

# Impact of Juvenile Idiopathic Arthritis on School Attendance and Performance

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**Abstract:** Juvenile idiopathic arthritis (JIA) includes a group of disorders characterized by chronic arthritis. It is the most common chronic rheumatic illness in children and is a significant cause of morbidity, disability and dysfunction. Therefore, the potential for school attendance and academic performance become compromised and these children are often confronted with educational difficulties. Objectives: To assess the impact JIA on academic difficulty, academic performance, potential causes of absenteeism, school failure and relationship between schooling and different types of JIA. Materials and Methods: All school going JIA patients between 6-16 years of age who had at least 2 years of schooling (1 year before disease onset and 1 year during the course of disease) were included for the analysis. Two hundred JIA patients were selected by purposive sampling method. A detailed questionnaire was completed for each participant which included socio-demographic, clinical and laboratory characteristics, data related to schooling, academic difficulties and their causes, absenteeism and causes, sports and cultural activities, school failure and school re-entry if any. Fifty four controls were taken who were the healthy sibs of those JIA patients having at least 2 previous years of schooling. Results: Mean age of JIA patients were 10.8 years, 67% were male and male female ratio was 2:1. Academic difficulties were observed for reading, writing and both due to disease process and deformity. Number of absent days and poor attendance in examination was significantly higher in JIA patients ( $p$  value < 0.001). Moreover, in case group, only 18% had improved result than the academic year prior to disease onset, 3% had no change, 57% deteriorated and 22% stopped schooling. There were 44 cases of school failure among JIA patients, 30 had school re-entry. No children had school failure or re-entry among the control group. Multiple causes of absenteeism like flare, hospitalization, side effects of drugs, movement difficulties, parental non-interest and some other factors like rainfall, delayed rising from sleep etc co-existed for most of the cases. In control group, mean percentage of absenteeism was 1.6%, mostly due to some febrile illness, cold weather, rainfall, lack of transport, sickness of caregiver etc. Children who did not participate in sports activities were 9.3% in control group and 48.5% in case group ( $p$  value < 0.001). Conclusion: It is evident from this study that JIA has negative impact on schooling characterized by poor attendance and academic performance.

**Keywords:** Juvenile Idiopathic Arthritis, School Attendance, Academic Performance

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## 1. Introduction

Juvenile idiopathic arthritis (JIA) is an umbrella term which includes a group of disorders characterized by chronic arthritis [1]. It is the most common chronic rheumatic illness in children and is a significant cause of both the short and long term morbidity, disability and dysfunction [2]. Different

chronic diseases like bronchial asthma, epilepsy, congenital hemolytic anaemia, hemophilia, congenital heart diseases etc affect school attendance and performance to a varying degree [3], and there are evidences that chronic arthritis is disruptive because of marked pain, fever, deformity and physical restrictions[4]. As a result, the potential for school attendance, academic performance and extra-curricular

activities become compromised, and these children are often confronted with educational difficulties [4]. Frequent absences from school cause lack of involvement in school activities. This limits the opportunities to establish friendship and development of feeling of inferiority [5]. Several studies have been done and the researchers have observed negative correlations between chronic illness, absenteeism and academic performance. Some studies have examined the consequences of childhood-onset rheumatic diseases when patients reach adulthood, including the impact they may have on long-term health, psychosocial functioning, education, and employment. [6]. These studies performed in several countries having different cultures and healthcare systems, published in the last two decades have reported divergent results [7]. However, to the best of our knowledge, there is no data on Bangladeshi children with JIA concerning education. The aim of our study was to assess the impact of different types of JIA on Bangladeshi children's schooling.

## 2. Materials and Methods

This was a case - control study conducted in paediatric rheumatology clinic, Department of Paediatrics, Bangabandhu Sheikh Mujib Medical University (BSMMU), Dhaka, Bangladesh from April 2014 to July 2015. All JIA patients between 6-16 years of age attending the paediatric rheumatology clinic during the study period, having at least 1 year of schooling before disease onset, and at least 1 year of schooling after becoming sick were included as cases. To minimize the effects of confounding variables, healthy sibs of JIA patients between 6 to 16 years of age having at least 2 years of schooling were taken as controls. Fifty four children could fulfill the inclusion criteria for control. Children or parents unwilling to give consent, children known to be suffering from any other associated chronic systemic diseases like asthma, epilepsy, congenital heart disease, tuberculosis, wilson disease etc that may also affect schooling were excluded from the analysis. Ethical clearance was taken from Institutional Review Board (IRB) of BSMMU. Informed written consent was taken from the parents or guardians of both cases and controls. Data were collected by using a structured questionnaire including age, gender, subtype of JIA, age at onset and disease duration of affected patients. Regarding schooling, data included name of school, educational level and class roll number (on the basis of merit), academic difficulty, academic performance and school attendance.

## 3. Working Definitions

Academic difficulty was assessed considering whether the child could prepare school tasks, complete class works and home works. Preparing 80% of school tasks and home works at a point of time or as a whole was considered as 'regular'. Completion of class work was graded into 'possible' or 'impossible'. If the child could do 80% of the task, it was considered as 'possible' [5]. For assessment of reading difficulty, the question was whether the child could study and

memorize class tasks regularly (ie. > 80% of the task in each working day) and whether he or she could reproduce it in class works as per instruction of the teacher [4]. For writing difficulty, ability to complete written class works and home works regularly was asked for [8, 9]. All these information were collected from the parents.

Academic performance was assessed by some variables like examination attendance and result of different examinations. Total number of examinations in a year was taken as 100%. Then the percentage of exams that the child could appear at was calculated. If a child failed to appear at  $\geq 50\%$  of examinations throughout the year, he was labeled as 'did not appear' at the tests [3, 10]. The average grade of results in last academic year was compared with the final exam result anytime before the onset of the disease.

For school attendance, the number of days over the previous academic year that the child had been absent due to JIA was collected and measured as percentage. A continued absence for a period of 6 months or more was considered as School failure [11]. School re-entry, that is rejoining school after school failure was another important variable [12]. Last of all, causes of absenteeism were investigated.

After editing, data were entered into the computer by using statistical package for social science (SPSS) software for Windows Version 17. Analyses included descriptive statistics (mean, SD, range and percentage), unpaired students t test and Chi-square test where applicable. P value < 0.05 with 95% confidence interval was considered as the level of statistical significance.

## 4. Result

Mean age of JIA patients was 10.8 years. Male female ratio was 2:1. Six subtypes of JIA were available during the study period where enthesitis related arthritis (ERA) were the most common (34.5%) type followed by systemic onset JIA (SoJIA) (22.5%). Mean disease duration of the study group was 3.8 years.

Academic difficulty in the form of reading difficulty, writing difficulty and both were found in each types of JIA (Table 1). Reading difficulty was most common in seropositive polyarticular JIA cases (80%), followed by persistent oligoarticular JIA (74.1%). Writing difficulty was also most common in seropositive polyarticular JIA, followed by ERA and SOJIA (Table 1).

Rate of absenteeism were higher in polyarticular JIA (RF positive) and SoJIA cases (Table 2). Patients with extended oligoarticular subtype could attend 100% examination throughout the year (Table 2). SoJIA and polyarticular JIA (RF positive) could appear at only about half of the examinations held in the previous academic year (Table 2). Number of absent days and poor attendance in examination was significantly higher in JIA patients compared to controls (Table 3). Among cases, only 18% had improved result than the academic year prior to disease onset, 3% had no change, 57% deteriorated and 22% stopped schooling (Table 4). Among controls only 13% had deteriorated their results. There were 44 cases of school failure among JIA patients and

30 had school re-entry. No children had school failure or re-entry among the control group. Both the school failure and school re-entry rate among the cases were statistically significant than the controls.

Multiple causes of absenteeism like flare, hospitalization, side effects of drugs, movement difficulties, parental non-

interest and some other factors like rainfall, delayed rising from sleep etc co-existed for most of the cases. In control group, mean percentage of absenteeism was 1.6%, mostly due to some febrile illness, cold weather, rainfall, lack of transport, sickness of caregiver etc.

**Table 1.** Academic Difficulty in different types of JIA Patients (n = 200).

JIA patients	(N = 200)	Academic difficulty		
		In reading n (%)	In writing n (%)	Both reading and writing, n (%)
ERA	(n = 69)	48 (69.5)	45 (65.2)	39 (56.5)
SoJIA	(n = 45)	31 (68.8)	29 (64.4)	17 (37.7)
Polyarticular (RF negative)JIA	(n = 41)	20 (48.7)	22 (53.6)	15 (36.5)
Polyarticular (RF positive)JIA	(n = 10)	8 (80.0)	8 (80.0)	6 (60.0)
Oligoarticular (Persistent)JIA	(n = 31)	23 (74.1)	18 (58.0)	19 (61.2)
Oligoarticular (Extended)JIA	(n = 4)	1 (25.0)	1 (25.0)	1 (25.0)

**Table 2.** Effects of Types of JIA on School and Examination Attendance.

JIA type	n	Total absent days	Total absenteeism(%)	Exam attended(%)
		(Mean ± SD)	(Mean ± SD)	(Mean ± SD)
ERA	69	95.9 ± 91.9 (0.0 - 300.0)	33.9 ± 32.7 (0.0 - 107.1)	71.8 ± 37.9 (0.0 - 100.0)
SoJIA	45	135.6 ± 110.1 (4.0 - 290.0)	47.3 ± 38.3 (1.4 - 100.0)	56.1 ± 43.3 (0.0 - 100.0)
Polyarticular (RF negative)JIA	41	82.0 ± 94.3 (2.0 - 290.0)	28.9 ± 33.1 (0.6 - 100.0)	73.41 ± 40.1 (0.0 - 100.0)
Polyarticular (RF positive)JIA	10	150.8 ± 114.1 (7.0 - 300.0)	51.8 ± 38.8 (2.4 - 100.0)	54.0 ± 49.9 (0.0 - 100.0)
Oligoarticular (Persistent)JIA	31	56.8 ± 82.8 (0.0 - 300.0)	19.7 ± 28.6 (0.0 - 100.0)	79.6 ± 35.5 (0.0 - 100.0)
Oligoarticular (Extended)JIA	4	68.0 ± 64.9 (12.0 - 150.0)	31.4 ± 35.2 (4.2 - 82.4)	100.0 ± 0.0 (100.0 - 100.0)
Total	200	98.1 ± 99.2	34.5 ± 34.8	69.5 ± 40.3

JIA, Juvenile idiopathic arthritis; ERA, Enthesitis related arthritis; SoJIA, Systemic onset JIA; RF, rheumatoid factor; SD, standard deviation.

**Table 3.** Comparison of School and Examination Attendance Between Cases and Controls (n = 200 + 54).

Variables	Case	Control	p value
Total absent days			
Mean±SD	98.15±99.21	4.63±4.25	<0.001***
Range	0.00-300.00	0.00-17.00	
Absenteeism (%)			
Mean±SD	34.58±34.86	1.63±1.50	<0.001***
Range	0.00-107.14	0.00-5.96	
Exam attended (%)			
Mean±SD	69.51±40.32	93.15±16.49	<0.001***
Range	0.00-100.00	0.00-100.00	

Unpaired Student's 't' test

ns = Not significant

\*\*\* = Significant

SD, standard deviation

**Table 4.** Examination Results in Comparison to the Previous Examination Among Cases and Controls (n = 200 + 54).

Examination results in comparison to the previous examination	Case(n=200)N (%)	Control(n=54)N (%)	p value
Improved	36 (18.0)	21(38.9)	<0.001***
No change	6 (3.0)	20(37.0)	
Deteriorated	114 (57)	13(24.1)	
Deteriorated and stopped schooling	44 (22)	0 (0)	

Chi-square test

\*\*\* = Significant

## 5. Discussion

Juvenile idiopathic arthritis is one of the major causes of childhood disability [13]. In spite of large therapeutic advances in the last decades, patients experience pain, fatigue, limitation of movement and lack of physical and social participation in daily activities [14, 15]. It is well known that academic performance is the outcome of education [16]. Individual differences in academic performance have been linked to differences in intelligence, personality, effort, achievement motivation, academic settings, health status, learning environment, parent's educational qualification, socioeconomic status and so on [17]. So, it was very difficult to compare the academic performance of JIA patients with those of healthy controls as a large number of confounders might be there. To minimize the effects of confounding variables, healthy sibs of JIA patients were selected as control group.

In this study mean age of the patients (10.8 years) were similar to the study done by Bouaddi et al where mean age was 11 years [18] which can explain the juvenile onset of the disease in most of the contexts. We got ERA as the predominant subtype probably due to gender difference in child rearing practice in Bangladesh and higher discriminative attitudinal preference for boys. SoJIA was the second most common subtype probably due to severe clinical manifestation and complications (Table 1).

It is well known that seropositive polyarticular JIA is one of the worst subtype having overwhelming clinical course and complications. But persistent oligoarticular JIA is one which has favorable outcome. In this study, this subtype has more reading difficulty (Table 1) than ERA and SoJIA patients. Possible explanation might be that some other confounders might have been associated with this condition. Minimal reading difficulty was present in oligoarticular JIA extended variety (Table 1). It was not expected, but may be due to very small number of patients (only 4) representing the group may not be representing the actual situation.

Children with JIA often report difficulties in handwriting as a major restriction at school, and complain of 'slow, messy and painful' handwriting [19]. In our study, maximum writing difficulty was found in seropositive polyarticular JIA. In this regard, a study was conducted in Netherlands, where the JIA children reported pain during handwriting, and inability to sustain handwriting for a longer period of time [20]. Due to arthritis, these children may suffer from pain and limited range of motion of the wrist or finger joints, in combination with reduced grip force [21, 22].

Sturge et al. (1997) found that children with JIA had an overall mean school attendance rate of 92% (equivalent to 15 days absent per year) [22]. These findings are matching with the natural course of the diseases and prognostic criteria. On an average, among 200 cases, mean percentage of absenteeism was 34.5%, which is quite higher than that of the control group (1.63%). The study conducted by Bouaddi et al (2013) showed that mean percentage of absenteeism in JIA

patients was 33% like our study [18]. The difference between case and control was significant. In almost all of the cases, causes of absenteeism were flare, hospital visit for follow up or admission, some physical symptoms like nausea, vomiting, abdominal pain, headache, hypertension etc which might be iatrogenic, movement difficulty due to pain, morning stiffness, deformity, avascular necrosis of femur, lack of transport, long distance of school from home, school at early morning, lack of assistance etc. In some cases, absenteeism was due to parental sympathy for pain and unwilling child. Among other causes, cold, rainfall, illness of caregiver, feeling shy of body configuration, fear of scolding by teachers, visiting relative's house were present.

Attending different examinations was a major challenge for the JIA patients. In our study, we found that patients with extended oligoarticular subtype could attend 100% of examinations throughout the year (Table 2). Very little sample size in this regard may not represent the actual scenario. SoJIA and polyarticular JIA (RF positive) could appear at only half of the examinations held in the previous academic year probably due to waxing and waning course of disease.

We have also compared the current result with the result any time prior to the onset of the disease in case of 'cases' and the current result with the result of immediately previous academic year in case of 'controls' with an intention to avoid confounders (Table 4). Surprisingly, 18% of JIA patients had improvement than their healthy states, probably due to internal motivation, strong self inspiration to overcome physical limitations, more parental attention and good compliance. As high as 56.5% children deteriorated due to poor attendance, disease process, deformities etc (Table 4). Bouaddi et al. (2013) showed 48.5% JIA children with deteriorated result which is lower than our observation [18]. But in his study, only 12% affected children had stopped schooling whereas in our study we have as many as 22% of such children [18].

In 2015, Diaz-Mendoza et al (2015) published an article where the aim was to determine the maximum academic level achieved, employment rate, working life and social status of patients with JIA. There a higher percentage of students in the case group (82%) had completed studies beyond the compulsory education level but the time period needed to complete their studies was longer [7]. The findings from this study supported the widely accepted strategy of multidisciplinary management of these patients, in which psychological support and vocational guidance should have a prominent role.

In the current study, sports and cultural activities of the affected children were also taken into account and compared with healthy controls. Games were categorized by indoor games and outdoor games. Most of the JIA patients did not take part in any kind of games. Among them who play, it was surprising that most of them had fascination for outdoor games. We found a gold medalist in annual school sports among the JIA patients. There was 1 athlete in each group. There was no significant difference in cultural activities

between two groups. But some of the JIA children had participation in different aspects of cultural fields. One of our JIA patients was an enlisted singer of Bangladesh Television.

Finally, School is the focus not only for education but also for children's social and sporting activities. During a long absence from school a child can fall behind in their studies, lose their place on teams, and sometimes lose their place in friendship groups. The longer it takes to return to school, the more difficult it may be for the child to settle back in. It will be helpful to make a 'return to school' plan with the help of the child's treatment team. Information sheets about JIA for teachers should be given to the school. It may also be helpful for the child if classmates are also informed about the disease by the teachers with explanation why the affected child remains absent from school. Stress from trying to achieve high grades or catch up on missed work may make pain worse, or increase the risk of depression. Alternatively, the child may need to be encouraged to work hard at school, to remind them that JIA does not have to limit their achievements. It is important to help the child to be realistic and to pace themselves with schoolwork.

## 6. Conclusion

The study demonstrated that, most of the JIA patients encounter academic difficulties like difficulties in reading and writing. Percentage of absent days in school was significantly higher in JIA patients due to flare, hospitalization, movement difficulties etc. They also had poor attendance in different examinations and deterioration of results. School failure was significantly higher in JIA patients. So, it may be concluded from this study that JIA has a negative impact on school attendance and academic performance.

## Recommendation

Our study suggests that schooling is affected by JIA. Disease activity and functional impairment seem to influence the school attendance and performance. Hence the multidisciplinary team approach should include school professionals as well to address this issue. Also, additional research, with a larger sample of children, is needed to confirm our findings.

## Limitation

It was a single centered study. There was a risk of bias by parents as the exact duration of symptoms might be difficult to recall.

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