19 (11). Although the disease itself does not directly affect children with JIA, COVID-19 infection may have a significant social impact on the quality of life of these young patients (12).

The study holistically examined the effects of the COVID-19 pandemic in children and adolescents with JIA.

MATERIALS AND METHODS

This study design was cross sectional study. The study was conducted in the pediatric rheumatology clinic and the pediatric rheumatology physiotherapy and rehabilitation unit of a university hospital between January and June 2022. All patients admitted between these dates were included in the study. Ethical approval of the study was obtained from the local ethics committee at the meeting number of 21 dated 11.30.2021. All individuals were informed verbally and informed consent forms were signed. The patients with JIA were prospectively registered.

Participants

Forty-five children/adolescents diagnosed with JIA (29 female, 16 male) were included in the study. Participants were divided into two groups diagnosed with COVID-19 confirmed by PCR test between 2021 and 2022: JIA with COVID-19 (n=21) and without COVID-19 (n=24).

The inclusion criteria were as follows: JIA diagnosis based on the international league of associations for rheumatology classification (13), age ranging from 8 to 18 years, and willingness to participate. The 8-18 age range was preferred because this study was conducted in the pediatric rheumatology clinic and the pediatric rheumatology physiotherapy and rehabilitation unit of a university hospital, considering the age ranges in the child and parent forms of the Pediatric Quality Of Life Inventory 3.0. Module Arthritis and the fact that children/adolescents with JIA can easily express their own experiences while answering the outcome measures questions.

Exclusion criteria were: presence of any neurological, orthopedic, cardiopulmonary, or other autoimmune disorders, psychiatric conditions impacting cooperation, history of orthopedic surgery within the past year, stable symptoms and medications,

The impact of coronavirus was questioned with the Numerical Analog Scale, disability level with the Childhood Health Assessment Questionnaire (CHAQ), and quality of life with the Pediatric Quality Of Life Inventory 3.0. Module Arthritis (PedsQL). We asked participants to answer the surveys retrospectively, considering the quarantines during the COVID-19 period.

***Numerical Analog Scale*:** The Numerical Analog Scale (NAS) is a scaling tool commonly used to measure subjective emotional or physical states such as pain. NAS provides participants with the ability to assign a numerical value to evaluate a specific condition. This scale is expressed on a numerical scale ranging from 0 to 10, where 0 represents no distress or symptoms and 10 represents the highest level of distress or symptoms. Participants expressed how intense or bothersome they found a particular condition based on their own experiences using a numerical value on this scale. NAS is a reliable measure frequently used in clinical trials or healthcare research (14).

In this study, NAS was used to evaluate the general health, psychosocial, activity, and education impact of coronavirus.

Childhood Health Assessment Questionnaire (CHAQ): CHAQ was developed to assess the functional abilities of children/adolescents. The questionnaire can be applied to all children between the ages of 6 months and 18 years. It consists of 30 questions and 8 subsections. The disability index is a score ranging from 0 to 3, with higher scores indicating greater disability (15).

Pediatric Quality Of Life Inventory 3.0. Module Arthritis (PedsQL): The PedsQL 3.0 Arthritis Module was developed to assess the health-related quality of life in children with rheumatic diseases. The PedsQL 3.0 Arthritis Module includes the subsections "Pain and Hurt" (4 items), "Activities of Daily Living" (5 items), "Treatment" (7 items), "Worry" (3 items), and "Communication" (3 items). It contains 22 items. The PedsQL 3.0 Arthritis Module has child and parent forms for 2-4 years, 5-7 years, 8-12 years and 12-18 years, divided into different age groups. In this study, 8-12 years old and 12-18 years old child and parent forms were used. A high total score on the PedsQL scale means a high quality of life (16).

Statistical Analysis

Power analysis was performed using the G-Power 3.1 program to determine the sample size of the study. In the power analysis based on the HRQoL (KIDSCREEN-10 T-Score) of male children parameter in pre-COVID-19 and within-COVID-19 data of the reference article, it was calculated that 95% confidence and 85% power could be obtained with 38 patients (JIA with COVID-19=19 patients, and JIA without COVID-19=19 patients) (d= 1.0193 effect size) (17).

Data were analyzed using SPSS (SPSS Inc., Chicago, IL, USA) version 26. Demographic data, survey data and parameters obtained by measurement were evaluated with descriptive analysis and given as the average (mean, standard deviation, median, interquartile range, percentage). The Kolmogorov-Smirnov test was employed to assess the distribution of the sample. As the dataset did not conform to a normal distribution, non-parametric statistical methods were used. To compare the impact from coronavirus between the groups, t-test or Mann Whitney-U test was used for the independent groups. Spearman correlation was used to determine the relationship between the impact of coronavirus and the Childhood Health Assessment Questionnaire and the Pediatric Quality Of Life Inventory 3.0. Module Arthritis. The significance level was set as 0.05.

RESULTS

The mean age of the children/adolescents diagnosed with JIA's mean age was 13.16 ± 3.53 and disease duration was 3.58 ±2.93 years. JIA with COVID-19 was 21 children/adolescents (46.7%) and JIA without COVID-19 was 24 children/adolescents (53.3%). When the participants were divided into two groups: JIA with COVID-19 and without COVID-19, there was a significant difference in age (p=0,01). The demographic and disease-related data of children and adolescents with JIA are shown in Table 1.

There was no difference in the impact of coronavirus, quality of life, and disability level between JIA with COVID-19 and without COVID-19 (p>0.05) (Table 2). General health impact from coronavirus had negatively moderate correlation with quality of life-child (r=-0.371) and positively high correlation with disability level (r=0.511). Psychosocial impact from coronavirus had negatively moderate correlation with quality of life-child (r=-0.493) and quality of life-parent (r=-0,361) and positively high correlation with disability level (r=0.536). Activity impact from coronavirus had a negatively moderate correlation with quality of life-child (r=-0.371) and a positively moderate correlation with disability level (r=0.444) (Table 3).

DISCUSSION

According to our results, during the pandemic, children/adolescents with JIA were found to have similar levels of impact from the coronavirus, regardless of whether they had COVID-19 or not. Their quality of life and disability levels were also found to be similar. In both groups, the coronavirus affected general health and activities, leading to a decrease in the quality of life and an increase in disability levels. Psychosocially, it also reduced the quality of life of parents.

The use of immunosuppressive therapy in chronic rheumatological patients, such as those with JIA, has been a topic of research concerning the risk of increased susceptibility to infection (18,19). The COVID-19 pandemic has led rheumatologists to consider the potential negative impact on the immune system, particularly in relation to a higher risk of COVID-19 and a more severe course of the infection in patients with rheumatic diseases undergoing immunosuppressive therapy (20, 21). Although symptoms and exposure are generally similar to the course of COVID-19 in the healthy pediatric population, it remains a concern for patients and their families (22). Hausmann et al. (2021) demonstrated that during the COVID-19 period, nearly all individuals with rheumatic diseases adopted protective behaviors. Most of them implemented physical distancing or isolation strategies, used masks and gloves, and avoided activities that could

increase the risk of COVID-19. Moreover, the pandemic had serious effects on the education of participants (19). In the present study, the level of impact of the coronavirus, quality of life, and disability among JIA patients was found to be

Table 1. Demographic and disease-related data of children and adolescents with JIA

	JIA with COVID-19 (n=21) Median (IQR) (Min-Max)	JIA without COVID-19 (n=24) Median (IQR) (Min-Max)	p
Age (years)	15.00 (7.00) (7.00-18.00)	12.00 (6.00) (6.00-16.00)	**0.013**
Body Mass Index (kg/m²)	17.30 (7.02) (11.87-33.22)	18.61 (7.45) 12.94-27.34	0.865
Disease Duration (years)	2.00 (3.00) (1.00-9.00)	3.50 (5.00) (1.00-11.00)	0.458
	n (%)	**n (%)**	**p**
Gender Female Male	13 (61.9) 8 (38.1)	16 (66.7)8 (33.3)	0.742
Type of JIA			
Oligoarthritis	17 (81)	18 (75)	
RF+ polyarthritis	2 (9.5)	3 (12.5)	
Enthesitis related arthritis	1 (4.8)	3 (12.5)	
Juvenile psoriatic arthritis	1 (4.8)		
Pharmacological Treatment			
No	9 (42.9)	6 (25)	
NSAII	3 (14.3)	5 (20.8)	
Methotrexate	5 (23.8)	3 (12.5)	
Biological therapy	4 (19)	10 (41.7)	

Mann Whitney-U Test, IQR=Interquartile Range, min=minimum, max=maximum.

Table 2. The relationship between impact from coronavirus and quality of life and disability level

	JIA with COVID-19 (n=21) Median (IQR) Min-Max	JIA without COVID-19 (n=24) Median (IQR) Min-Max	p
General health impact from coronavirus	2.60 (4.50) 0.00-6.80	1.80 (2.05) 0.00-6.60	0.255
Psychosocial impact from coronavirus	2.00 (4.85) 0.00-8.75	2.77 (4.10) 0.00-7.75	0.804
Activity impact from coronavirus	2.16 (5.00) 0.00-9.00	2.91 (3.71) 0.67-8.00	0.690
Education impact from coronavirus	3.00 (4.67) 0.00-9.33	3.83 (3.16) 0.00-10.00	0.671
PedsQL-Child	85.20 (31.82) 30.68-100.00	82.35 (18.75) 62.50-98.86	0.285
PedsQL-Parent	89.13 (14.00) 37.00-100.00	83.15 (23.00) 60.00-98.00	0.747
CHAQ	0.37 (0.93) 0.00-3.50	0.12 (0.62) 0.00-2.25	0.310

Mann Whitney-U Test, IQR=Interquartile Range, Min=minimum, Max=maximum, CHAQ= Childhood Health Assessment Questionnaire, PedsQL=Pediatric Quality of Life Inventory 3.0 Arthritis Module.

Table 3. The relationship between impact from coronavirus and quality of life and disability level

	PedsQL-Child		PedsQL-Parent		CHAQ	
	r	**p**	**r**	**p**	**r**	**p**
General health impact from coronavirus	−0.371	0.012	−0.290	0.053	0.511	<0.001
Psychosocial impact from coronavirus	−0.493	0.001	−0.361	0.015	0.536	<0.001
Activity impact from coronavirus	−0.328	0.028	−0.234	0.122	0.444	0.002
Education impact from coronavirus	0.029	0.850	−0.063	0.681	0.021	0.893

CHAQ=Childhood Health Assessment Questionnaire, PedsQL=Pediatric Quality of Life Inventory 3.0 Arthritis Module.

the same regardless of whether the patients had contracted COVID-19. This means that COVID-19 did not have a distinct effect on children based on their infection status. Because disease-related restrictions such as curfews, online education in schools, and the use of masks do not change depending on whether the individual is infected or not, these effects on patients and their families may have remained consistent.

In this study, the general health and activity impact of the coronavirus decreased the quality of life and increased disability in children and adolescents. Defects in routine medical checks for children and adolescents during the pandemic, the fear of chronic disease progression, and stress during the quarantine period may have contributed to the decline in quality of life and increased disability by causing general health effects (23). Studies conducted during the pandemic period have shown that the emotional burden increases in individuals with chronic diseases (24). Wilkinson et al. (2021) found that medical treatment was interrupted in 40% of patients with juvenile dermatomyositis and that parents expressed themes of stress, fear, and anxiety throughout the pandemic (24). Similarly, Wahezi et al. (2023) Stated that 30% of patients with juvenile idiopathic myopathy experience interruption of medical care and almost 40% report mental health concerns. In addition, they reported that caregivers mostly discuss the stress they experience regarding protective measures and social isolation, as well as their fears about social isolation (23). In the present study, general health effects such as disruption of children's medical check-ups and increased levels of pain and swelling during the COVID-19 period may have reduced the patients' quality of life and increased disability.

During this period, the quality of life decreased, and the level of disability increased due to the curfew, the closure of gyms and clubs, and the reduction in physical activity. Additionally, as demonstrated in other studies, the increase in screen time among children may have contributed to the decline in physical activity (25). Decreased physical activity levels may also have increased the medical symptoms of these participants and had a greater overall health impact. In addition, the psychosocial impact of coronavirus reduced the quality of life of their families. Duncan et al. (2021) showed that the depression and anxiety scores of patients with rheumatic disease over the age of 13 and their parents were higher than those of the control group, and more than half of the parents believed that their child's rheumatological disease increased the risk of contracting COVID-19 (10). During this period, the closure of schools led to psychosocial effects as well as physical health problems (26). The increase in unemployment and the additional time spent at home with children staying at home and the decrease in interactions with relatives and friends may have caused problems in interpersonal relationships. In a cohort study, the daily lives of families and children with pediatric rheumatological disease changed during the COVID-19 period (27). The increased psychosocial impact due to both the anxiety caused by the disease and the increasing negative relationships within the family may have contributed to a decrease in the quality of life.

The strength of this study is that, to our knowledge, it is the first controlled study that makes a specific assessment of the situation of children/adolescents with JIA during this pandemic that affects the whole world. It provides information about the perspectives of both children/adolescents and parents. The first limitation is that data on children's sedentary behavior were not recorded. For example, if data on how many hours of television or computer/tablet play were recorded at home, clearer results could be given about how time is spent at home. Second, if data such as fat mass and muscle mass were evaluated before and after a certain period of time, comments could be made about the changes occurring in the body. Another limitation is that we asked participants to respond retrospectively based on the COVID-19 quarantine and lockdown periods. This could have affected individuals' ability to recall accurately, potentially influencing the accuracy of their responses. In addition, disease activity could have been assessed using the Juvenile Arthritis Disease Activity Score (JADAS) to evaluate the outcomes in cases. Disease activity may also have influenced the outcomes.

The findings of this study hold significant relevance for the implementation of preventive measures in the event of future occurrences of natural disasters, pandemics, or similar restrictions. It may guide further research aimed at improving the quality of life and providing psychosocial support for children and their families. In the event of a recurrence of such a period, additional measures, such as remote physical activity interventions facilitated by technology and the ability to conduct medical consultations, could be implemented to minimize the adverse effects on health and quality of life.

CONCLUSIONS

According to our data results, during the pandemic period, children/adolescents with JIA were affected by the coronavirus at the same level whether they had COVID-19 or not. Coronavirus has reduced the quality of life and increased the level of disability in children and adolescents with JIA by affecting their general health and activities. Psychosocially, it reduced the quality of life of both the individual with JIA and the family.

Ethics Committee Approval	Ethical approval of the study was obtained from the Pamukkale University ethics committee at the meeting number of 21 dated 11.30.2021.
Informed Consent	Informed consent was not obtained as it was a retrospective study.
Author Contributions	Conception/Design of Study: EGK, BBC, SY; Data Acquisition: BBC, SY, GK; Data Analysis/Interpretation: EGK, SY; Drafting Manuscript EGK, SY ; Critical Revision of Manuscript: BBC, SY; Final Approval and Accountability: SY
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Author Details

Sinem Yenil

[1] Pamukkale University, Faculty of Physiotherapy and Rehabilitation, Denizli, Türkiye

0000-0001-6603-4172

Elif Gür Kabul

[2] Uşak University, Faculty of Health Sciences, Physiotherapy and Rehabilitation, Uşak, Türkiye

0000-0003-3209-1499 elifgur1988@hotmail.com

Bilge Başakcı Çalık

[1] Pamukkale University, Faculty of Physiotherapy and Rehabilitation, Denizli, Türkiye

0000-0002-7267-7622

Gülşah Kılbaş

[3] Pamukkale University, Faculty of Medicine, Department of Pediatric Rheumatology, Denizli, Türkiye

0000-0001-5932-1990

Selçuk Yüksel

[4] Canakkale Onsekiz Mart University, School of Medicine Department of Pediatric Rheumatology, , Canakkale, Türkiye

0000-0001-9415-1640

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