

Patient-Reported Barriers at School for Children with Juvenile Idiopathic Arthritis

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Objective. The objective of this study was to identify patient-reported school barriers and their associated impact in juvenile idiopathic arthritis (JIA).

Methods. A cross-sectional observational study of children aged 8 to 17, diagnosed with JIA, and followed in the rheumatology clinic/Alberta Children's Hospital was performed. Demographics, diagnosis, and disease course were obtained from health records. A questionnaire was administered to the child to assess the barriers experienced by JIA patients at school. The questionnaire collected information about school attendance/performance, impact of JIA symptoms (eg, pain and fatigue), physical challenges and accommodations, communication, participation and peers, and school support. Descriptive statistics were used to analyze the data.

Results. A total of 98 children with JIA were recruited into the study. The median age of participants was 13 years (interquartile range 11–15). The JIA subtypes in this cohort reflected the normal JIA distribution. Physical challenges at school (eg, gym, writing, and sitting for long periods of time) were reported by 42.1% of patients. Accommodations (eg, modified gym, accommodation letter, and computer access) were used by 23% of patients. The inability to participate in activities in class or outside with their peers occurred for 32.2% of patients and in gym for 40.7% of patients. Social concerns included embarrassment from talking about their illness, worry regarding being treated differently, and being told they were fabricating their illness.

Conclusion. Children with JIA experienced barriers at school, especially physical challenges, with a need for accommodations in a proportion of children. Decreased participation and increased social anxiety were additional key barriers.

INTRODUCTION

Juvenile idiopathic arthritis (JIA) is the most common childhood rheumatic disease with an estimated incidence of 1 to 22 per 100,000 children below the age of 16 years (1). Although the outcomes of JIA have improved over the last decade, many of these children “face possible continuing disease activity, medication-associated morbidity, life-long disability and risk for emotional and social dysfunction” ((2), p.1). Disease symptoms (eg., pain and limited range of motion) and associated medication side effects may significantly impact school performance, participation, and peer relationships in children with JIA. There is substantial data on the general impact of JIA on health-related quality of life; however, barriers at school and school-related problems associated with JIA have not been studied in detail (3–6).

Therefore, the aim of this study was to identify the barriers and associated impact perceived by JIA patients at school. The findings of this study will fulfill the urgent need to develop effective resources and inform solutions to improve patients' experience at school and future academic achievement.

METHODS

Patients. A cross-sectional observational study of children with JIA who were followed in the rheumatology clinic at Alberta Children's Hospital was performed over a period of two years. Patients were consecutively approached during scheduled rheumatology appointments followed by six different pediatric rheumatologists. Purposive sampling was used to recruit eligible patients if they were a) 8 to 17 years old and b) had a confirmed diagnosis of JIA according to the International League of Associations

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SIGNIFICANCE & INNOVATIONS

This was the first cross-sectional observational study to identify detailed patient-reported barriers at school in a large cohort of juvenile idiopathic arthritis patients.

Children with juvenile idiopathic arthritis experienced multiple notable barriers at school, including physical challenges, a need for accommodations, decreased participation, and increased social anxiety. These results fulfill the urgent need to develop effective resources and implement solutions to improve patients' experiences at school and future academic achievement.

for Rheumatology classification criteria. Patients were excluded from the study if they were a) homeschooled, b) not attending school, c) had insufficient English reading comprehension skills to complete the questionnaire, or d) had additional diseases that might cause barriers at school (other chronic diseases or physical disabilities unrelated to JIA). Demographics, diagnosis, and disease course were obtained from health records. The study was approved by the Conjoint Health Research Ethics Board of the University of Calgary (REB16-0439). Informed consent from all patients or their legal guardians was obtained according to the Declaration of Helsinki.

Questionnaire and data collection. A self-report exploratory instrument was designed to explore and gather detailed information about barriers at school in JIA patients. The following steps for development and face validity were conducted: 1) detailed review of relevant literature (KC, HS); 2) semistructured interviews (30-45 min) with pediatric rheumatologists and allied health professionals (physiotherapist, occupational therapist, nurse, psychologist, and social worker) were conducted; 3) development of the questionnaire by integrating steps 1 and 2; 4) the questionnaire was reviewed by the researchers, physicians, allied health professionals, and revised; and 5) the questionnaire was pretested by 10 JIA patients and their families for acceptability (content, format, feasibility).

The final questionnaire consisted of six identified major domains that related to 1) school attendance/performance, 2) impact of JIA symptoms (eg, morning stiffness, pain, and fatigue), 3) physical challenges/accommodations, 4) communication, 5) participation and peers, and 6) school support. Items included a 5-point Likert scale of how often the barrier occurred (ie, never, almost never, sometimes, often, almost always), and a 10-point visual analogue scale was used to determine the impact of the barrier (0, not challenging; 10, very challenging). There was also the option to include open written comments to provide insight on items not included in the questionnaire. The questionnaire was completed in approximately 20 minutes.

Statistical analysis. The Likert scale responses were transformed into dichotomous variables for analysis; a "school barrier" was categorized by the selection of sometimes, often, and almost always, whereas "no barrier" was categorized by never or almost never. The 10-point visual analogue scale was used to evaluate patient-perceived disease activity. Descriptive statistics (ie, median, interquartile range, and percentage) were used to analyze the data, and results were calculated from the number of patients who answered each question.

RESULTS

Patient characteristics. The JIA cohort was a representative sample that included a total of 98 children (Table 1). Some patients had comorbidities; specifically, seven of them had JIA-related uveitis, and three of them had a secondary pain amplification syndrome. In general, there were no differences in reported barriers between these and the patients without comorbidities; however, the patient numbers were too small to be conclusive.

Domains: physical challenges and accommodations.

Physical challenges (eg, writing, gym, and sitting for long periods of time) at school were experienced by 42.1% of participants (sometimes, 32.6%; often, 6.3%; almost always, 3.2%). Accommodations at school were used by 23% (sometimes, 11.5%; often, 6.3%; almost always, 5.2%). Social concerns related to the reasons for not using accommodations included worry about being treated differently (n = 9), concerns about fitting in (n = 8),

Table 1. Patient characteristics

	Total Cohort	N = 98
Female sex, no. (%)		68 (69.4%)
Age at onset, median (IQR) years		13 (11-15)
Disease duration, median (IQR) years		5 (3-8)
JIA subtype, no. (%)		
Systemic JIA		2 (2.0%)
RF-negative polyarticular JIA		37 (37.8%)
RF-positive polyarticular JIA		1 (1.0%)
Persistent oligoarticular JIA		30 (30.6%)
Extended oligoarticular JIA		13 (13.3%)
Enthesitis-related arthritis		12 (12.2%)
Psoriatic arthritis		3 (3.1%)
Undifferentiated JIA		0 (0%)
Treatment, no. (%) ^a		
DMARDs		66 (68.8%)
Biologics		43 (44.8%)
NSAIDs		36 (37.5%)
Steroids		4 (4.2%)
None		10 (10.4%)

^aPatients could be treated with more than one medication group.

Table 2. Physical challenges and accommodations

Physical Challenges	No. (%)	Accommodations	No. (%)
Gym class	43 (43.9%)	Modified gym	24 (24.5%)
Writing by hand	29 (29.6%)	Accommodations letter	20 (20.4%)
Sitting for long periods of time	27 (27.6%)	Computer access	19 (19.4%)
Field trips	25 (25.5%)	Backpack with two straps	17 (17.3%)
Sitting on the ground	29 (29.6%)	iPad or tablet/laptop	16 (16.3%)
Stairs	16 (16.3%)	Extra time	15 (15.3%)
Carrying a backpack with heavy items	15 (15.3%)	Government disability code/ individualized program plan	15 (15.3%)
Playing outside	10 (10.2%)		

^aPatients could select more than one item.

and worry about looking differently ($n = 8$). The main physical challenges reported and accommodations used are listed in Table 2.

Domains: participation and peers. The inability to participate in activities either in class or outside with their peers occurred for 32.2% of patients (sometimes, 28.1%; often, 1.0%; almost always, 3.1%) and 40.7% in gym class (sometimes, 35.2%; often, 5.5%). Participants could select items from a checklist about experiences that had occurred with their teachers and peers when they were unable to participate. The main findings demonstrated that childrens' teachers understood when they had to sit out ($n = 39$), modified ($n = 25$), or provided alternative ($n = 20$) activities, and let them pick which activities to participate in ($n = 21$). Moreover, some participants identified that their peers understood when they had to sit out ($n = 20$) and helped them to participate in activities ($n = 13$). Some patients, however, expressed social anxiety in regard to being unable to participate with their peers. For instance, being worried it may look like they were not trying ($n = 11$), worried about being unable to participate ($n = 13$), and embarrassed about being unable to participate ($n = 10$) were causes of this anxiety.

Domains: communication. The majority of participants told their classroom teachers (77.4%) and gym teachers (78%) about their disease. However, 75% of patients did not continue to update their classroom teachers and 67% did not continue to update their gym teachers about their disease. Patients also reported that their classroom teachers (12.2%) and gym teachers (23.4%) did not understand their illness (ie, "they think I am making excuses to skip gym");. 82.3% of patients told their friends about their disease. However, only 44.7% told their classmates. The main reason for not telling their classmates was because they didn't feel the need to tell them ($n = 68$). Additional reasons for not informing classmates included concern over being treated differently ($n = 16$), worried about being told that they were fabricating their illness ($n = 13$), and being embarrassed to talk about their illness with their classmates ($n = 13$) (Figures 1-3).

Domains: appointments, illness, and JIA-related symptoms. Appointments and JIA-related illness (eg, medication side effects) had a minor impact on patient-perceived school attendance and performance. The median number of days absent

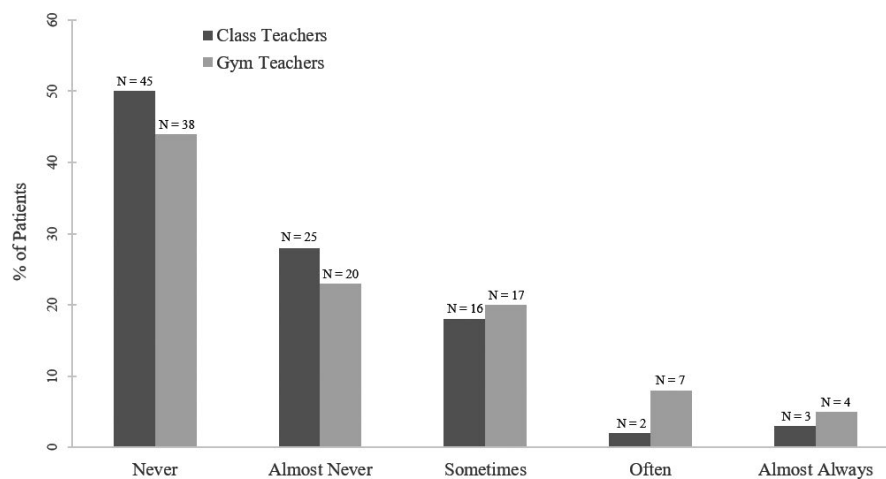


Figure 1. Frequency of patients who updated their classroom teachers and gym teachers about their illness.

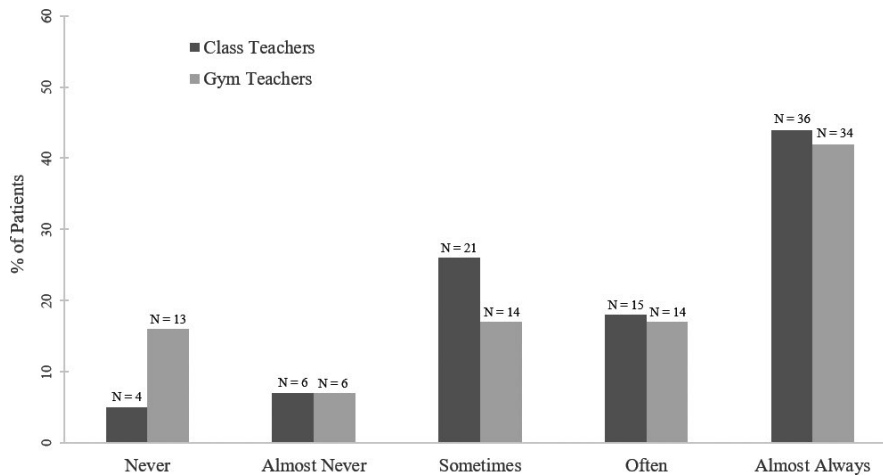


Figure 2. Frequency of patients who perceived their classroom teachers and gym teachers understood their illness.

from school per year that was due to appointments and illness was 6 days (interquartile range: 3.3-12) and 1 day (interquartile range: 0-4), respectively. Being late or leaving school early for an appointment occurred in 70.1% of patients (sometimes, 41.2%; often, 10.3%; almost always, 18.6%) and 31.3% of patients were late or left school early because of JIA-related illness (sometimes, 24%; often, 6.3%; almost always, 1.0%). However, the survey did not include a question of how many times/per year they were late or left early. Overall, patient-perceived performance in school was affected by appointments for 32% of patients (sometimes, 25.8%; often, 6.2%) and JIA-related illness for 19.6% of patients (sometimes, 13.4%; often, 6.2%). Notably, 89.3% patients felt that their teachers were willing to provide additional resources when they were absent because of appointments (sometimes, 18.3%; often, 30.1%; almost always, 40.9%) and 77.1% for JIA-related illness (sometimes, 15.2%; often, 21.7%; almost always, 40.2%).

Overall, patients had low self-reported disease activity: morning stiffness (median = 0 minutes; n = 90), pain (median = 2/10; n = 94), fatigue (median = 1.5/10; n = 94), and other symptoms (median = 0.5/10; n = 92), with an overall median well-being

of 1/10 (0-very good; 10-very poor), n = 90). However, some patients reported that particular JIA symptoms impacted their ability to keep up at school. These JIA symptoms included fatigue for 21.7% of patients (sometimes, 15.5%; often, 3.1%; almost always, 3.1%) and pain for 28.1% of patients (sometimes, 20.8%; often, 6.3%; almost always, 1%).

Domains: school support. Overall, 84.4% of participants (sometimes, 16.9%; often, 22.9%; almost always, 44.6%) reported that the school was supportive of their illness. Here, participants felt the school was supportive when their teachers understood their problems and provided support (eg, checking in), provided accommodations and modified activities when they were unable to participate, educated other teachers/students about JIA, and contacted parents with any concerns.

DISCUSSION

This was the first cross-sectional observational study to identify detailed patient-reported barriers at school and their

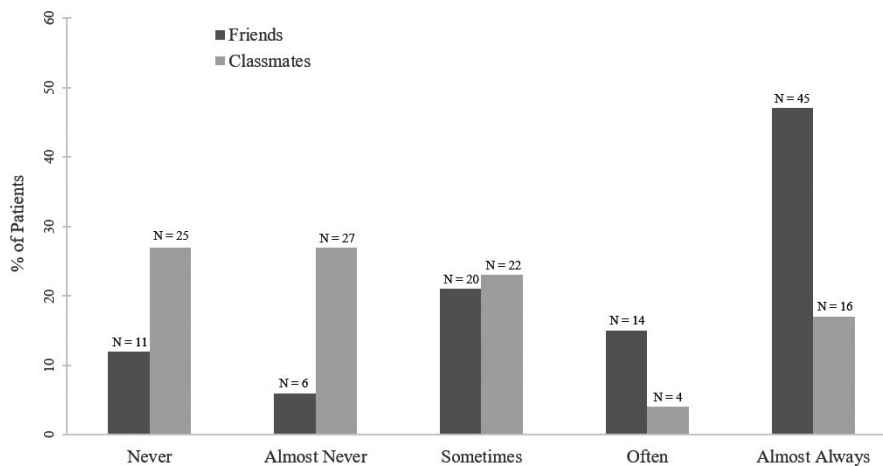


Figure 3. Frequency of patients who told their friends and classmates about their illness.

associated impact in a large cohort of JIA patients. Using a questionnaire designed by the research team, a preliminary list of barriers at school was identified. Physical challenges, a need for accommodations, decreased participation, and increased social anxiety were key barriers at school for children with JIA.

In our study, 42.1% of children experienced physical challenges at school (eg, during gym, writing, and sitting for long periods of time), and 23% of patients used accommodations. A cohort study performed in the Netherlands with the aim “to determine the prevalence of hand-and wrist-related symptoms” in 121 JIA patients (mean age of 13.7 years [$SD = 1.4$]) revealed that 54% of the children reported hand- or wrist-related problems at school and about 40% used devices, braces, and/or splints (7). In our study, there were also social concerns related to the reasons for not using accommodations. It will be necessary to address the social implications related to the limited use of accommodations when developing targeted resources at school for children with JIA to avoid joint deterioration, deformity, and long-term disability.

Patients were often unable to participate in the classroom or play outside and in gym class. Stinson et al (6) displayed similar results in a qualitative study of 41 children (aged 8-11 years) and 48 parents that aimed to describe the information needs of children with JIA. The participants in that study “felt that JIA (ie, symptoms like pain, stiffness, and fatigue) has at some point negatively impacted their participation in sports and other activities, both at school and outside of school” (6 ;p.130). JIA patients are encouraged to be physically active to promote positive psychosocial and biological effects (eg, decreased cartilage damage and improved bone mineral density) (8). Therefore, any decreased participation shown by JIA patients (either outside or in gym class) is of particular concern, especially because children with JIA have previously been shown to be less physically active than their healthy peers (9).

Patients in our study had concerns regarding inability to participate with their peers (ie, worried or embarrassed about being unable to participate). A qualitative study of 14 youth aged 13-18 with disabilities (eg, juvenile rheumatoid arthritis and spina bifida) revealed that participants wanted to be able to participate in the same setting with their peers (eg, remain in the gym) and be “similar” to their peers (10). Stinson et al. (6) also described that “missing out on activities affected children’s perceived connection to peers” (6; p10).

The majority of patients told their classroom teachers and gym teachers about their disease and felt that their teachers understood their disease and that the school was supportive. In contrast, other studies have reported problems communicating with teachers (3,5, negative experiences with teachers (6), and a lack of overall understanding about JIA (11). The results of our study were promising, as a previous study by Asbjørnslett and Hemmingsson (10) identified that “students’ experiences of participation seemed to be linked to their opportunities to estab-

lish some cooperation with the teacher, to have a say, and thus influence their own schooling in order to optimize possibilities for adaptation to their learning environments” (10; p158).

Compared with other JIA studies on school absenteeism, our patients missed fewer days of school (median: 6/year because of appointments; 1/year because of illness) and reported better school performance. Abdul-Sattar, Magd, and Negm (12) examined school absenteeism in 52 Egyptian patients with JIA, and the mean days of school missed was 25 days/year, and 46% of the population had poor school functioning. Similarly, Bouaddi et al (13) reported that of the 67% of children with JIA who could continue to attend school in Morocco, there was a 63% absenteeism rate per year compared with 20% in healthy controls. Notably, 48.5% of children with JIA had failed a year of school (13). However, these countries vary drastically from North America in regard to their educational, economic, political, and health care systems. To our knowledge, our study was the first study to examine school absenteeism in JIA in North America, and it would be beneficial to compare school absenteeism in a similar setting to further interpret these results.

The results of our study revealed that JIA symptoms (eg, pain, fatigue, and stiffness) had a minor impact on patient-perceived school attendance/performance. Notably, participants reported minor JIA symptoms and a good overall well-being. Overall, there is limited information available from other studies that examined the relationship between school attendance and mood/stiffness (4), fatigue (4,14,15), and tender joints (13).

This study may be confounded by disease severity, gender, and selection bias. However, our sample was purposively recruited over the span of two years to reflect the normal population seen in the rheumatology clinic at the Alberta Children’s Hospital. Secondly, there may have been barriers that were not captured within the domains of this study. This limitation was mitigated by the ability to provide open-ended comments if a participant had a barrier that was not listed in the survey; however, no additional barriers were reported in the open-ended comments. Lastly, attendance records and transcripts were not collected because of the feasibility of this study. The inclusion of school records would provide a cross-reference for the patient self-reported data and a detailed understanding of the impact of JIA on school attendance and performance in future studies. In addition, school records of JIA patients could be compared with those of healthy controls to assess the magnitude of the difference in school attendance and performance.

In conclusion, this was the first study to identify detailed patient-reported barriers at school for children with JIA. Surprisingly, JIA had a minor impact on patient-perceived school attendance and performance. Many patients, however, experienced some notable challenges. These included physical challenges, the need for accommodations, limited participation, and increased social anxiety. It will be necessary to involve all stakeholders (ie, teachers and education boards) and partner with advocacy groups (eg, The Arthritis Society and Cassie &

Friends) to develop effective resources and implement solutions in the future. Given the barriers revealed by this study, it would be worthwhile to formally develop and validate a school impact measure for clinical use in JIA patients. Future research could also evaluate the school impact experienced by patients with JIA when compared with healthy children and/or children with other chronic diseases.

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AUTHOR CONTRIBUTIONS

All authors were involved in drafting the article or revising it critically for important intellectual content, and all authors approved the final version to be published. Dr. Schmeling had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

Study conception and design. Chomistek, Johnson, Stevenson, Luca, Miettunen, Benseler Schmeling.

Acquisition of data. Chomistek, Veeramreddy, Schmeling.

Analysis and interpretation of data. Chomistek, Johnson, Stevenson, Luca, Miettunen, Benseler, Veeramreddy, Schmeling.

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