



Factors that influence school attendance and participation in children and adolescents with juvenile idiopathic arthritis - a systematic review of the literature

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Abstract

Introduction Juvenile Idiopathic Arthritis (JIA) is an umbrella term for causes of inflammatory arthritis in children and adolescents. Symptoms include pain, stiffness and fatigue and this can have an impact on a child's ability to attend school or participate in school activities, such as physical education.

Methods Using Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) methodology, the research databases Pubmed, EMBASE and CINAHL were searched using key words related to JIA and school attendance and participation. Inclusion criteria were being 18 years old or under, having a diagnosis of JIA and examining JIA's impact on either school attendance or participation in a school activity. Included studies were examined for factors that affected attendance or participation.

Results Twelve research articles were included in the literature review. Six themes were identified as affecting attendance and participation. They were (1) Symptoms and treatment of JIA (2) Disability (3) Psychological symptoms (4) Disease activity and JIA subtype (5) Communication and school support and (6) Factors that increased participation.

Conclusion Children and adolescents with JIA have reduced levels of school attendance and often cannot participate fully in school life due to their medical condition. Targeted strategies may improve participation rates in this population. Further research is needed in this area to develop interventions and strategies to facilitate the optimal educational and school experience possible for this cohort.

Keywords Juvenile idiopathic arthritis, Disability, Absenteeism, Presenteeism, Rheumatology, Paediatrics, Systematic review

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Introduction

Juvenile Idiopathic Arthritis (JIA) is a term used to describe a number of inflammatory conditions causing chronic arthritis in children and adolescents. As this is a complex, chronic condition that occurs in a school-aged population, school attendance is negatively influenced by the resulting physical, emotional, psychological and social factors.

Presenteeism, defined as attendance despite a medical condition that prevents one from fully functioning, [1] is also a feature in this population due to physical impairments, pain and fatigue.

The term JIA encompasses a variety of heterogenous conditions of various aetiologies and clinical manifestations. The International League of Associations for Rheumatology (ILAR) developed a criteria for the diagnosis of JIA, defining it as an arthritis in children under the age of 16 lasting longer than six weeks. The classification system developed by ILAR recognises six distinct subtypes based on the expression of the disease within the first six months. These include systemic, oligoarthritis, rheumatoid factor positive and negative polyarthritis, psoriatic arthritis and enthesis-related arthritis. A seventh category known as undifferentiated arthritis accounts for cases that do not fit into another subtype, or that fulfils the criteria for two subtypes [2].

JIA can present with a variety of symptoms and comorbidities that include joint pain and stiffness, uveitis, skin rashes and constitutional symptoms such as weight loss, fatigue and night pain [2].

Adolescents with JIA navigate a variety of challenges as a result of their condition. These include health care demands (attending appointments and taking medication), social challenges (fitting-in, navigating the challenges of adolescence and a changing body, dealing with a chronic disease at a young age) and educational challenges (keeping up with school work and asking for additional support) [3].

A child's health condition is a key component of their ability to participate in their day to day lives according to the International Classification of Functioning (ICF), a framework for defining ability endorsed by the World Health Organisation [4].

Several studies have reported on the higher levels of absenteeism in children and adolescents with JIA [5, 6, 7]. One study notes that those with JIA missed an average of 2.7 days over a two month period [14], in comparison with the general school population who missed two days per two month period, reflecting a 35% higher rate of absenteeism. When compared with asthma, a study of school aged children with asthma in the USA found that they missed on average 54% more school days per year than those without asthma [8]. New treatments for JIA and other paediatric rheumatic diseases have been developed in recent years. These aim to improve disease control and quality of life in this population. New therapies that aim to reduce symptoms and improve quality of life for those with JIA should improve school attendance rates and participation levels [9].

The aim of this literature review is to identify the factors associated with school attendance and participation in school activities in children and adolescents with JIA.

Methods

Search strategy

A structured search strategy was employed to search the EMBASE, PubMed and CINAHL databases between the 22nd and 26th of July 2024 using PRISMA guidelines. A search was conducted using key words and phrases relating to JIA and School Attendance, as well as Boolean operators to find appropriate material. No time limitations were applied to the search strategy.

Key terms and phrases used in the search were 'Juvenile Idiopathic Arthritis', 'JIA', 'Juvenile Arthritis', 'School Attendance', 'School Absence', 'Non-Attendance', 'Presenteeism' and 'Participation'. Boolean Operators "AND" and "OR" were used to combine the search terms.

The inclusion criteria were defined as follows: (1) Subjects had to be under eighteen years of age. (2) Subjects must have a diagnosis of JIA as per the ILAR criteria [2] (3) The research must examine either (a) attendance at school (b) participation in school activity such as social outings, PE, school sports or (c) ability to engage in school work. (4) Research is puplished in the English language.

Exclusion criteria were defined as follows: (1) Research that examines subjects over the age of eighteen (2) Subjects that have been diagnosed with another rheumatic disease or pain syndrome such as fibromyalgia and (3) Subjects do not meet the ILAR criteria for diagnosis of JIA (4) The research does not include reference to school attendance or activities.

Titles and abstracts of relevant research articles were screened in order to identify material that met the inclusion criteria. Full text papers were accessed and downloaded. Duplicates were identified and removed. Reference lists were also screened to identify additional relevant research.

Study appraisal

Articles that met the inclusion criteria were examined to identify the measures used in each. Factors found to be statistically significant in their association with reduced levels of participation or attendance in school were identified and collated.

Studies were appraised using the JBI Tool for Cross Sectional Studies [10] and the JBI Tool for Qualitative

Table 1 Study appraisal using JBI cross sectional study tool. Y=Yes, NN=No, N/A=Not Applicable

JBI Cross Sectional Study Tool [10]	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8
Abdul-sattar et al., 2014[5]	Y	Y	Y	Y	Y	Y	Y	Y
Armbrust et al., 2016[20]	Y	Y	Y	Y	Ν	N/A	Y	Y
Bouaddi et al., 2013[6]	Y	Y	Y	Y	Ν	N/A	Y	Y
Chomistek et al., 2019[15]	Y	Y	Y	Y	Y	Ν	Y	Y
Hoeksma et al., 2014[12]	Y	Y	Y	Y	Ν	N/A	Y	Y
Milatz et al., 2019[13]	Y	Y	Ν	Y	Ν	N/A	Y	Y
Nordal et al., 2019[14]	Y	Y	Ν	Y	Y	Ν	Y	Y
Nørgaard and Herlin, 2018[15]	Y	Y	Y	Y	Y	Ν	Y	Y
Yildiz-Kabak et al., 2024[21]	Y	Y	Y	Y	Ν	N/A	Y	Y

Table 2 Study appraisal using JBI qualitative study tool. Y=Yes, N=No, N/A=Not Applicable

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JBI Qualitative Analysis Tool [11]	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10
Kembe and Regardt, 2023[16]	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Stinson et al., 2012[19]	Y	Y	Y	Y	Y	Ν	Ν	Y	Y	Y
Van Gulik et al., 2020[17]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

Studies [11]. The results of this appraisal are shown in Tables 1 and 2.

Results

Study characteristics

EMBASE, Pubmed and CINAHL databases yielded 147 records for assessment. Duplicates were removed and the titles and abstracts of the remaining records were examined for suitability. 88 records were excluded at this stage as they did not report on an outcome of interest. Of the remaining 30 records, 6 were conference abstracts for which the full text article was not available. The reference lists of these articles were also screened to identify further potential sources of information.

Twelve articles were excluded based on eligibility criteria; five for not reporting on an outcome of interest, three for including subjects over the age of 18, two for including subjects that had another condition distinct from JIA and two for including subjects that did not fit the current classification for the diagnosis of JIA.

Twelve articles were included in the final analysis, nine were observational cohort or cross-sectional studies and three were qualitative studies utilising interviews with patients with JIA.

See the PRISMA flow diagram (Figure 1) for a breakdown of the study selection process.

Themes identified

After all included articles had been appraised, findings were grouped into 6 main categories based on their influence on attendance rates and participation. The themes identified were: (1) Symptoms and treatment of JIA (2) Disability (3) Psychological symptoms (4) Disease activity, (5) Communication and Support from School (6) Factors that Increased Participation. See Figure 2 for an overview of themes identified. A summary of the characteristics of included studies can be found in Table 3.

Theme: symptoms and treatment of JIA

Ten of the twelve studies included in this analysis reported that symptoms and treatment of JIA influenced school attendance and ability to participate in school activities, such as physical education (PE).

Symptoms of pain, stiffness, and fatigue were the most commonly referenced symptoms that impacted on schooling and participation. One study, Hoeksma et al., 2014 [12], examined symptoms of the hand and wrist, including range of motion, stiffness, pain and deformity. Symptoms were quantified using tools such as question-naires and structured interviews that provided insight into the experience of the subjects in dealing with their symptoms during school.

Two studies, Milatz et al., 2019, [13] and Nordal et al., 2019, [14] highlighted that treatment of JIA was also an important factor, remarking on those who needed to take Disease Modifying Anti-Rheumatic Drugs (DMARDs) and attend physiotherapy sessions, and on those that did not comply with their treatment regimens.

The need to attend hospital appointments was also identified in three studies (Chomistek et al., 2019, [15] Kembe and Regardt, 2023 [16] and Van Gulik et al., 2020 [17], causing difficulty in keeping up with assigned classwork.

Theme: disability

Seven of the twelve included studies reference disability as a factor in reduced attendance at school and altered participation levels. Disability was measured in a majority of studies using questionnaires like the Childhood Health Assessment Questionnaire (CHAQ), and did not





Fig. 1 PRISMA Flow Diagram and Study Selection



Fig. 2 Summary of Themes Identified

further analyse the tasks at school which were problematic for children with JIA.

Of the twelve studies included, two describe in detail the domains in which disability was experienced: Chomistek et al., 2019 [15] detailed the physical challenges associated with prolonged periods of sitting, writing and attending PE, while Norgaard and Herlin, 2018 [18] describe the PE-specific tasks that caused difficulty, including running, jumping and performing hand-stands.

Theme: psychological symptoms

Psychological symptoms such as depression, anxiety and coping are discussed in five of the reviewed research articles.

Chomistek at al, 2019, [15] highlighted that the subjects in their study had anxiety and embarrassment about being treated differently or being seen to "make excuses" for not engaging in class as much as others. Kembe and Regardt, 2023, [16] in their qualitative analysis of experiences of JIA, found that there were feelings of embarrassment associated with requiring a walking aid.

Stinson et al., 2012, [19] explored the feelings of social isolation, sadness and loneliness associated with their disease.

Abdul-sattar et al., 2014 [5] attributed depressive symptoms and poor psychological adjustment to reduced school attendance in their individual studies.

Theme: disease activity & JIA subtype

Four of the twelve articles assessed disease activity to be a factor relating to absenteeism and participation in school. There was significant heterogeneity across studies when it came to assessing disease activity, and findings differed study to study. Disease activity was quantified using validated tools that examined the extent of joint involvement and the severity of the inflammation. Three of the four studies that analysed disease activity used the Juvenile Arthritis Disease Activity Score (JADAS) [5, 13, 14], while one study [6] utilised the Disease Activity Score 28 (DAS28) and the Bath Ankylosing Spondylitis Index (BASDAI).

Studies conducted by Abdul-sattar et al., 2014, [5] Bouaddi et al., 2013, [6] Nordal et al., 2019 [14] and

Table 3 Summary of studies included in the literature review. Theme key: 1 = symptoms and treatment of JIA, 2 = disability, 3 = psychological symptoms, 4 = disease activity and JIA subtype, 5 lone = communication and support 6 = factors that increased participation

Study Author and Year	Sub- jects (n)	Population & Centre	Age Profile	Measures	Themes
1. Abdul-sattar et al., 2014[5]	52	Rheumatology inpatient and outpatient clinics at a university hospital, Egypt	Range: 7–17 Median: 9.5	Children's Depressive Inventory (CDI), Juvenile Arthritis Disease Activity Score (JADAS)	3, 4
2. Armbrust et al., 2016[20]	80	Multicentre study across three pae- diatric rheumatology departments, Netherlands	Range: 8–13 Median: 9.8	Pediatric- Quality-of Life-Inventory Multidimensional Fatigue Scale (PedsQI-MFS)	1
3. Bouaddi et al., 2013[6]	33	Paediatric and rheumatology department at a university hospital, Morocco	Range: 5.75-14 Median: 11	-Childhood Heath Assessment Questionnaire (CHAQ) -Visual Analog Scale (Pain) -Disease Activity Score (DAS28) -Bath Ankylosing Spondylitis Disease Activity Index (BASDAI)	1, 2, 4
4. Chomistek et al., 2019[15]	98	Rheumatology outpatient clinic at a children's hospital, Canada	Interquartile Range: 11–15 Median: 13	-Self-Reported questionnaire designed by the researchers	2, 3, 5
5. Hoeksma et al., 2014[12]	121	Two paediatric rheumatology departments in two children's hospitals, Netherlands	Mean Age: 13.7 Standard Devia- tion: 4.2	-Childhood Heath Assessment Questionnaire (CHAQ) -Structured interview regarding symptoms experienced and participation	1, 2
6. Kembe and Regardt, 2023[16]	8	Subjects that met inclusion criteria were identified through the Swedish Paediatric Rheumatology Registry	Median Age: 15	-Structured telephone interview regarding experiences with participation in activities	1,6
7. Milatz et al., 2019[13]	23,016	Data gathered from German National Paediatric Rheumatologic Database	Reported as: -Minimum of 7.4 ± 4.1 (2000) -Maximum of 8.5 ± 4.2 (2012)	-Juvenile Arthritis Disease Activity Score (JADAS) -Childhood Heath Assessment Questionnaire (CHAQ) -Numerical Rating Scale (Pain, fatigue, well-being, coping)	1, 2, 4
8. Nordal et al., 2019 ¹⁴	347	Data gathered from a prospective, multicentre cohort across Norway, Sweden, Finland and Denmark	-13.6 Interquartile Range: 10.6–17.6	-Juvenile Arthritis Disease Activity Score (JADAS) -Childhood Heath Assessment Questionnaire (CHAQ) - Self Reported Questionnaire	1, 2, 4
9. Nørgaard and Herlin, 2018[15]	68	Outpatient clinic in a university hospital in Denmark	Mean: 12.7 Standard Devia- tion: 1.7	-Physical Activity and Sport Questionnaire (PASQ) -Juvenile Arthritis Disease Activity Score (JADAS) -Childhood Heath Assessment Questionnaire (CHAQ)	1, 2, 5, 6
10. Stinson et al., 2012[19]	41	Multicentre recruitment at four tertiary rheumatology centres at university hospitals across Canada	Mean: 9.7 Standard Devia- tion: 1.7	-Semi-Structured Interviews on experience managing JIA	1, 3, 6
11. Van Gulik et al., 2020[17]	22	Outpatient clinic at a university hospital in Amsterdam	Median: 16.7 Range: 15–17	- Semi-Structured Interviews on experience managing JIA and on future work perspectives	1
12. Yildiz- Kabak et al., 2024[21]	49	Paediatric rheumatology depart- ment at a university hospital in Turkey	Mean: 13.4 Standard Devia- tion: 3.3	-Childhood Heath Assessment Questionnaire (CHAQ) -Juvenile Arthritis Biopsychosocial and Clinical Question- naire (JAB-Q) -Bruininks–Oseretsky Test of Motor Proficiency-2 Short Form (BOT-2 SF)	1, 2, 3

Milatz et al., 2019 [13] found disease activity did impact outcome.

Several papers also assessed whether or not JIA subtype influenced outcomes. The study by Abdul-sattar et al., 2014, [5] found no link between subtype and school attendance. With regards to participation in school activity, Nordal et al., 2019 [14] found that those with Enthesis-Related Arthritis (ERA) and Undifferentiated Arthritis had lower levels of participation, but research by Milatz et al., 2019 [13] found that those with oligoarthritis had lower rates of attendance and polyarthritis and ERA had higher levels or participation.

Theme: communication and support from school

Communication and receiving support from their teachers and school was another barrier to attendance and participation in this population, and was examined by two of the studies, Chomistek et al. 2019 [15] and Norgaard and Herlin, 2018 [18].

Requesting that accommodations be made on their behalf generated fear that they were being treated differently to classmates [15]. Not informing their teachers about their illness, and having teachers not believe their symptoms were described in both studies.

Theme: factors that increased participation

Three studies identified factors and strategies that helped to improve the attendance and participation in those with JIA.

Kembe and Regardt, 2023, [16] found that when subjects identified activities that were meaningful to them, they participated and engaged more in school. The authors highlighted that when a child used a mobility aid or assistive device like a walking stick or an adapted pen grip, their participation levels increased.

Stinson et al., 2012, [19] noted that some children had adopted adaptive behaviours allowing them to better manage their symptoms and increase engagement in school. These strategies include taking breaks as needed, performing stretches or using heating pads. Norgaard and Herlin, 2018, [18] noted a similar approach with respect to taking breaks or modifying the activity in order to continue their participation.

Discussion

This literature review aimed to look at the various factors that influence school attendance and participation in children and adolescents with JIA. Analysis of the twelve research papers included in this review identifies a number of themes that play a role in the experiences of young people with JIA in school.

The most common trend across the included papers was the influence of symptoms and the treatment of these symptoms on school attendance. Increased levels of pain, stiffness, fatigue, lack of energy are, unsurprisingly, linked with lower levels of attendance and participation.

An interesting link between treatment of symptoms was uncovered during the literature review. Across several studies, [13, 14] increased levels of treatment were linked with decreased levels of attendance. Those that need higher levels of treatment may have concurrently high levels of disease activity, disability and pain, and so do not participate as much in school.

The second most frequently reported trend across reviewed studies was the influence of disability on attendance and participation. Despite this, only two studies examined in detail the domains in which this population experience disability when it comes to schooling. Further qualitative research in this area will help to identify key areas of intervention to aid patients with JIA to fully participate in school life.

Psychological symptoms, such as anxiety and depression, are discussed in five of the articles. Two separate domains of psychological symptoms appear in the literature. The first is feelings of depression and difficulty coping with their disease. Subjects across a number of studies highlight the social isolation their disease causes them and worry about whether their disease will ever improve [15, 19].

The second domain is the sense of anxiety felt in being different from other classmates. Several studies report on the difficulty this population has in being treated differently to their peers, in having to ask for accommodations to be made on their behalf, and in feeling that they often had to "make excuses" as a result of their illness.

Analysis of the relationship between disease activity and school attendance reveals complicated and often conflicting results. Disease activity was found to have an impact on attendance and participation in 5 studies, while one of the included studies found that there was no association.

What impact JIA subtype has on participation is also unclear; there was disagreement on this between several articles. Of the twelve included studies, only four explore the relationship between JIA subtype and school attendance. JIA is a condition with significant heterogeneity and disease course. This presents a challenge to those looking to study JIA and the impact it has on the lives of those who have this condition. It may also explain some of the conflicting findings presented in this paper.

An interesting link between participation and communication was noted across two of the included studies. Chomistek et al., 2019, [15] reports that most subjects felt well supported in school. However, asking for support or accommodations to be made as a result of JIA was reported as a source of anxiety and a barrier to schooling in this study.

Subjects in the same study reported not telling their teachers about their illness for fear of being seen to "make excuses". Those in the Norgaard and Herlin [18] study experience a lack of support from their teachers.

Of the twelve studies included in this literature review, only three discussed ways in which subjects increased their participation levels in school [16, 18, 19]. Identifying and partaking in activities that were considered meaningful to the subjects was a facilitator to increasing participation.

Using mobility aids and assistive devices, as well as adopting strategies like stretching and taking breaks during the school day were also identified as positive factors [16].

The strategies employed by those with JIA to facilitate improved attendance and participation are simple, low cost and non-disruptive to the pupils themselves, their classmates or their teachers. As such, schools should endeavour to facilitate short breaks for stretching, modify activities in classes such as PE to maximise participation and ensure classes are equipped to accommodate those who use mobility aids and assistive devices. Clear communication between individuals with JIA, their parents, the teachers and school administrators is critical in creating a supportive environment for these students. Two of the studies [15, 18] in this review described a sense of embarrassment when asking for accomodations to be made on their behalf, and also a sense that their teachers did not believe their symptoms. Defining accomodations between students, families and teachers, as well as training of staff members would help to overcome these barriers to attendance and participation.

Much of the research in this field focusses on the barriers to attendance and participation. Future research should include focus on further strategies to improve these outcomes in this cohort.

Limitations

There were a number of limitations in this literature review. Firstly, there is some heterogeneity among the types and methods used in examining the effect JIA has on schooling. There were three qualitative studies, four cohort studies and five cross-sectional studies included.

Secondly, the studies examined in this literature review originate from a diverse selection of countries across Europe, North America and Africa. Differences in access to healthcare and education, as well as the socio-economic status of the populations studied are all potential confounding factors when it comes to school attendance rates.

The study by Bouaddi et al., a study from Morocco, highlighted the influence of parents literacy levels on school attendance, while Abdul-sattar, a study from Egypt references the challenges living in a rural area has on school attendance. In contrast to this, the studies carried out in Europe do not highlight literacy levels or access to schooling in their studies.

Conclusions

Children and adolescents with JIA have reduced levels of school attendance and often cannot participate fully in school life due to their medical condition.

This literature review examines the factors associated with decreased attendance and participation in a systematic way. Factors relating to the symptoms and treatment of JIA, psychological factors, disability, disease activity and communication were factors explored in the included studies. Strategies for increasing participation levels were also examined in the included literature. School is a critical time in the life of any young person. Further research is necessary to enable children and adolescents with JIA to engage optimally in school life with their peers.

Abbreviations

JIA	Juvenile Idiopathic Arthritis
ILAR	International League of Associations for Rheumatology
ICF	International Classification of Functioning
WHO	World Health Organisation
EULAR	European League Against Rheumatism
ACR	American College of Rheumatology
PRISMA	Preferred Reporting Items for Systematic Reviews and
	Meta-Analyses
PE	Physical Education
DMARD	Disease-Modifying Anti-Rheumatic Drug
CHAQ	Childhood Health Assessment Questionnaire
DAS28	Disease Activity Score 28
BASDAI	Bath Ankylosing Spondylitis Disease Activity Index
JADA	Juvenile Arthritis Disease Activity
ERA	Enthesis-Related Arthritis

Acknowledgements

No additional acknowledgements.

Author contributions

- T.S. performed the literature review and collated the results. - K.M. was the academic supervisor for this project. - Both authors reviewed the manuscript prior to submission.

Funding

No funding was received for this project.

Data availability

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics and Consent

Not applicable.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

Received: 28 January 2025 / Accepted: 24 April 2025 Published online: 08 May 2025

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