

Chronic inflammatory arthritis prevalence estimates for children and adolescents in three Canadian provinces

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Abstract There is a paucity of published population-based estimates of the prevalence of chronic inflammatory arthritis in the pediatric population. We used administrative health data to estimate the prevalence of chronic inflammatory arthritis in individuals ≤ 18 years in three Canadian provinces: Quebec, Manitoba, and Saskatchewan. Cases aged ≤ 18 years were identified by meeting any one of the following criteria: (a) ≥ 1 hospital discharge abstract with an ICD-9 code of 714 or ICD-10-CA codes of M05, M06 or M08, or (b) ≥ 2 ICD-9 714 billing codes ≥ 8 weeks apart, but within 2 years, or (c) ≥ 1 ICD-9 714 billing code by

a rheumatologist. Crude prevalence estimates per 10,000 population were estimated with 95 % confidence intervals (CIs). Prevalence estimates were 11.7 per 10,000 individuals ≤ 18 years of age in Manitoba, 9.8 per 10,000 in Saskatchewan, and 8.0 per 10,000 in Quebec. In pairwise comparisons of rate differences, Manitoba and Saskatchewan had higher estimates than Quebec. Prevalence estimates were higher for females than males, with a difference of 5.9 cases per 10,000 residents (95 % CI 5.1, 6.7). Saskatchewan was the only province with a higher estimate in urban compared to rural residents (5.2, 95 % CI 2.5, 8.0).

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Variations in provincial estimates may be due to differences in underlying population characteristics. Although these estimates have face validity and are in keeping with the range of previously published pediatric prevalence estimates, studies to establish the empiric validity of case-finding algorithms are needed to advance research in pediatric chronic disease epidemiology.

Keywords Prevalence · Epidemiology · Juvenile rheumatoid arthritis · Arthritis · Pediatrics · Administrative databases

Introduction

Administrative health data are widely used for chronic disease research and surveillance in Canada and internationally. Though not originally intended for these purposes, administrative health data provide a large and easily accessible amount of population-based information for disease surveillance to inform healthcare decision-making [1]. Chronic disease surveillance is important to estimate burden of disease for resource planning and evaluation of management strategies [2]. Although administrative health data are being used for chronic disease research and surveillance in adult populations, their use in pediatric populations has lagged in the medical literature.

Administrative health data have been used to study adult rheumatoid arthritis in multiple settings [3–6], but similar pediatric studies are limited [7–9]. Chronic inflammatory childhood arthritis is the most common pediatric rheumatic disease [10]. Manners et al. [11] reviewed all epidemiological studies of incidence and prevalence of chronic childhood inflammatory arthritis from 1966 to 1998, and in the 34 studies identified internationally, prevalence estimates ranged from 0.7 to 40.1 per 10,000 children. This range can be partially explained by differences in geography, study design, and study populations [10, 11]. However, these

Table 1 ICD codes included in the case-finding algorithms

| ICD version | Code | Diagnosis |
|-------------|------|---|
| ICD 9 | 714 | Rheumatoid arthritis and other inflammatory polyarthropathies |
| ICD 10 CA | M05 | Seropositive rheumatoid arthritis |
| ICD 10 CA | M06 | Other rheumatoid arthritis |
| ICD 10 CA | M08 | Juvenile arthritis |

estimates were based on community or clinic samples, and therefore may have limited generalizability.

Our study uses population-based administrative health data to estimate the prevalence of chronic inflammatory arthritis in individuals <19 years of age for the Canadian provinces of Quebec, Manitoba, and Saskatchewan using a consistent methodology and study design. Manitoba and Saskatchewan are central Canadian Prairie provinces with a high proportion of First Nations and large rural populations, while Quebec is a more eastern province with a smaller proportion of First Nations and a larger urban population.

Methods

Administrative health data, including hospital discharge abstracts and physician billing claims, that capture diagnostic information on all residents with provincial healthcare coverage, were accessed for the Canadian provinces of Quebec (1996–2005), Manitoba (1995–2004), and Saskatchewan (1998–2007). All Canadian provinces have universal healthcare programs. However, administrative health data in Canada are collected and maintained at a provincial level, thus these dates represent the data available from each province at the time of this study. Diagnoses in administrative data are recorded using the International Classification of Diseases (ICD). Hospitalization data in these provinces contain ICD-9 or ICD-10-CA codes, while physician billings contain ICD-9 or ICD-9-CM codes.

Case definitions were based on case ascertainment algorithms previously validated or used in studies of adult rheumatoid arthritis. Cases in this pediatric study were defined by: (a) one or more hospitalizations with any discharge diagnosis of ICD-9 code 714 or ICD-10-CA code M05, M06 or M08 [5, 9] (Table 1) or (b) two or more billing claims with a diagnosis of ICD-9 code 714 at least 8 weeks apart, but within a 2-year period [11–13] or (c) one or more billing claims with a diagnosis of ICD-9 code 714 by a rheumatologist [13, 14]. An individual was defined as a case if he/she satisfied at least one of these definitions, had provincial health coverage as of the final year of ascertainment, and was <19 years of age at the end of the study period. Cases satisfying more than one definition were only counted once.

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Table 2 Crude prevalence per 10,000 population and counts of cases of chronic inflammatory arthritis in individuals ≤18 years

| Province | Overall prevalence (95 % CI ^a) | | | | Overall cases and population counts | | | | | |
|---|--|-------------------|-------------------|-------------|-------------------------------------|------------------|------------------|------------------|------------------|------------------|
| | Rural | | Urban | | Total cases | Total population | Rural cases | Rural population | Urban cases | Urban population |
| | Total | 95 % CI | Total | 95 % CI | | | | | | |
| (A) | | | | | | | | | | |
| Quebec | 8.0 (7.6, 8.4) | 7.6 (6.9, 8.3) | 8.2 (7.7, 8.8) | 1,316 | 1,649,306 | 455 | 601,621 | 861 | 1,047,685 | |
| Manitoba | 11.7 (10.5, 13.0) | 11.4 (9.6, 13.3) | 12.0 (10.3, 13.8) | 345 | 295,097 | 152 | 133,554 | 193 | 161,543 | |
| Saskatchewan | 9.8 (8.6, 11.1) | 7.8 (6.5, 9.3) | 13.0 (10.8, 15.6) | 238 | 243,877 | 119 | 152,545 | 119 | 91,332 | |
| Prevalence in females (95 % CI ^a) | | | | | | | | | | |
| Total | | Rural | Urban | Total cases | Total population | Rural cases | Rural population | Urban cases | Urban population | |
| (B) | | | | | | | | | | |
| Quebec | 10.7 (10.0, 11.4) | 10.3 (9.1, 11.5) | 10.9 (10.0, 11.8) | 860 | 807,372 | 301 | 293,388 | 559 | 513,984 | |
| Manitoba | 16.0 (14.0, 18.2) | 14.0 (11.3, 17.2) | 17.6 (14.8, 20.8) | 230 | 144,000 | 91 | 64,952 | 139 | 79,048 | |
| Saskatchewan | 13.0 (11.1, 15.3) | 11.9 (9.5, 14.6) | 16.2 (12.6, 20.3) | 160 | 118,889 | 88 | 74,317 | 72 | 44,572 | |
| Prevalence in males (95 % CI ^a) | | | | | | | | | | |
| Total | | Rural | Urban | Total cases | Total population | Rural cases | Rural population | Urban cases | Urban population | |
| (C) | | | | | | | | | | |
| Quebec | 5.4 (4.9, 5.9) | 5.0 (4.2, 5.9) | 5.7 (5.0, 6.3) | 456 | 841,934 | 154 | 308,233 | 302 | 533,701 | |
| Manitoba | 7.6 (6.3, 9.1) | 8.9 (6.8, 11.4) | 6.6 (4.9, 8.5) | 115 | 151,097 | 61 | 68,602 | 54 | 82,495 | |
| Saskatchewan | 6.0 (4.7, 7.5) | 4.0 (2.7, 5.6) | 10.1 (7.4, 13.4) | 78 | 124,988 | 31 | 78,228 | 47 | 46,760 | |

(A) Overall, (B) Females, (C) Males

^a CI = confidence interval

These case definitions were intended to estimate the cumulative prevalence of chronic inflammatory arthritis in the pediatric population at the end of the study period in each province. Individuals with chronic inflammatory arthritis diagnosed in the pediatric age range but who were older than 19 years at the end of the study period were excluded from this study. We chose a cutoff of 19 years in order to produce estimates of the burden of chronic inflammatory arthritis in the pediatric population at the end of the study period, as individuals up to 18 years are normally treated by pediatric specialties in the Canadian healthcare system. These estimates include children <16 years with juvenile rheumatoid arthritis and juvenile idiopathic arthritis [15], as well as adolescents 16 to 18 years of age with juvenile rheumatoid arthritis, juvenile idiopathic arthritis, and early onset rheumatoid arthritis.

Statistics Canada Census data from the last year of the study period were used to estimate prevalence per 10,000 residents aged <19 years. Prevalence estimates were stratified by sex, as well as urban and rural residence location. Urban residence, which included census metropolitan (population greater than 100,000) or census agglomeration (population greater 10,000 but <100,000) areas, was determined by postal code in Quebec and Manitoba and by residence code in Saskatchewan. All other areas were considered rural.

Crude prevalence estimates were calculated, with 95 % confidence intervals (CIs) calculated using an exact binomial approach. Differences between binomial proportions were calculated using a normal approximation to the exact binomial differences. This research was approved by data access and institutional ethics review boards in each province.

Results

The provincial prevalence estimates (Table 2) reveal that the highest estimate was in Manitoba (11.7 cases per 10,000 residents <19 years of age) and the lowest was in Quebec (8.0 cases per 10,000 residents). Pairwise comparisons confirmed that Manitoba had higher estimates than either Saskatchewan (rate difference 1.9, 95 % CI 0.2, 3.7) or Quebec (rate difference 3.7, 95 % CI 2.4, 5.0), while the estimate in Saskatchewan was also higher than that in Quebec (rate difference 1.8, 95 % CI 0.5, 3.1).

As expected, overall prevalence estimates were higher for females than males, with a rate difference of 5.9 cases per 10,000 residents (95 % CI 5.1, 6.7). Overall estimates were also marginally higher in urban than rural areas, with a rate difference of 0.8 (95 % CI 0.05, 1.6) cases per 10,000 residents. When further analyzed by province, Saskatchewan was the only province with a higher estimate in urban than rural residents (5.2, 95 % CI 2.5, 8.0). The rate

differences for the estimates from Manitoba (0.6, 95 % CI -1.9, 3.0) and Quebec (0.7, -0.02, 1.5) had confidence intervals too wide for definitive conclusions. Overall and females estimates were higher in urban than rural areas, though in Manitoba males, the estimates suggested the reverse trend.

Discussion

Our study uses administrative health data to provide prevalence estimates of chronic inflammatory arthritis in children and adolescents for three provinces within Canada. Estimates ranged from 8.0 to 11.7 per 10,000 residents <19 years of age. We calculated these estimates up to age 19 years to describe the burden of disease treated in the pediatric setting.

Rheumatic diseases are between 5 and 7 times more common in adult Native Americans than in Caucasians [16], and the small number of studies examining these conditions in Native American children and youth suggest a similar pattern [16, 17]. In Canada, the term Aboriginal refers to descendants of the original inhabitants of North America and includes First Nations (formerly referred to as Indians, which would most closely correspond to the term Native Americans used in the USA), Métis (mixed European and First Nations), and Inuit (Aboriginal people in Northern Canada) [18]. The highest estimates in our study were in Manitoba, which had the highest Aboriginal population of the three provinces studied (15.5 %), and the lowest was in Quebec, which has the smallest Aboriginal population (1.5 %). Saskatchewan, with an Aboriginal population between those of Manitoba and Quebec (14.9 %), also had an overall prevalence estimate that was lower than that in Manitoba, but higher than that in Quebec. In Manitoba, 57.4 % of the Aboriginal population were First Nations and 40.9 % were Métis, whereas in Saskatchewan 33.9 % were First Nations and 64.4 % were Métis [19]. It is not clear if the Métis population has a higher risk of pediatric onset chronic inflammatory arthritis. There were very few Inuit in any of the provinces studied. Although our results suggest a potential influence of Aboriginal ethnicity on prevalence rates, we were not able to estimate the influence of ethnicity because this information was not available in the data.

As expected, prevalence estimates were higher for females than males, as a number of autoimmune diseases, including juvenile idiopathic arthritis, are more common in females [20]. In Saskatchewan, there was a higher prevalence in urban than rural areas, but this was not evident in either Manitoba or Quebec. Theoretically, this could reflect a difference in the distribution of First Nations and/or Métis populations in Saskatchewan compared to Manitoba and Quebec.

Differences in prevalence estimates for rural and urban areas may either result from underlying differences in population characteristics or systematic differences in the available data. In the USA, administrative data from large, urban centers are more likely to contain coding errors [21], while rural areas in Alberta, Canada tend to use less specific ICD codes [22]. Our study results may be similarly influenced. Geographic barriers to care are known to exist in Canada, despite its system of universal healthcare. Differences in accessibility could also influence prevalence estimates based on administrative health data.

Strengths and limitations

The strengths of this study include that it is population based and allows for comparisons among provinces and between rural and urban environments. However, although validation studies of case ascertainment algorithms have been conducted for adult rheumatoid arthritis [3–6, 11, 12, 14, 23], and the specific algorithms in our study were refined from this work, our case definitions were not independently validated. Algorithm performance may differ in pediatric and adult populations [24]. One study has since validated case finding algorithms for pediatric chronic inflammatory arthritis in a US managed care setting. It found that the best case ascertainment algorithm for prevalent cases required at least two diagnostic codes by any provider, with a case finding algorithm sensitivity of 87% (95% CI 76–93%) and PPV of 91% (95% CI 80–96%). Our study did not use the same diagnostic codes as this validation work. Additionally, the validity of case finding algorithms varies according to setting [24], and therefore may differ between the Canadian universal healthcare system and the managed care system in the United States. To date, there are no published validated algorithms for ascertaining cases of pediatric chronic inflammatory arthritis in Canadian administrative health data. We elected to include single diagnoses in the study algorithms to optimize sensitivity, recognizing that this may result in an over-estimate of prevalence due to a higher false positive rate than a more stringent definition.

ICD-9 codes do not reflect current terminology describing chronic pediatric inflammatory arthritis, juvenile idiopathic arthritis. ICD-9 codes use older terminology for pediatric chronic inflammatory arthritis (juvenile rheumatoid arthritis). Unlike juvenile rheumatoid arthritis, juvenile idiopathic arthritis encompasses seven different types of arthritis [15], some of which have distinct ICD-9 codes and would not be captured by the 714 codes. For example, prior to the development of the juvenile idiopathic arthritis classification system, juvenile psoriatic arthritis and juvenile ankylosing spondylitis would have been coded as ICD-9 696.0 (psoriatic arthropathy) and 720.0 (ankylosing spondylitis), respectively. Psoriatic arthritis and

juvenile ankylosing spondylitis are now considered subtypes of juvenile idiopathic arthritis and are now therefore likely to be coded as 714 instead of 696.0 and 720.0. Thus, prevalence estimates using ICD 714 may not have captured patients with these types of pediatric chronic inflammatory arthritides if they were assigned diagnostic codes other than ICD-9 714. This could lead to underestimates of disease prevalence. These additional diagnostic codes were not available to the authors.

In some provinces, such as Quebec, pediatric rheumatologists may be identified as general pediatricians or internists and not as rheumatologists, and therefore would not have been captured in our case ascertainment algorithm. Pediatric rheumatologists would not submit billing claims if they are reimbursed through alternate funding plans (salaried positions); billing data would only capture their patients if they submit parallel (i.e., “shadow”) billings. The quality and completeness of the shadow billing may vary, which could influence administrative data-based prevalence estimates. In Quebec, additional fees are paid for patients with a diagnosis of a chronic disease such as juvenile idiopathic arthritis or juvenile rheumatoid arthritis, and the impact of this form of reimbursement on administrative data-based prevalence estimates is unclear. Additionally, when a diagnosis is not yet clear, physicians will often state in their notes that the diagnosis is “possible” or that they must “rule out” this diagnosis. In such cases, the diagnosis may be incorrectly coded as the condition that was being considered or ruled out. It is not possible to distinguish “rule out” diagnoses from true diagnoses in administrative health data. While our confidence intervals account for random error in the data, uncertainty in point estimates may also arise because of systematic errors and gaps in the databases. Finally, residence was captured during the index year and may not reflect province of residence at the end of the study period.

Conclusion

In summary, we estimated the prevalence of chronic inflammatory arthritis using administrative data from three Canadian provinces and found estimates of 11.7 per 10,000 individuals <19 years of age in Manitoba, 9.8 per 10,000 in Saskatchewan, and 8.0 per 10,000 in Quebec. These estimates have face validity, as they are within the range of published estimates [11], though published estimates were not from population-based data. Both Manitoba and Saskatchewan had significantly higher prevalence estimates than Quebec. Although overall urban areas had a slightly higher prevalence rates than rural areas, Saskatchewan was the only province in which this held true when provinces were examined separately. Further comparisons with data from additional provinces are necessary to determine

patterns of differences in prevalence rates between urban and rural areas in other Canadian jurisdictions. Studies to establish the empirical validity of case-finding algorithms are also needed to advance epidemiological research in pediatric rheumatic diseases such as juvenile idiopathic arthritis.

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Conflict of interest None of the authors have competing interests.

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