What is the Impact of Adolescent Arthritis and Rheumatism? Evidence from a National Sample of Canadians

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ABSTRACT. ***Objective***. Adolescent arthritis or rheumatism (AAR) has been shown to influence the activities, mental health, and healthcare utilization of affected individuals. However, these effects have never been estimated in a population-based sample. We examined the association of AAR with health status, health services use, health behaviors, and activity limitations. We also investigated the effect of socioeconomic status and family background on respondents with AAR.

Methods. The 1996 National Population Health Survey is a nationally representative survey exploring the health status and behaviors of Canadians. Among the 26,012 individuals aged 12 to 19 with complete responses on the presence of chronic illnesses, the 213 self-reporting arthritis or rheumatism (AAR) were compared to: (1) all other adolescents as a single group; or (2) the group of 9161 adolescents reporting other chronic diseases (OCD) but not AAR, and the group of 16,638 adolescents without chronic disease (WCD). Between-group differences were examined for the following variables: health status; use of health services; presence of activity limitations in school, work, or at home; and school enrollment and work status.

Results. Compared to those without, respondents with AAR reported more diagnoses of non-AAR chronic illnesses. Depression among AAR individuals was more prevalent than among non-AAR individuals, as was suffering from moderate or severe pain. Those with AAR were more likely than WCD individuals to use physician services, hospital services, and pain relief medications. AAR patients were more likely to be limited in their activities, and less likely to be enrolled in school than OCD or WCD individuals.

Conclusion. This study indicates a broad range of effects of AAR in a nationally representative sample. Arthritis or rheumatism affected measures of mental health, health service use, and the school, work, and home activities of affected individuals, compared to individuals without chronic disease or with other chronic disease. (J Rheumatol 2005;32:354–61)

Key Indexing Terms:
JUVENILE IDIOPATHIC ARTHRITIS PEDIATRIC RHEUMATOLOGY PAIN
ACTIVITY LIMITATIONS HEALTH SERVICE UTILIZATION DEPRESSION

Rheumatic diseases in children and adolescents comprise a heterogeneous group, including juvenile idiopathic arthritis (JIA), juvenile dermatomyositis, juvenile systemic lupus erythematosus, and other connective tissue diseases and vasculitides[1]. This group of diseases, while affecting a small proportion of the population, has significant effects with high rate of persistence into adulthood[2-7]. A recent study by Bowyer, *et al* highlights increased referral of patients with nonspecific musculoskeletal pain syndromes, as well as reflex neurovascular dystrophy and fibromyalgia, to pediatric rheumatologists[8]. The latter problems now constitute an ever-increasing proportion of pediatric rheumatology practice.

Pediatric chronic diseases are often associated with chronic pain and physical restrictions, which frequently translate into significant impairment in the daily activities of affected children[2,9-15]. During the vulnerable adolescent period, the burden of chronic pain, the feeling of isolation due to restricted activities, and the constraints of medical

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followup can lead to depressive symptoms[11,13]. The extent of these effects for children with rheumatic symptoms, however, has not been described. Although one study has examined the effect of socioeconomic status (SES) and family structure on the risk of developing JIA[16], the impact of SES status on children with rheumatic symptoms has yet to be studied.

The literature on the association of childhood rheumatic diseases with chronic pain and the ability to pursue activities is limited because of the difficulty in assembling representative samples of children with rheumatic diseases and in assembling relevant comparison groups. Previous studies have relied on clinic-based samples that are not nationally representative. In this article, we extend the literature on rheumatic diseases affecting adolescents by examining a nationally representative sample of Canadians, the 1996/1997 cross section, or wave, of the National Population Health Survey (NPHS). We examined the association of adolescent arthritis and rheumatism (AAR) with health status, health services use, health behaviors, and activity limitations. We also investigated the effect of SES and family background on respondents with AAR. Our study is unique in that we examined associations that had not been previously evaluated, and as well determined whether results from small, clinic-based samples were verified in a large, nationally representative sample.

MATERIALS AND METHODS

The National Population Health Survey. The NPHS is a nationally representative longitudinal survey of Canadians begun in 1994 that surveys households every second year on an ongoing basis[17]. Households in all provinces are surveyed, but those living in Indian Reserves, Canadian Forces bases, and the northern territories were excluded. Our study examined data on respondents aged 12 to 19 from the 1996 cross section of the NPHS, since this cross section contained a large one-time supplement to the sample. We focus only on adolescents because data on the presence of specific chronic illnesses were not available for children under 12 years of age. For each of the more than 60,000 households interviewed for the 1996 NPHS, General File information was collected on all household members, and Health File information was collected on one person from each household.

The General File (including 26,105 adolescents) included data on: socio-demographics, health status, use of healthcare services, days confined to bed due to illness, cutdown days due to illness, activity limitations due to a longterm condition, and work activity and school enrollment. The Health File (including 6952 adolescents) included data concerning: the intensity of usual pain, a measure of mental health, routine medical examinations, medication use, and the amount of activities forgone because of pain. Since we sought to link the adolescents' characteristics to those of their families as well as to access certain data elements omitted from the NPHS Public Use File, our computations had to be carried out on the Master File of the NPHS at a Statistics Canada site.

Definition of arthritis or rheumatism and other chronic diseases. All members of NPHS households (or their proxy respondents) aged 12 years or older were asked if they suffered from a chronic illness (lasting 6 months or more) diagnosed by a health professional. The question was phrased as follows: "Now I'd like to ask about certain chronic health conditions which you (your child) may have. We are interested in "longterm conditions" that have lasted or are expected to last 6 months or more and that have been diagnosed by a health professional. Do you (does your child) have _____?" A list of conditions was read to the respondents, and they were asked to indicate the condition(s) for which they had been diagnosed. The list included: food allergies, other allergies, asthma, arthritis or rheumatism, back problems, high blood pressure, migraine headache, chronic bronchitis or emphysema, sinusitis, diabetes, epilepsy, heart diseases, cancer, stomach or intestinal ulcers, effects of a stroke, urinary incontinence, bowel disorders, Alzheimer's disease or dementia, cataracts, glaucoma, thyroid condition, or other chronic problem.

Mental health. To measure the severity of depressive symptoms, Statistics Canada uses a subset of items from the Composite International Diagnostic Interview to create a derived depression scale[17]. Since Statistics Canada has not published data indicating which values on this derived depression scale correspond to clinical cases, based on the NPHS-derived depression scale and published statistics on depression prevalence, we generated our own derived depression indicator. Since 5.59% of Canadian adolescents aged 12–19 years suffer from depression[18], we classified respondents to be depressed if their scores on the depression scale were among the 5.6% highest in the distribution of this scale for all respondents in the NPHS. It was not possible to verify that this classification corresponded to clinical cases of depression in our sample subjects.

Analysis

Comparison groups. To understand the impact of AAR, we used 2 methods of comparing AAR respondents to other respondents. First, we constructed 3 groups among respondents aged 12 to 19 years: (1) those with AAR; (2) those without AAR but with one or more of the other chronic diseases (OCD); and (3) those without chronic disease (WCD). These groupings allow us to compare outcomes for children with AAR versus children with other chronic diseases and healthy children. Second, we categorized respondents as living with AAR and not living with AAR (no AAR).

Descriptive analysis. The descriptive part of our analysis examines how AAR respondents compare to other respondents according to 3 broad categories of variables: socio-demographics, health status, and health service utilization and activity limitations. To analyze the differences between groups, Fisher tests and confidence intervals (CI) at the 95% level were computed.

Socio-demographics. The socio-demographic variables of AAR respondents were compared to those of OCD and WCD respondents. These variables included: age, sex, years of education, school enrollment, employment status, household income, and living in a single-parent household.

Health status. Health status variables were compared across 2 groups of respondents, those with AAR and those without. The health status variables included: number of chronic diseases other than AAR, presence of specific frequent adolescent chronic diseases, presence of a clinical case of depression (as previously defined), and presence of moderate or severe pain. For health status variables, we compared AAR respondents to the ensemble of non-AAR respondents since, by definition, the relevant comparison group for the AAR respondents is all other respondents. OCD respondents might have the OCD in higher proportion than the AAR children, and the WCD respondents, by definition, would have no OCD.

Health services utilization and activity limitations. The third category of comparison includes utilization of healthcare resources and activity limitations or restrictions. These comparisons were made across the 3 categories of respondents (AAR, OCD, WCD). The health service utilization variables included: number of medical consultations with generalists and specialists in the last 12 months; utilization of preventive medicine, including: dental visits, eye checkups, routine medical checkup, and flu shots; psychologist visits; and use of codeine/demerol/morphine, sleeping pills, antidepressants, and tranquilizers; and hospitalization in the last 12 months.

Variables that reflect restrictions or limitations in daily activities included: number of days spent in bed in the last 14 days, number of disability days in the last 14 days resulting from a longterm health problem; presence of activity limitation due to pain; and presence of limitation in activities at:

(1) home, (2) school, (3) work, (4) transportation or leisure; and (5) home, school, work, or transportation or leisure.

Multivariate analysis. We estimated a series of logistic regressions to see whether AAR affects probability of reporting a limitation in: any activity, working in the last 12 months, being enrolled in school, and being depressed as defined by our algorithm. We also estimated linear regressions for the number of years of completed schooling. In all multivariate analyses we included the following control variables: age, sex, immigrant status, province of residence, family income, and single-parent household.

Statistical analysis. For each analysis, we computed parameter estimates and CI at the 95% level using Stata™ 6.0 software (Stata Corp., College Station, TX, USA). We used the information on clusters and stratification from the NPHS Master File, located at Statistics Canada sites, and the survey commands of Stata to address these aspects of the NPHS survey design in the estimation. All analyses employed the NPHS population weights.

RESULTS

Descriptive analysis. *Sample*. Among the 210,377 respondents in the NPHS, 26,105 were aged between 12 and 19 years old. The 26,012 respondents having complete responses for the questions on the presence of chronic diseases made up our study sample.

Socio-demographics. The demographic characteristics of the 26,012 respondents are summarized in Table 1. The AAR respondents are primarily female, on average, one year older than the OCD respondents, and have one more year of education. Individuals without chronic illness represent 64.5% of respondents. Household income is not significantly different among the 3 categories, but AAR respondents are more likely to live in a single-parent household.

Our weighted estimate of the prevalence of AAR in Canadian 12- to 19-year-olds is 7/1000, and the prevalence of OCD is 348/1000.

Health status. We first compare the number of chronic diseases (excluding AAR) in subjects with AAR to all those without AAR (Table 2). AAR subjects have more chronic diseases, excluding AAR, than other respondents. The main concomitant chronic diseases among AAR subjects are allergies, back problems, and migraines/headaches. They also suffer more often from bowel disease, stomach or intestinal ulcers, and from chronic bronchitis than the respon-

Table 1. Demographic characteristics of the adolescents.

	AAR	95% CI	OCD	95% CI	WCD	95% CI	p*	N
N, General File	213	—	9161	—	16,638	—	—	26,012
Male, %	38	(24;53)	48	(46;51)	53	(51;55)	0.006	26,012
Age, yrs, mean	17	(16;18)	16	(15;16)	15	(15;16)	< 0.001	26,012
Years of education, mean	11	(10;12)	10	(9;10)	9	(9;10)	< 0.001	25, 855
School enrollment, %	76	(62;86)	86	(84;88)	87	(85;88)	0.059	25,982
Has worked[a], %	65	(49;79)	55	(52;58)	46	(44;49)	< 0.001	16,067
Household income, mean	44,133	(37,547; 50,719)	48,089	(46,803; 49,375)	47,898	(46,934; 48,861)	0.514	19,799
In a single-parent household, %	31	(18;47)	20	(18;22)	17	(15;19)	0.011	25,993

AAR: Adolescent arthritis or rheumatism individuals; OCD: adolescents with a chronic disease other than AAR; WCD: adolescents without a chronic disease. * Based on a Fisher test at 5% significance. [a] Reference period is the last 12 months. Question asked to those 15 years and older.

Table 2. Health characteristics of the adolescents.

	AAR	95% CI	No AAR	95% CI	p*	N
No of chronic diseases[a] other than AAR, mean	1.5	(1.1;1.9)	0.53	(0.5;0.6)	< 0.001	26,012
Allergies, %	54	(38;69)	23	(22;24)	< 0.001	26,012
Back problem excluding arthritis, %	25	(12;46)	3	(2;5)	< 0.001	26,012
Migraine/headaches, %	14	(7;25)	4	(3;5)	< 0.001	26,012
Bowel disease, e.g., Crohn's disease, %	5	(0.8;27)	0.3	(0;0.5)	< 0.001	26,012
Stomach or intestinal ulcers, %	3	(0.9;8)	0.4	(0;0.6)	< 0.001	26,012
Chronic bronchitis, %	3	(1;7)	1	(0;2)	0.007	26,012
Depression scale, mean	0.9	(–0.2;1.9)	0.3	(0.2;0.4)	0.211	6,614
Depressed, %	19	(5;51)	5	(4;7)	0.041	6,614
Usually suffers moderate or severe pain, %	23	(7;54)	3	(1;4)	< 0.001	6,939

No AAR: the union of the groups OCD (adolescents with a chronic disease other than AAR) and WCD (adolescents without a chronic disease). * Based on a Fisher test at 5% significance. [a] Includes asthma, high blood pressure, sinusitis, diabetes, epilepsy, heart disease, cancer, thyroid condition, and other chronic conditions.

dents without AAR. No significant differences were noted between these 2 groups for all other chronic diseases (asthma, blood pressure, sinusitis, diabetes, epilepsy, heart diseases, cancer, or thyroid conditions). However, they were much more likely to be depressed (19% vs 5%), as defined by our depression scale, and they were more likely to usually suffer from moderate to severe pain (23 vs 3%).

Health services utilization and activity limitations. Although respondents with OCD have significantly more consultations with physicians than WCD respondents, there is no significant difference between AAR and OCD respondents [Table 3 (some comparisons that were not statistically significantly different are not reported)]. The variables concerning medical followup (time since last dentist visit, time since last eye examination, physical examination without having a health problem, flu shot, psychologist visits) do not show significant differences among the 3 categories, although there was a slightly greater difference between the number of eye specialist consultations in the AAR versus the WCD respondents. Although the estimated use of codeine/demerol/morphine is much higher in the AAR respondents, there is no statistical difference between the AAR and OCD respondents. There is also no statistical between-group difference in utilization of sleeping pills, anti-depressants, tranquilizers, or laxatives. Fifteen percent of AAR respondents had been hospitalized in the year preceding the survey, compared to 5% and 2% of OCD and WCD respondents, respectively.

AAR respondents reported considerably more days confined to bed and disability days than OCD and WCD respondents, and some or most of their activities were much more likely to be limited by pain (21% vs 3% and 0.5% for OCD and WCD respondents, respectively). AAR and OCD respondents were much more likely to be limited in one of their usual activities (home/school/work/leisure) than WCD respondents, and the AAR respondents were significantly more limited than the OCD group (19% vs 11%; p = 0.04) (Table 3).

Taking each of the categories of activities separately, the percentage of respondents reporting limitations at home because of a longterm health problem is significantly different for the 3 groups, the AAR group being significantly more limited than both the OCD (p = 0.02) and WCD respondents. The estimated rate of school limitations is higher for the AAR group than for the OCD and WCD groups, but the difference between the chronically ill groups (AAR and OCD) is not statistically different. Whether these limitations imply lower rates of school enrollment or educational attainment was investigated in the multivariate analysis below. For those who worked in the previous year, the estimated rate of work limitation was much higher for the AAR group than the other groups, and the difference between the chronically ill groups is statistically significant (p = 0.04). However, since the AAR group is older and has a higher proportion of respondents who worked in the previous year, it is necessary to investigate the effect of AAR and OCD on workforce participation in a multivariate context. Finally, AAR respondents were significantly more likely than both their OCD (p = 0.01) and WCD peers to be limited in leisure and other activities. Yet AAR individuals were

Table 3. Health service utilization and activity limitations.

	AAR	95% CI	OCD	95% CI	WCD	95% CI	p*
Health service utilization							
No. of consultations with a medical doctor[a], mean	6.4	(3.8;9.2)	3.9	(3.6;4.1)	1.8	(1.6;1.9)	< 0.001
Consultations only with GP[a], %	61	(46;74)	64	(61;66)	59	(57;61)	0.001
No. of consultations with a dentist[a], mean	2.2	(1.3;3.1)	1.9	(1.8;2.1)	1.7	(1.6;1.8)	< 0.001
No. of consultations with an eye specialist[a], mean	1.1	(–0.2;2.4)	0.5	(0.4;0.6)	0.5	(0.3;0.5)	< 0.001
Use of codeine/demerol/morphine[b], %	18	(4;53)	5	(3;7)	2	(1;3)	< 0.001
Spent at least one night in hospital[a], %	15	(6;29)	5	(4;7)	2	(1;3)	< 0.001
Activity limitations							
No. of last 14 days spent in bed due to illness or injury, mean	0.6	(0.2;1.1)	0.2	(0.1;0.3)	0.1	(0;0.2)	< 0.001
No. of disability days in the last 14 days due to illness or injury, mean	1.3	(0.5;2.1)	0.6	(0.5;0.8)	0.3	(0.2;0.4)	< 0.001
Some/most activities prevented by pain, %	21	(6;53)	3	(1;5)	0.5	(0;1)	< 0.001
Limited[c] at home, %	12	(6;23)	6	(4;8)	0.5	(0.3;0.8)	< 0.001
Limited[c] at school, %	14	(6;25)	9	(7;10)	1	(0.7;2)	< 0.001
Limited[c] at work, %	8	(3;16)	4	(2;5)	0.4	(0.2;0.6)	< 0.001
Limited[c] in other activities such as transportation or leisure time, %	17	(9;27)	8	(7;10)	1	(0;2)	< 0.001
Limited[c] at home/school/work/transportation/leisure, %	19	(11;30)	11	(9;13)	1	(1;2)	< 0.001
Physical activities on a regular basis, %	90	(76;97)	75	(70;78)	70	(67;73)	0.027

AAR: Adolescent arthritis or rheumatism; OCD: adolescents with a chronic disease other than AAR; WCD: adolescents without a chronic disease. * Based on Fisher test at 5% significance. [a] In the last 12 mo. [b] In the past month. [c] Because of a longterm physical or mental condition or a health problem.

more likely to report regular physical activity (defined in the NPHS as 12 or more days in the last month of more than 15 min physical activity). However, the overall duration and intensity of this activity is not specified and is probably systematically different for AAR individuals. Given their reported physical limitations, it is likely that these respondents are more aware of their pursuit of physical activities or that these activities are the result of medical directives at an appropriate level of intensity.

Multivariate analysis. In Panel A, Table 4, odds ratios (OR) are presented for presence of chronic conditions (AAR and OCD) and remaining variables of interest that had a statistically significant association with the probability of a limitation in home/school/work/other activities. Limitation is very

Table 4. Multivariate analysis of limitations of the adolescents.

A. Logistic regression among all 12–19-year-old adolescents. Probability of being limited[d] at home, at school, at work, or in other activities (N = 19,773).

	Odds Ratio	955 CI	p
AAR[a]	17.3	(7.6;39.3)	< 0.001
OCD[a]	10.2	(7.5;13.9)	< 0.001
Immigrant	0.4	(0.1;0.8)	0.004
Household income > 60,000 $CAN[c]	0.6	(0.3;0.9)	0.011

B. Logistic regression among all 16–19-year-old adolescents. Probability of having worked in the last 12 months (N = 11,920).

AAR[a]	1.7	(0.8;3.5)	0.116
OCD[a]	1.5	(1.2;1.8)	< 0.001
18–19 years[b]	3.3	(2.7;3.9)	< 0.001
Immigrant	0.5	(0.3;0.7)	< 0.001
Ontario	0.6	(0.4;0.8)	< 0.001
Prairies	1.7	(1.2;2.2)	< 0.001
Household income 20,000–39,999 $CAN[c]	1.7	(1.2;2.3)	< 0.001
Household income 40,000–59,999 $CAN[c]	1.9	(1.4;2.6)	< 0.001
Household income > 60,000 $CAN[c]	2.8	(2.1;3.8)	< 0.001

C. Logistic regression among all 12–19-year-old adolescents. Probability of being enrolled in school (N = 19,771).

AAR[a]	0.5	(0.2;0.9)	0.019
OCD[a]	0.9	(0.7;1.2)	0.438
16–17 years[b]	0.6	(0.4;0.9)	0.001
18–19 years[b]	0.1	(0;0.2)	< 0.001
Male	0.7	(0.5;0.9)	< 0.001
Immigrant	1.9	(1.2;3)	0.002
Ontario	1.7	(1.2;2.3)	< 0.001
Household income > 60,000 $CAN[c]	1.7	(1.2;2.4)	0.001

D. Logistic regression among all 12–19-year-old adolescents. Probability of suffering from depression (N = 4980)

AAR[a]	4.2	(0.9;18.1)	0.055
OCD[a]	1.4	(0.9;2.3)	0.101
16–17 years[b]	3.2	(1.7;6.1)	< 0.001
18–19 years[b]	3.7	(1.9;7.1)	< 0.001
Male	0.3	(0.2;0.6)	< 0.001

Except for the AAR and OCD variables, only statistically significant variables (at the 0.05 level) are reported. The models included indicators for education of the mother and for single-parent family. All models also included indicators for age, male sex, immigrant status, province, and income group. The reference province group was the Maritimes (Quebec, Ontario, British Columbia, and Prairie Provinces were included). A constant was included but not reported. N: number of respondents with complete data on all included variables. [a] WCD is the reference group. [b] Included indicators for 2-year age groupings. 12–13 years old is the age reference category in A, C, and D. 16–17 years old is the reference category in B. [c] The reference category is for family income < 20,000 $CAN (indicators for 20–39,999, 40–59,999, and 60,000 and over were included). [d] Because of a longterm physical or mental condition or a health problem.

strongly associated with the presence of AAR and OCD and with household income (those from higher income households being less likely to have limitations). In an auxiliary analysis (not shown), we examined the subsample of 5216 adolescents for whom the presence of moderate or worse pain was available from the Health File. Adding this variable to the regression, we saw that the presence of moderate or severe pain was strongly associated with activity limitation (OR = 6.2, $p < 0.001$).

The multivariate analysis shown in Panel B confirms the result from Table 1 that the older age of the AAR group partly explains their higher probability of having worked in the last 12 months relative to healthy respondents. Although the estimated OR is significant from an economic and clinical point of view (OR = 1.7), the CI of the estimate includes 1. Again, in the auxiliary analysis of the subsample of respondents for whom data on chronic pain was available from the Health File (not shown), we saw that presence of chronic moderate to severe pain is strongly associated with probability of having worked in the last 12 months (OR = 3.2, $p = 0.001$).

In Table 4, Panel C, we report results from logistic regressions on the probability of being enrolled in school. In this case, the presence of AAR does seem to affect school enrollment (OR = 0.5), even when controlling for the age of respondents. This effect, however, does not seem to be present for respondents with OCD. Other variables associated with school attendance — sex, immigrant status, and income — conform to our a priori predictions of the effects of these variables. In a subsample analysis on the adolescents responding to the Health File, the estimated OR for the presence of moderate or severe pain is 1.5, but the CI included 1 ($p = 0.399$). Although these logistic regressions indicate that AAR is negatively associated with schooling, in a separate linear regression analysis (not reported in Table 4), we detected no link between the years of education of the respondents and the presence of AAR.

In Panel D, Table 4, we explore determinants of the presence of depression. Again, as in Table 2, the estimated effect of AAR is quite significant clinically (OR = 4.2), but the CI for the odds ratio includes 1 ($p = 0.055$). This is likely due to the lack of power inherent in predicting differences for a small group (AAR) of relatively low probability events (5.6% of respondents are classified as depressed). Focusing on the magnitude of the OR, we saw in a subsample analysis (data not shown in Table 4) that when the moderate or severe pain variable was introduced into the logistic regression (OR = 4.2, $p = 0.002$), the OR of AAR was nearly halved (2.4, $p = 0.364$), indicating that much of the effect of AAR on depression may be associated with uncontrolled pain.

DISCUSSION

In a 2000 article, Palermo[11] stressed the importance of identifying the functional limitations associated with pediatric diseases involving chronic pain to be able to intervene effectively. She deplored the paucity of research on pediatric chronic pain and identified a clear need for prevention-focused treatment for these children.

We used a nationally representative sample to analyze the impact of AAR on the health status, healthcare utilization, and activities of 12- to 19-year-old respondents. Univariate analysis revealed that respondents with AAR suffered from more chronic diseases, in addition to AAR, than adolescents without AAR. Respondents with AAR were also more likely to have depressive symptoms, which are strongly related to uncontrolled pain. AAR individuals were more likely to use healthcare resources than WCD adolescents, including physician visits, hospitalizations, and certain medications. Our univariate and multivariate results showed that respondents are more limited in their daily activities than OCD and WCD respondents.

One limitation of our study is that, because our broad categorization of AAR combines a heterogeneous group of inflammatory and noninflammatory "rheumatisms," our results may not provide a useful guide to understanding the experiences of adolescents with arthritis or rheumatism of a particular type. Also, since our study focuses on adolescents aged 12 to 19, the comparability of our results to those from the literature may be limited, since most previous studies have included subjects under age 12.

Our study estimated a prevalence of AAR of 7 per 1000, which is considerably higher than the 0.5 to 1 per 1000 reported for JIA[5]. However, our sample was composed of adolescents aged 12 to 19 years, so it is not surprising that our prevalence estimate was higher than those based on children aged 0 to 16 years, since prevalence is strongly associated with age. In addition, the self-report category of "arthritis or rheumatism" is considerably broader than JIA, so our AAR sample contained adolescents reporting rheumatic illness other than JIA and probably contained a high proportion of individuals with idiopathic pain syndromes. Also, among the AAR individuals in our sample, many did not see a specialist in the previous year. These individuals would not be accounted for in prevalence survey methodologies requiring a specialist's diagnosis. One other study using a population survey — the Canada Health Survey (CHS), conducted in 1978 and 1979 — similar to the one used in our study estimated the prevalence of chronic "arthritis or rheumatism, and serious trouble with back or spine or other bones or joints (excluding those reporting missing appendages)" to be 13 per 1000 for persons under 15 years of age[19]. Although it is counterintuitive that arthritis and rheumatism prevalence would be higher in a younger group (0–14 years) than our sample of adolescents, back problems unrelated to arthritis are reported in a separate category in the NPHS and were not included in our definition of AAR. Indeed, in Table 1 we showed that chronic back

problems unrelated to arthritis affected 30 per 1000 adolescents, among those unaffected by AAR.

Twenty-three percent of our sample of respondents with AAR usually experience moderate to severe pain, compared to only 3% of those without AAR. Our results confirm in a representative sample the finding of Ruperto, *et al*, who showed that among 227 adults and children who had been diagnosed with JIA, 30% usually experienced moderate to severe pain[20]. The results might also indicate that some of those self-reporting AAR may have idiopathic pain syndromes; frequent referral of such patients to pediatric rheumatology clinics has been described[8]. In addition to experiencing more pain, AAR individuals reported a greater number of chronic illnesses, other than AAR, than those without AAR.

In our study, 19% of adolescents with AAR displayed enough depressive systems to be classified as a case of depression, compared to only 5% of those without AAR. In our multiple logistic regression, AAR children tended to be more depressed than respondents without AAR; an auxiliary regression analysis indicated that much of this effect was due to presence of chronic moderate to severe pain, which was strongly (and statistically significantly) associated with depression. This confirms findings of Palermo[11], Varni, *et al*[15], and Schanberg, *et al*[21] that respondents with pain experience more depressive symptoms and that symptoms increase with patient-perceived pain intensity. Although our results are counter to 3 clinic-based studies, specifically on JIA, that concluded that children adapt well[22-24], increasingly, data suggest that for JIA this is not the case[25,26].

Unfortunately, the NPHS did not contain a survey instrument of general child health status such as the Child Health Questionnaire (CHQ), which has been validated for use in children with rheumatic illness[27].

Our results were consistent with those of Palermo[11], that children with JIA are higher users of physicians compared to children with OCD. However, although mean values in the 3 groups were shown to be statistically different, the difference between the AAR and OCD respondents was not statistically significant. Interestingly, 88% of physician contacts for the AAR children were with general practitioners (GP), and 61% of the AAR respondents saw only a GP in the previous 12 months. As noted, reliance on GP may explain the difference in AAR prevalence based on self-reports and prevalence estimates based on methods requiring a specialist diagnosis. The greater number of visits to eye specialists provides some support that a self-report of AAR corresponded to adolescents with inflammatory rheumatic conditions, since these patients are monitored by ophthalmologists for possible visual effects of inflammation and the use of corticosteroids or antimalarial drugs.

Although researchers have expected that emotional distress may result in sleep disturbances[11], we did not find a statistical difference in the use of sleeping pills among children with AAR. However, we did find higher estimated rates of use of pain medications (codeine/demerol/morphine) in the previous month among AAR respondents (18%) when compared to OCD respondents (5%) or WCD respondents (2%). Consistent with having higher levels of depression than other respondents, AAR respondents had higher estimated rates of antidepressant use (5%) than OCD (1.7%) or WCD respondents (1.1%), although the difference was not statistically significant. Surprisingly, although AAR respondents were more likely to experience depressive symptoms, the average number of psychologist contacts for AAR respondents was very low (0.2 visits) and not statistically different from either OCD or WCD respondents.

We have shown that AAR children are more limited in the activities at home, school, work, and other activities such as leisure or transportation. It would be desirable to confirm these self-report limitation estimates with a survey instrument such as the Childhood Health Assessment Questionnaire (CHAQ) or the Juvenile Arthritis Quality of Life Questionnaire, which have been shown to be valid and reliable instruments for functional disability in children with rheumatic conditions[28,29]. Palermo[11] has called for additional research validating the Functional Disability Inventory (FDI) in patients with chronic illness.

Although not statistically significant, the estimated effect of AAR on working was positive; also, the effect of chronic moderate or severe pain was positive and statistically significant. This was surprising to us, since individuals affected by JIA have been shown to have difficulty finding work in adulthood[30]. However, it is possible that AAR causes some adolescents to leave school, and that some of these school leavers are able to find some sort of work — at whatever level of intensity — that is less sensitive to their limitations. In this sense the effect of arthritis would be similar for adults and adolescents: living with arthritis makes it more difficult to pursue the main activities typical for their age group.

Indeed, we found that AAR respondents were less likely to be enrolled in school. However, since our estimate of the effect of AAR on work status is not statistically significant, this interpretation of school-work substitution needs to be confirmed in a larger sample. The NPHS also reveals that AAR respondents spent 11 more days in bed (because of disease or injury) annually than the OCD respondents. It would be probable that this results in more school absences, confirming previous research[12] showing that JIA is associated with more school absences for enrolled students. However, our finding that AAR individuals were less likely to be enrolled in school has not been previously shown in the literature. Although our results indicate that AAR respondents may have a more difficult schooling path than other respondents, we did not find evidence of a link in the completed years of education of adolescents and the presence of AAR. Also, our data were not detailed enough to

confirm the results of Fowler and colleagues[9], where half of their sample of children reported that the disease had influenced their school performance. In principle, questions of educational performance and attainment can be studied in future waves of the NPHS, as the respondents in the sample become adults and complete their schooling.

Limitations in the ability to carry out activities at home were not documented previously in the literature. Our multivariate analysis confirmed that the presence of AAR is a determinant of these limitations.

Our NPHS sample is one cross section, or wave, of a longitudinal survey, which began in 1994. As more waves of the NPHS become available, future research will be able to explore how AAR affects the health status, healthcare utilization, professional choices, and family life of these respondents as they mature.

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