

## Original article

## Juvenile-onset inflammatory arthritis: a study of adolescents' beliefs about underlying cause

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## Abstract

**Objective.** Patients' beliefs regarding the cause of illness may influence treatment adherence and long-term outcome. Little is known of adolescents' beliefs regarding the cause of JIA. This study aims to identify adolescents' beliefs about the underlying cause of their arthritis at first presentation to the paediatric rheumatology department.

**Methods.** One hundred and twenty-two adolescents aged  $\geq 11$  years participating in the larger prospective Childhood Arthritis Prospective Study, an inception cohort of childhood-onset inflammatory arthritis, were asked to complete a questionnaire regarding underlying beliefs about their arthritis. The top-listed causes were identified, and associations between beliefs and characteristics of the adolescents and their arthritis were compared across the different causal beliefs.

**Results.** The most common causal beliefs were genetics (27.1%), the immune system (21.3%), accident or injury (15.6%) and infection (13.1%). Association between causal beliefs and gender, disease duration, International League Against Rheumatism subtype and source of referral was observed, although small numbers prevented robust statistical comparisons.

**Conclusion.** This first report on adolescents' beliefs about the cause of their juvenile arthritis found the most common causal beliefs to be related to genes or the immune system. Brief assessments of adolescents' beliefs at presentation will enable providers to modify or adapt potentially unhelpful beliefs and provide age-appropriate information regarding arthritis.

**Key words:** juvenile idiopathic arthritis, aetiology, illness beliefs, adolescents.

## Introduction

JIA represents the most common inflammatory arthritis of childhood. With an estimated prevalence of 10/10 000 children [1], JIA encompasses a heterogeneous group of inflammatory arthritides with an onset before the age of 16 years and has no proven cause [2]. JIA has a large impact on patients, both physically and psychologically. Issues that affect the quality of life of a patient with JIA include disability, growth and development abnormalities, absence from school and extra-curricular activities, identity and body image crises, pain and loss of function [3, 4]. Complications include local joint dysfunction, abnormal growth, anxiety due to unpredictable prognosis and altered body image perception. JIA is not a benign disease, and up to one-third of patients do not achieve remission, with many patients continuing to experience symptoms from active disease and/or reduced function

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throughout life [5–8]. In particular, a large proportion of patients with JIA continue to have significant levels of pain, despite treatment of their disease, and this is often under-assessed [9].

The Self-Regulatory Model (also known as Leventhal's Common Sense Model) has shown how beliefs about illness, its causes and its management can affect coping and adherence to management plans (behaviours) of a patient with a chronic disease [10, 11]. This model shows that people who believe that their illness is unable to be controlled or that the treatment has more disadvantages than advantages have poorer coping strategies and are much less likely to adhere to treatment regimens than those patients who believe there is a clear benefit from their treatment. In RA, illness beliefs have also been shown to contribute independently to pain and disability, even when controlling for levels of disease activity [12, 13].

To date, little research has investigated the beliefs of adolescents with JIA about the cause of their disease. A study in 1983 [14] into the beliefs of children with JIA about the nature of their illness and treatment found that there was a significant difference in the way children (aged 7–11 years) and adolescents (aged 12–17 years) think about their JIA-related symptoms. They concluded that age affects their causal beliefs, with older children more likely to recognize their arthritis as a condition of internal pathology. Other factors such as gender and socio-economic status were not related to differences in health beliefs.

By providing the patient with information that is targeted to both the age and developmental stage of the patient, the clinician is more likely to influence the beliefs of the patient, thereby empowering adolescents with JIA to exercise control over their disease and its management [9]. It is therefore important to investigate how adolescents perceive JIA and attribute its cause so that information provided in the consultation is tailored to address patients' specific needs. This will result in more effective management of paediatric illness [15–17].

Few studies have specifically investigated adolescent patients' understanding of JIA, meaning that little is known about how adolescents with JIA perceive the cause of their illness. Using data from adolescents enrolled in the Childhood Arthritis Prospective Study (CAPS), the aims of this analysis were to (i) describe the beliefs about the causes of arthritis in a cohort of adolescent (aged 11–16 years) patients with recently diagnosed inflammatory arthritis and (ii) compare the beliefs about the cause held by adolescents of different ages and gender and with different JIA disease subtypes and disease severity.

## Methods

### Study population

Participants were recruited as part of CAPS. Details of the project, launched in 2001, have been described elsewhere [18], but in brief, this is an ongoing prospective

multi-centre inception cohort study of new-onset inflammatory arthritis in children investigating the role of clinical, environmental and genetic factors on outcome. Children/adolescents with new inflammatory arthritis in one or more joints persisting for at least 2 weeks are recruited from one of five paediatric rheumatology centres in the UK. Exclusion criteria include septic arthritis, haemarthrosis, malignancy, history of traumatic injury to the joints and connective tissue disease.

### Data collection within CAPS

At the first visit, the rheumatologist performs a rheumatological examination and completes a 100-mm physician global assessment visual analogue scale (VAS). An International League Against Rheumatism (ILAR) subtype [2] is assigned if the suspected diagnosis is JIA. Within 3 months of the first visit, the parent(s) and child/adolescent are interviewed by a rheumatology research nurse, and the medical records are reviewed to extract information on demographics, diagnosis, disease characteristics including disease duration at first presentation, medical history, medications and relevant blood tests. The parent (or the child/adolescent where age appropriate) completes a Childhood Health Assessment Questionnaire (CHAQ) validated for use in the UK population [19], including a 100-mm pain VAS and a 100-mm parent general evaluation (PGE) VAS and the revised Illness Perception Questionnaire (IPQ-R) [20, 21]. The latter form is completed by the parent for children aged <11 years and by the child if aged  $\geq 11$  years. A similar review is undertaken annually for a minimum of 5 years.

The IPQ-R, introduced to CAPS in 2003, is a tool to assess beliefs about illness and its causes. The IPQ-R includes 26 questions to assess beliefs within five specific domains. These are as follows: the causes of the illness, the illness identity (the symptoms that the person associates with arthritis), chronicity (acute, chronic or cyclical), the severity of the consequences of the illness and the controllability of the illness. Causal beliefs are assessed by selecting from a list of 18 possibilities, with the participants asked to select and rank up to three causes that they consider the most important.

### Analysis

This analysis was limited to adolescents aged  $\geq 11$  years registered with CAPS before 30 April 2010 who completed a baseline IPQ-R, and it focuses specifically on the question regarding perceived causes of arthritis. Subjects are given the option to select up to three causes but are asked to rank these in order of importance. For the purpose of analysis, where more than one cause was listed, the highest-ranked (or first listed) cause was selected. The causes of arthritis were grouped into one of six categories: genetics and immune system, accident or injury, infection, lifestyle and behaviour, environmental exposures (non-infectious) and chance/bad luck (Table 1). Groups of causes were compared across the data set to look for associations between demographic factors (age, gender and ethnicity), source of referral and disease

**TABLE 1** Adolescents' perceived cause of inflammatory arthritis

Perceived cause	n (%)
Genetics or immune system	62 (50.8)
Runs in family	33 (27.1)
Getting older	3 (2.5)
Immune system in body	26 (21.3)
Accident or injury	19 (15.6)
Infection	16 (13.1)
Chance or bad luck	11 (9.0)
Environment and well-being	10 (8.2)
Diet or eating habits	2 (1.6)
Drinking alcohol	0 (0)
Smoking	0 (0)
Own behaviour	0 (0)
Doing too much	7 (5.7)
Poor health or bad medical care in past	1 (0.8)
Pollution or toxins in the environment	0 (0)
Psychological	4 (3.3)
Family problems, family worries	0 (0)
Stress or worry	2 (1.6)
Attitude about life	1 (0.8)
Feeling down, lonely, etc.	0 (0)
Type of person I am	1 (0.8)

Totals for the grouped category are given with values for individual causes (where applicable) listed below.

features (disease duration, arthritis diagnosis and disease severity). Non-parametric statistics were used to analyse continuous data (Kruskall-Wallis test for comparing medians). Categorical data were analysed using a  $\chi^2$  test or Fisher's exact test where cell frequencies were <5. Statistical significance was set at a *P*-value < 0.05. Statistical analysis of the data was performed using STATA version 10.1 (StataCorp, College Station, TX, USA).

The study was approved by the North West Multicentre Research Ethics Committee (02/8/104). Parent(s)/guardians are asked to provide written consent, and adolescents, if considered able, are asked to provide assent.

## Results

### Study population

Between April 2004 and April 2010, 287 adolescents aged  $\geq 11$  years were registered with CAPS. Of these, 147 had a returned baseline IPQ-R recorded. Of these 147 returned forms, 142 were completed by the adolescent themselves. The other five were completed by the parents, although it was not indicated why they were not completed by the adolescents themselves. In 20 cases, the final question regarding beliefs about cause was omitted, leaving 122 patients for analysis. There were no significant differences between those children with and without a completed IPQ-R in terms of age at presentation, gender, disease duration, ILAR subtype or

source of referral (see supplementary Table 1, available at *Rheumatology* online).

The median age of the final cohort was 13.3 years with an even distribution between the ages of 11–15 years. Three adolescents were 16 years old at the time of IPQ-R form completion (Table 2). Fifty-eight per cent were female. The two main sources of referral were orthopaedics and general paediatric clinics, with a smaller proportion of children referred from either general practice or other sources, including physiotherapy and ophthalmology. The majority had a diagnosis of JIA (95%). The median disease duration [interquartile range (IQR)] at first presentation was 8.9 months (IQR: 4.2, 17.4), with the majority completing the IPQ-R within the first month of presentation [median: 1.1 months (IQR: 0.4, 1.9)].

### Perceived beliefs about cause of arthritis

The most common beliefs held by the adolescents about the underlying cause of arthritis were genetics (27.1%) and the immune system (21.3%). These were followed by accident or injury (15.6%) and infection (13.1%) (Table 1). Less frequent or rare beliefs included behaviours such as smoking and alcohol. Very few adolescents listed either exogenous exposures (other than infection) or psychological factors (stress, worry, family worries or general attitude) as the perceived cause.

### Relationship between perceived cause and demographic and disease features

The perceived causes were grouped into six categories for analysis (Table 1). Small numbers prevented robust statistical associations. Variations in causal beliefs were not associated with age (Table 3). Female patients were more likely to list genetics or the immune system as a cause, whereas male patients were more likely to list accident or injury. The perceived cause also varied according to the source of referral, and, in particular, participants referred from orthopaedics were more likely to list accident or injury as their perceived cause. There were also differences among the JIA subtypes. Those adolescents with systemic arthritis listed either infection or genetics/immune system exclusively as their perceived cause, whereas accident or injury was most common among adolescents with persistent oligoarthritis. Those with the shortest disease duration were more likely to list infection as their underlying cause. This final association reached statistical significance. The perceived cause of arthritis did not vary according to baseline disease severity as measured using joint counts, pain scores, CHAQ, physician global score or parent general evaluation (Table 4).

## Discussion

This article reported the first study of beliefs about the cause of JIA in adolescents (aged 11–16 years) at first presentation to a rheumatologist and investigated whether they are associated with a number of factors including age, source of referral, gender, ethnicity, subtype and severity. In rheumatology, the role of beliefs is now

**TABLE 2** Baseline characteristics (*n* = 122)

	Median (IQR) or <i>n</i> (%)
Demographics	
Age (years)	13.3 (12.0–14.6)
Female	71 (58.2)
Caucasian <sup>a</sup>	105 (86.1)
Source of referral	
Orthopaedic surgeon	36 (29.5)
Paediatrician	40 (32.8)
General practice	17 (13.9)
Other	20 (16.4)
Missing	9 (7.4)
Disease features	
JIA	116 (95) <sup>b</sup>
JIA subtype	
Systemic arthritis	7 (5.7)
Oligoarthritis, persistent	47 (38.5)
Oligoarthritis extended	4 (3.3)
RF (–) polyarthritis	24 (19.7)
RF (+) polyarthritis	5 (4.1)
Enthesitis-related arthritis	11 (9.0)
PsA	10 (8.2)
Undifferentiated	8 (6.6)
Symptom duration at first rheumatology visit, months	8.9 (4.2–17.4)
Symptom duration at completion of IPQ-R, months	9.6 (5.4–18.8)
Physician global score, mm (0–100)	31 (18, 49)
Pain score, mm (0–100)	40 (10, 62)
CHAQ score (0–3)	0.63 (0.13–1.25)
Active joint count	2 (1–6)
Limited joint count	1 (1–3)
Parent general evaluation, mm (0–100)	23 (7–50)

<sup>a</sup>Ethnicity unknown in six children. <sup>b</sup>Other diagnoses: enteropathic arthritis (2), reactive arthritis (1), missing (3).

recognized as an important influence on behavioural responses to diagnosis and treatment [22]. For example, a belief that arthritis is caused by trauma may lead to reluctance to engage in physical activity.

In the current study, analysis of the categories of perceived cause showed that the majority (50.8%) of participants believed that the cause of their JIA was their genetics or immune system. This would be expected as adolescents (aged 11–16 years) should have reached the formal operational phase of cognitive development that is associated with a basic understanding of the pathophysiology of disease [23]. It may also reflect their educational experiences, as at this age, the national school curriculum starts to include causes of disease in biology.

Age and ethnicity, albeit a limited distribution within the sample, were not shown to have an impact on beliefs about cause, whereas, of the investigated factors, there appeared to be an association with gender and ILAR subtype, the latter just reaching statistical significance. Patients with persistent oligoarthritis were more likely to list accident or injury as a cause. Patients with systemic-onset JIA were more likely to attribute their disease to an

infection, and patients with other subtypes, including polyarthritis and PsA, believed their genetics and immune system were to blame. It is plausible that these beliefs develop in response to the presentation of disease and the route of referral to paediatric rheumatology. It may also reflect what has been told to them by other health care professionals along their care pathway as initial investigations were being undertaken, perhaps to exclude other diagnoses.

Similarly, those with an oligoarthritis, which could have been attributed initially to an injury, may be more likely to be referred in the first instance to orthopaedics. It was also found that adolescents who believed injury was the underlying cause had the longest time to referral, suggesting that initially investigations for internal joint derangement may have delayed referral to a rheumatologist. The different journeys through the health care system appear to result in the patients drawing their own conclusions about what is causing their problems. Similarly, information given to them at the start of their illness may make such an impression that the adolescents may not be receptive to alter their current beliefs about cause. Patients who believed that an infection was the cause of their arthritis tended to report shorter symptom duration before their initial rheumatology consultation. These patients may have appeared systemically unwell at presentation and, therefore, had been treated for infection while other tests were carried out. Previous work from this cohort has confirmed that children with systemic arthritis have the shortest symptom duration at first presentation [24]. The presenting complaint and the signs elicited by the practitioner may have also pointed to more severe disease, resulting in a more prompt referral to a specialist than would be the case for patients presenting with more benign symptoms.

Interestingly, no participants attributed their JIA to smoking or alcohol consumption, even though significant numbers of adolescents took part in such activities. Likewise, no participants thought that their own behaviour was an important causative factor. In part, this might be explained by an increasing understanding of the pathological basis of disease.

This is the first study to report on the beliefs of adolescents about the cause of their arthritis. The findings are useful in highlighting the importance of initial consultations and sources of referral in influencing beliefs of adolescents with arthritis. Professionals should be alert to the importance of assessing beliefs during early consultations and of providing tailored information about diagnosis and treatment in ways that support the development of coherent understanding of the condition. This should include information about disease cause.

The subjects, enrolled from five tertiary referral centres across the UK, represent the distribution of JIA across the UK and, therefore, could be applied to the general population of adolescents with JIA. However, the largely Caucasian study population enrolled in this study may limit the applicability of the results to non-Caucasian populations. Furthermore, unfortunately, forms were only

**TABLE 3** Association between beliefs about cause of arthritis and demographic and disease features

	Genetics and immune system	Accident or injury	Infection	Chance or bad luck	Environment and well-being	Psychological	P
<i>n</i>	62 (50.8)	19 (15.6)	16 (13.1)	11 (9.0)	10 (8.2)	4 (3.3)	
Age (years)	13.2 (12.0–14.3)	13.9 (12.1–14.9)	13.9 (12.1–15.2)	14.0 (13.2–15.1)	13.4 (13.0–13.9)	12.4 (11.8–13.0)	0.31
Female	40 (56.3)	7 (9.9)	8 (11.3)	7 (9.9)	5 (7.0)	4 (5.6)	0.14
Male	22 (43.1)	12 (23.5)	8 (15.7)	4 (7.8)	5 (10.0)	0	
Caucasian	52 (49.5)	16 (15.2)	16 (15.2)	8 (7.6)	10 (9.5)	3 (2.9)	0.38
Other ethnicity	6 (55)	2 (18)	0	2 (18)	0	1 (9)	
Source of referral							0.67
General practice	8 (47.1)	1 (5.9)	2 (11.8)	4 (23.5)	1 (5.9)	1 (5.9)	
Orthopaedic surgery	20 (55.6)	8 (22.2)	2 (5.6)	2 (5.6)	3 (8.3)	1 (2.8)	
Paediatrics	20 (50)	5 (12.5)	7 (17.5)	3 (7.5)	4 (10)	1 (2.5)	
Other	10 (50)	4 (20)	3 (15)	1 (5)	1 (5)	1 (5)	
Symptom duration, months	9.9 (5.3–19.7)	13.6 (6.0–42.4)	2.3 (1.0–7.2)	10.0 (5.4–17.4)	7.7 (4.5–11.0)	5.3 (2.7–10.8)	0.004
Arthritis diagnosis							0.04
Systemic	3 (42.9)	0	4 (57.1)	0	0	0	
Oligoarthritis persistent	21 (44.7)	13 (27.7)	2 (4.3)	5 (10.6)	5 (10.6)	1 (2.1)	
Oligoarthritis extended	2 (50)	0	2 (50)	0	0	0	
Polyarthritis RF–	11 (45.8)	4 (16.7)	2 (8.3)	3 (12.5)	1 (4.2)	3 (12.5)	
Polyarthritis RF+	4 (80)	1 (20)	0	0	0	0	
Enthesitis-related arthritis	4 (36.4)	1 (9.1)	2 (18.2)	1 (9.1)	3 (27.3)	0	
PsA	9 (90)	0	0	1 (10)	0	0	
Undifferentiated	4 (50)	0	2 (25)	1 (12.5)	1 (12.5)	0	
Other arthritis/missing	4 (67)	0	2 (33)	0	0	0	

All values are *n* (%) or median (IQR).

**TABLE 4** Association between beliefs about cause of arthritis and disease severity

Disease feature	Genetics and immune system	Accident or injury	Infection	Chance or bad luck	Environment and well-being	Psychological	P
<i>n</i>	62 (50.8)	19 (15.6)	16 (13.1)	11 (9.0)	10 (8.2)	4 (3.3)	
Active joint count	2.5 (1–6)	1 (1–8)	2 (1–8)	1.5 (1–2)	2 (1–5)	3 (1–10)	0.39
Limited joint count	2 (1–5)	1 (1–3)	1 (0–2)	1 (1–2)	2 (1–3)	1 (1–8)	0.86
Global score (0–100)	31 (18–49)	34 (25–49)	40 (31–68)	16.5 (9–34)	25 (15–30)	56 (55–57)	0.05
CHAQ score (0–3)	0.63 (0.25–1.13)	0.50 (0–0.88)	0.81 (0.44–1.44)	0.25 (0.13–0.88)	1.13 (0.25–1.50)	1.1 (0.81–1.63)	0.26
Pain score (0–100)	42 (13–67)	32 (3–67)	32.5 (5–58)	40 (12–62)	26 (25–47)	47 (22–64)	0.783
Parent general evaluation (0–100)	24 (10–46)	16 (2–50)	20 (2–51)	30 (7–67)	31 (28–59)	29 (13–45)	0.76

All values are *n* (%) or median (IQR).

available for ~40% of the adolescent cohort, and, therefore, it is possible that further bias exists within the data set. In part, a large number of missing forms will relate to the temporary absence of a research nurse from two centres. As the IPQ-R is not a part of routine clinical care, this questionnaire would therefore not have been completed at first presentation. Therefore, the nature of the missing data was likely to be random, as demonstrated by the lack of significant differences between the two groups. The small sample size of this study limited the power of the study to find robust associations across the different groups. Despite this, it remains the largest study reported to date of illness belief in JIA.

A further limitation is the possibility that by giving patients a questionnaire, this can be seen in itself as an intervention. By using IPQ-R, restrictions are placed on

the options a patient has for answering the questions. Therefore, there is a risk that beliefs may be changed to fit the questionnaire or that new beliefs are provided, which the respondent had not previously thought of. Finally, further study could also include simultaneous collection of illness beliefs from the parent to see whether these are largely shared with the child or if beliefs are already independent at this stage.

As the aetiology of childhood-onset arthritis remains unclear, health care professionals are faced with a challenge when communicating with young patients and their parents about disease cause and disease prognosis. This is particularly important in relation to future management and self-care strategies. It is known that illness beliefs affect both adjustment and coping responses [12, 25]. A belief that physical trauma caused JIA may lead parents



and adolescents to restrict opportunities for physical activity, thereby leading to further disability. It is therefore crucial that information about cause and management is presented in ways that enable families to adapt optimally to the diagnosis.

In conclusion, this first report on adolescents' beliefs about the cause of their juvenile arthritis found the most common causal beliefs to be related to genes or the immune system. However, differences in beliefs were found to be associated with different JIA subtypes and routes of referral to rheumatology. It is important that health care providers involved in the care of these patients give age-appropriate information, and that the information is useful and consistent. Brief assessments of adolescents' and parents' beliefs will enable providers to modify or adapt potentially unhelpful beliefs. Future research will explore whether beliefs about causes of JIA change over time or whether patients maintain beliefs based on the first information that they receive.

#### Rheumatology key messages

- Beliefs of adolescents regarding cause of arthritis are varied.
- Beliefs of adolescents regarding the cause of their arthritis differ according to the subtype of their arthritis.
- Adolescents' beliefs about their arthritis are related to types of physician seen before rheumatology.

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### Supplementary data

Supplementary data are available at *Rheumatology* Online.

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