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Do Patterns of Early Disease Severity Predict Grade 12 Academic Achievement in Youths With Childhood-Onset Chronic Rheumatic Diseases?

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ABSTRACT. ***Objective.*** To test the association of early disease severity with grade 12 standards test performance in individuals with childhood-onset chronic rheumatic diseases (ChildCRDs), including juvenile arthritis and systemic autoimmune rheumatic diseases.

Methods. We used linked provincial administrative data to identify patients with ChildCRDs born between 1979 and 1998 in Manitoba, Canada. Primary outcomes were Language and Arts Achievement Index (LAI) scores and Math Achievement Index (MAI) scores from grade 12 standards test results as well as enrollment data. The secondary outcome was enrollment in grade 12 by 17 years of age. Latent class trajectory analysis identified disease severity groups using physician visits following diagnosis. Multivariable linear regression tested the association of disease severity groups with LAI and MAI scores, and logistic regression tested the association of disease severity with age-appropriate enrollment, after adjusting for sociodemographic factors and psychiatric morbidities.

Results. The study cohort included 541 patients, 70.1% of whom were female. A 3-class trajectory model provided the best fit; it classified 9.7% of patients as having severe disease, 54.5% as having moderate disease, and 35.8% as having mild disease. After covariate adjustment, severe disease was associated with poorer LAI and MAI scores but not with age-appropriate enrollment.

Conclusion. Among patients with ChildCRDs, those with severe disease performed more poorly on grade 12 standards tests, independent of sociodemographic and psychiatric risk factors. Clinicians should work with educators and policy makers to advocate for supports to improve educational outcomes of patients with ChildCRDs.

Key Indexing Terms: autoimmune disease, child, disease severity, education, health services research, juvenile arthritis

Of the childhood-onset chronic rheumatic diseases (ChildCRDs), juvenile arthritis (JA) is the most common, affecting 1 in 1000 Canadian children.[1] Systemic autoimmune rheumatic diseases (SARDs) are multisystem diseases, comprising systemic lupus erythematosus, inflammatory myositis, systemic sclerosis, and Sjögren syndrome.[2] SARDs affect approximately 1 in 4500 Canadian children.[3]

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Patients with ChildCRDs experience many disruptions as a result of the underlying disease, adverse effects from treatment, and need for outpatient visits and hospitalizations. These disruptions may adversely affect the educational outcomes of children with ChildCRD, which could affect future employment opportunities and socioeconomic achievements.[4] Few studies have focused on educational outcomes in patients with ChildCRDs.[5-12] Results have been conflicting, with some showing that patients with ChildCRDs perform better than or similar to siblings or study controls.[7-12] However, those studies were limited by small sample sizes, a lack of control patients or potentially biased controls (eg, friend controls), and failure to account for sociodemographic factors that can influence educational outcomes.[13,14] Graduation rate or school attendance was the most common outcome. However, neither is a good measure of academic performance, which is associated with students' cognition and learning, and is related to future employment.[15] In one study, patients with JA who had better grades were more likely to achieve future managerial or professional type employment.[4]

Recently, we showed that youths with ChildCRDs performed significantly worse than youths without ChildCRDs,

as measured by their grade 12 standards tests, and had lower odds of age-appropriate enrollment in grade 12.[16] ChildCRD was associated with grade 12 standards test performance independent of sociodemographic and psychiatric factors. However, not all youths with ChildCRDs performed poorly in school. Being able to identify those at higher risk would help ensure that youths who most need support receive it. We hypothesized that more severe disease would be associated with worse grade 12 standards test results.

There is no single disease severity construct in rheumatic diseases. Previous research developed disease-specific severity indices using medical records or insurance claims data.[17-20] Generally, the severity construct reflects high disease activity and is associated with increased morbidity and/or mortality, therefore requiring aggressive treatment.[20,21] Those with more severe disease have increased healthcare utilization.[18,22,23] Patients with different disease severities may have distinctive patterns of healthcare utilization. We envision these patterns of healthcare utilization as indicators of disease severity in multiple ChildCRDs. We aimed to test the association of disease severity with academic performance among youths with ChildCRDs, adjusted for sociodemographic and psychiatric morbidities.

METHODS

Study design and data sources. This was a retrospective, population-based, longitudinal cohort study from Manitoba, a Canadian province with a population of approximately 1.3 million (Statistics Canada 2016 Census) and a system of universal health care.[24] Between 1984 and 2015, one center in Manitoba provided all of the pediatric rheumatology care in the province and maintained a comprehensive clinical registry. Using this registry, we identified children in birth cohorts from 1979 to 1998. We then linked them through anonymized personal health identification numbers to population-based administrative data housed in the Population Research Data Repository (PRDR) at the Manitoba Centre for Health Policy for the period from 1979 to 2015.[25] Almost all Manitobans are eligible for universal health insurance.

Multiple health administrative databases were accessed within the PRDR. The Manitoba Health Insurance Registry provided dates of birth, dates of health coverage, and family codes linking a child to the biological mother. The Discharge Abstracts Database provided hospitalization dates and discharge diagnoses. The medical services database provided billing information from outpatient physician visits; the provider registry supplied information to distinguish rheumatologists from nonrheumatologists. The PRDR contains the complete longitudinal healthcare history for each individual from the initiation of their health insurance coverage (ie, from birth or immigration into Manitoba) until the loss of coverage (ie, death or emigration).

The PRDR also houses non–health-related administrative data from other government departments and the census data. We obtained grade 12 enrollment information and marks from the Enrollment, Marks and Assessment database; income assistance information from the Employment and Income Assistance database; and information about children in out-of-home care from the Child and Family Services Information Services database.

This study was approved by the University of Manitoba Health Research Ethics Board (REB; approval No. HS20191) and the Manitoba Health Information Privacy Committee of the Manitoba Ministry of Health (HIPC No. 2016/2017-37). Consent was waived by the REB because of the long study duration and the large numbers of patients involved.

Study population. The study cohort comprised patients with JA with chronic childhood-onset (age < 16 yrs) arthritis diagnosed according to the standards at the time of diagnosis; some of the children in this cohort were diagnosed before the International League of Associations for Rheumatology criteria of juvenile idiopathic arthritis were developed.[26] JA was divided into the following disease subtypes: oligoarticular JA (< 5 joints involved) and nonoligoarticular JA (≥ 5 joints involved). Patients with SARDs had 1 of 4 systemic autoimmune diseases and were diagnosed at age < 17 years; the age of transfer to adult services in Manitoba is 17 years.[2] The study period was from the date of diagnosis to the date of the standards tests.

Key predictor. We conceptualized disease severity as a latent (ie, unobserved) construct, measured by the number of physician visits.[22] This fits with the Andersen Model of Health Service Use, where after accounting for enabling (eg, access) and predisposing factors (eg, sex), need—as a result of disease severity—drives healthcare use.[22] In our study cohort, we expected the majority of healthcare encounters to be related to ChildCRD; previous studies based on Manitoba's data estimated the average number of major health conditions in children up to 18 years to be ≤ 0.3.[27] The number of physician visits have been used in the development of rheumatoid arthritis and systemic lupus erythematosus severity indices and as surrogate severity markers in chronic childhood illnesses.[20,23,27] To create the disease severity measure, we divided follow-up time into 6-month intervals to reduce the likelihood of intervals with sparse numbers of events and we summed the number of physician visits—both primary care and specialist visits—within each interval for each patient.

Sociodemographic factor covariates. We defined the following sociodemographic and disease-related covariates at diagnosis using administrative data: age, sex, disease duration (from date of diagnosis to date of the grade 12 tests), maternal age at first childbirth, children ever in out-of-home care, and receipt of income assistance. We also defined the Socioeconomic Factor Index version 2 (SEFI-2),[13,14,28-30] an area-based socioeconomic measure derived from several Statistics Canada census variables, including the following: proportion of the population who did not graduate from high school, proportion of single-parent families, average household income, and unemployment rate. The SEFI-2 was constructed for dissemination areas (ie, the smallest geographic units for census data). The lower the SEFI-2 value, the higher the socioeconomic status.

Psychiatric disorder covariates. We identified 6 disorders—depression, anxiety, psychosis, attention deficit hyperactivity disorder, autistic spectrum disorder, and substance use—using case definitions developed for Manitoba children based on diagnoses in hospital and at physician visits.[31] An individual was considered to have a psychiatric disorder if they had 1 of the 6 disorders. Psychiatric disorders were identified as premorbid if they were diagnosed before the date of ChildCRD diagnosis; alternatively, they were identified as intercurrent if they were diagnosed in the 12 months leading up to the date of the first grade 12 standards test.

Outcomes. The primary outcomes were as follows: (1) Language Arts Achievement Index (LAI) scores and (2) Math Achievement Index (MAI) scores.[32,33] In grade 12, every Manitoba student undergoes 2 mandatory standards tests in the language arts and math. The LAI and MAI scores were derived from test scores and enrollment information. There are 19 categories each for the LAI and MAI. The first 14 categories were logit-transformed from raw scores of the standards tests.[32,33] The last 5 (ie, other) categories documented the remaining student population without scores as follows: absent/dropped class, grade 12 but not tested, grade 11 or lower, not enrolled, or withdrawn from school. With the logit transformation, mean LAI and MAI scores are approximately 0 with SDs of 1. LAI and MAI categories correlate with the probability of graduating from high school over 4 years.[32] Given that the LAI and MAI are standardized, they can be interpreted using Cohen *d* effect size, where 0.2 denotes a small difference, 0.5 denotes a medium difference, and 0.8 denotes a large difference.[34]

The secondary outcome, age-appropriate enrollment, was defined as enrollment (yes or no) in grade 12 by 17 years of age. This is an overall measure of school performance.

Statistical analysis. Categorical variables were described using frequencies and percentages; continuous variables were described using means and SDs or medians and IQRs, as appropriate. Means were compared using *t* tests, and proportions were compared using chi-square tests of independence.

Group-based trajectory model to create the disease severity measure. We applied the group-based trajectory model (GBTM) to the total number of physician visits in each 6-month interval for the first 3.5 years after diagnosis to create the disease severity measure, DisSev.[35] The GBTM is a semiparametric longitudinal statistical method that can be applied to a heterogeneous population to delineate distinct group-based trajectories of ≥ 1 outcomes. A group comprises individuals with the same outcome trajectory. We limited the time frame to 3.5 years, as this was the period of maximal variability in visits, with ≥ 80% of the population having this length of follow-up and frequent visits during this period. A cubic trend provided the best fit for DisSev trajectories using a model that assumed a zero-inflated Poisson distribution. Model fit was assessed using the Bayesian information criterion (BIC), a penalized measure of the log-likelihood function, because it tends to select more parsimonious models than the Akaike information criterion. We first fit a 2-class model to the trajectory data, and then fit models with an increasing number of classes until the nadir of the BIC was achieved or when the smallest class included < 10% of the total population.[36] The choice of best-fit model was also guided by clinical experience.[36,37] The TRAJ procedure in SAS 9.4 (SAS Institute) was used for model fitting.

We tested disease subtype—oligoarticular JA, nonoligoarticular JA, or SARD—as a predictor of membership in latent disease severity trajectories, creating DisSevS (for subtype). DisSevS was constructed using the model-fitting process as for DisSev, except that it included disease subtype as a membership covariate. The model fits of DisSev and DisSevS were compared using the BIC to select the better model of disease severity to use for subsequent multivariable modeling of the LAI, the MAI, and age-appropriate enrollment.

Cohort members with a posterior probability of ≥ 0.8 of belonging to a disease severity latent class were assigned to that class for subsequent multivariable modeling of grade 12 performance.[37,38] Those with posterior probability of < 0.8 were excluded from the subsequent analysis to ensure that only those with clearly differentiated probabilities of belonging to 1 class were used in the analysis.[37,39]

Predicting grade 12 standards test performance. Univariable linear regression models were used to test associations between the LAI and MAI scores and disease severity groups, sociodemographic factors, and psychiatric comorbidities. Univariable logistic regression models were used to test associations between age-appropriate enrollment and the same covariates as above. Subsequently, multivariable linear regression models were fit to the LAI and MAI scores that included disease severity groups, sociodemographic factors, and psychiatric comorbidities. A multivariable logistic regression model was fit to age-appropriate enrollment with the same covariates. Linear and logistic regression models were applied using the GENMOD procedure in SAS 9.4 (SAS Institute). Adjusted regression coefficients and their standard errors were reported for the multivariable linear regression models, and adjusted odds ratios with 95% CIs were reported for the multivariable logistic regression models. The scaled Pearson chi-square test was used to assess model fit for the linear regression models, and the *C* statistic was used to assess discriminative performance for the logistic regression models.

RESULTS

Population characteristics. We included 541 patients (Figure 1) with ChildCRDs; 497 patients had JA, 44 patients had SARDs (Table 1), and most were female (70.1%). Approximately half of the study population had more than 8 years of data, including diagnosis to the date of the first of grade 12 standards tests, and LAI or MAI scores, and one-quarter had more than 13.5 years of data. Mean disease duration for the study population was 7.5 years (see Supplementary Table S1, available with the online version of this article, for disease duration quintiles).

Outcomes. The mean LAI scores for the JA and SARD groups were −0.2 (SD 1.0) and −0.2 (SD 1.1), respectively. The mean MAI scores for the JA and SARD groups were −0.2 (SD 1.0) and −0.2 (SD 1.1), respectively. The mean LAI and MAI scores did not differ significantly between the 2 groups. We compared the pass, fail, and nonparticipation rates for the standards tests by disease severity group; none were significantly different (Figure 2). In addition, we compared the differences in test-taking rates across disease severity groups and did not find significant differences (Supplementary Table S2, available with the online version of this article).

Disease severity. When DisSev and DisSevS models were compared using the BIC, the fit was similar (Supplementary Table S3, available with the online version of this article). Therefore, we used DisSev, the most parsimonious model, in subsequent modeling.

The best-fit model for DisSev had 3 latent trajectory classes. Class 1 (35.8%) was the mild disease group with the fewest visits, class 2 (54.5%) was the moderate disease group, and class 3 (9.7%) was the severe disease group with the greatest number of visits (Figure 3). The mean posterior probability of group membership was 0.96 (lower limit [LL] 0.51), 0.97 (LL 0.51), and 0.98 (LL 0.67) for the 3 classes, respectively. Overall, 93.3% (505/541) of individuals were classified into 1 group using the criterion of posterior probability ≥ 0.8 (Supplementary Table S4, available with the online version of this article).

Compared to patients with oligoarticular JA (65.7%) and patients with nonoligoarticular JA (61.3%), more patients with SARD (76.2%) clustered in the moderate and severe disease groups (Supplementary Table S5, available with the online version of this article). Patients with SARD, when compared to patients with oligoarticular or nonoligoarticular JA, had higher odds of belonging to the severe group than the mild or moderate groups (Table 2). Compared to patients with oligoarticular JA, patients with nonoligoarticular JA did not differ in their probability of belonging to a disease severity group (Table 2).

Univariable models. Univariable models (Supplementary Table S6, available with the online version of this article) revealed that severe disease, worse SEFI-2, younger maternal age at first childbirth, receipt of out-of-home care, and receipt of income assistance were associated with worse LAI and MAI scores. Male sex was associated with worse LAI scores but not worse MAI scores. Similar factors, except sex, were associated with reduced odds of age-appropriate enrollment. Psychiatric morbidities were not associated with educational outcomes.

Multivariable models for LAI and MAI scores. After covariate adjustment, worse LAI scores were predicted by severe disease as compared to mild disease, male sex, the lowest family socioeconomic status, having a mother who had her first child at younger than 25 years old, and being a member of a family requiring income assistance (Table 3). Those with moderate disease

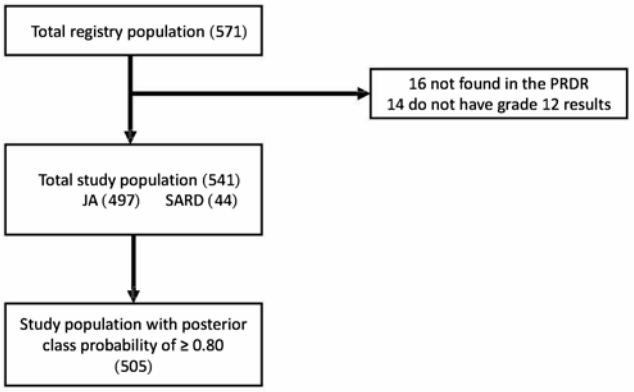

Figure 1. Derivation of study population. JA: juvenile arthritis; PRDR: Population Research Data Repository; SARD: systemic autoimmune rheumatic disease.

Table 1. Characteristics of the ChildCRD study population (N = 541).

	Patients With JA, n = 497	Patients With SARDs, n = 44
Female sex	342 (68.8)	37 (84.1)
Disease duration, yrs, median (IQR)	7.5 (4.3-13.6)	6.9 (2.6-8.8)
Disease type		
Oligoarticular JA	199 (40)	NA
Nonoligoarticular JA	298 (60)	NA
SLE	NA	23 (52.3)
Inflammatory myositis/Sjögren syndrome/ systemic sclerosis	NA	21 (47.7)
SEFI-2[a]		
< −1	102 (20.5)	8 (18.2)
−1 to < 0	201 (40.4)	11 (25)
0 to < 1	125 (25.2)	15 (34.1)
≥ 1	69 (13.9)	10 (22.7)
Maternal age at first birth, yrs		
≤ 17	43 (8.7)	S[b]
18-19	63 (12.7)	S[b]
20-24	150 (30.2)	17 (38.6)
≥ 25	237 (47.7)	16 (36.4)
Received income assistance	91 (18.3)	8 (18.2)
Out-of-home care	25 (5)	S[b]
Premorbid psychiatric morbidity	42 (8.5)	S[b]
Disease course psychiatric morbidity	59 (11.9)	8 (18.2)
Intercurrent psychiatric morbidity	26 (5.2)	S[b]

Data are in n (%) unless otherwise indicated. [a] Negative SEFI-2 scores indicate better socioeconomic status. [b] Suppressed value because of small cell size (< 6) in compliance with privacy and confidentiality requirements. ChildCRD: childhood-onset chronic rheumatic disease; JA: juvenile arthritis; NA: not applicable; S: suppressed value; SARD: systemic autoimmune rheumatic disease; SEFI-2: Socioeconomic Factor Index version 2; SLE: systemic lupus erythematosus.

performed better than those with severe disease (P = 0.001; results not shown).

Worse MAI scores were predicted by severe disease as compared to mild disease, lower family socioeconomic status, having a mother who had her first child at younger than 25 years old, being a child who had been in out-of-home care, or being a member of a family receiving income assistance. Those with moderate disease had higher MAI scores compared to those with severe disease (P < 0.001; results not shown). There was no significant difference in MAI performance between those with moderate disease and those with mild disease.

Multivariable model for age-appropriate enrollment. Age-appropriate enrollment was not associated with disease severity (Table 3). Those in the lowest vs highest socioeconomic group, those whose mother had a first child at age < 20 years vs ≥ 25 years, those who had been in out-of-home care, or those whose family received income assistance were less likely to be enrolled in grade 12 at an appropriate age.

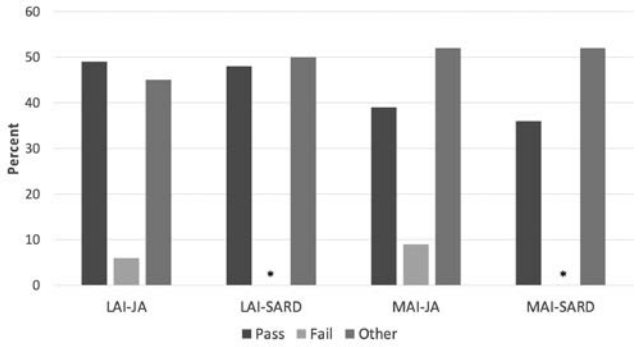

Figure 2. LAI and MAI results by disease group. * Results were suppressed because of low cell counts (< 6) to comply with privacy and confidentiality requirements. "Other" means that there were 5 categories of the LAI and MAI where the grade 12 standards tests were not taken for various reasons (see Methods). JA: juvenile arthritis; LAI: Language Arts Achievement Index; MAI: Math Achievement Index; SARD: systemic autoimmune rheumatic disease.

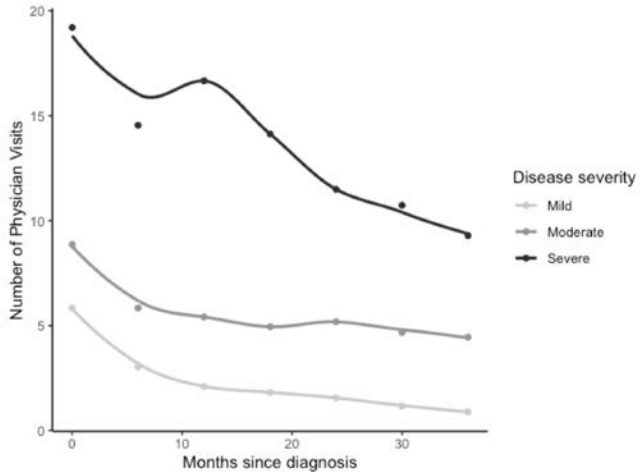

Figure 3. Disease severity group trajectories in childhood-onset chronic rheumatic diseases.

DISCUSSION

We developed a disease severity indicator based on all physician outpatient visits and used it to predict grade 12 standards test performance and age-appropriate grade 12 enrollment among youths with ChildCRDs. Differences in disease severity trajectories were discernible within 3.5 years from diagnosis. There were 3 latent classes of disease severity trajectories. Severe disease predicted worse language arts and math performance but not age-appropriate enrollment in grade 12. Sociodemographic factors, including family socioeconomic status, maternal age at first childbirth, child ever in out-of-home care, and family receiving income assistance, had associations as large or larger than those of having severe ChildCRD.

We created a disease severity indicator, based on health administrative data research, applicable to multiple ChildCRDs. The nonoligoarticular group did not cluster significantly differently from the oligoarticular group in the disease severity groups. This could be due to the use of baseline JA designations. Approximately 50% of patients with oligoarticular JA develop extended oligoarticular arthritis over time, behaving more like patients with polyarticular JA (ie, like nonoligoarticular JA).[26] In clinical practice, patients with difficult oligoarticular JA who have frequent flares or difficult-to-treat disease could also require more visits and disease-modifying antirheumatic drugs.

Table 2. Analysis of ChildCRD disease subtypes as predictors of disease severity for individuals whose highest posterior class probability was > 0.80 (n = 505).

Comparisons[a] and Class Comparisons	OR (95% CI)
SARD (ref: oligoarticular)	
Severe (ref: mild)	**8.63 (3.15-23.65)**
Moderate (ref: mild)	1.11 (0.49-2.53)
Severe (ref: moderate)	**7.76 (3.16-19.11)**
SARD (ref: nonoligoarticular)	
Severe (ref: mild)	**7.70 (2.83-17.44)**
Moderate (ref: mild)	1.43 (0.64- 3.18)
Severe (ref: moderate)	**4.93 (2.22-10.94)**
Nonoligoarticular (ref: oligoarticular)	
Severe (ref: mild)	1.23 (0.58-2.60)
Moderate (ref: mild)	0.78 (0.53- 1.14)
Severe (ref: mild)	1.58 (0.76-3.27)

Values in bold are statistically significant. [a] Oligoarticular and nonoligoarticular are juvenile arthritis subtypes. ChildCRD: childhood-onset chronic rheumatic disease; OR: odds ratio; ref: comparison reference group; SARD: systemic autoimmune rheumatic disease.

We chose the LAI and MAI because they are more informative outcome measures than high school graduation or attendance. Most high school students will graduate, but the paths to graduation could be very different; students could take academically demanding subjects or vocational-type subjects. Academic performance is reflective of a complex underlying construct, including cognitive ability, school experience, and learning.[15,40] ChildCRDs disrupt the school experience to different degrees for individuals. Patients' test scores or reasons for nonparticipation, as measured through the indices, provided richer information than would a binary graduation measure.

As expected, sociodemographic/economic factors strongly predicted educational outcomes. The relationships between child health, parental socioeconomic status, and later educational and employment outcomes are complex, with many interactions among the measures and bidirectional effects. The socioeconomic associations identified in our study are consistent with the findings in economics and education literature, which have shown that parental socioeconomic factors intersect with child health and educational outcomes.[41] In studies from Canada, the United States, and the United Kingdom, children from lower-income families had worse health, had more health insults, and were more limited by chronic illnesses compared to those not from lower-income families.[27,41-43] Even after controlling for parental education and income, individuals who had poor health as a child had significantly lower adult education, poorer health, and lower social status.[41,44] The association of childhood chronic illnesses with poorer grade 12 standards test

Table 3. Multivariable model results for LAI and MAI scores and age-appropriate grade 12 enrollment among ChildCRD patients (n = 505).

	LAI, *b* (SE)	MAI, *b* (SE)	Age-Appropriate Enrollment, OR (95% CI)
Disease severity			
Severe	**−0.33 (0.16)**	**−0.42 (0.15)**	0.50 (0.23-1.08)
Moderate	0.15 (0.10)	0.12 (0.10)	1.55 (0.92-2.62)
Mild	Ref	Ref	Ref
Age at diagnosis	0.00 (0.04)	−0.02 (0.04)	1.02 (0.84-1.23)
Quintile of disease duration, yrs			
1 (shortest)	0.23 (0.49)	0.58 (0.49)	1.22 (0.09-16.28)
2	0.19 (0.41)	0.44 (0.41)	1.65 (0.19-14.23)
3	0.27 (0.33)	0.51 (0.33)	1.74 (0.31-9.66)
4	0.17 (0.18)	0.39 (0.18)	1.75 (0.69-4.43)
5 (longest)	Ref	Ref	Ref
Sex			
Male	**−0.29 (0.09)**	−0.09 (0.10)	0.79 (0.48-1.29)
Female	Ref	Ref	Ref
SEFI-2			
≥1	**−0.54 (0.17)**	**−0.74 (0.17)**	**0.21 (0.09-0.50)**
0 to < 1	−0.18 (0.13)	−0.24 (0.13)	0.60 (0.29-1.27)
−1 to < 0	−0.09 (0.12)	−0.24 (0.12)	0.76 (0.38-1.54)
< −1	Ref	Ref	Ref
Maternal age at first birth, yrs			
≤17	**−0.54 (0.18)**	**−0.48 (0.18)**	**0.25 (0.10-0.59)**
18-19	**−0.60 (0.15)**	**−0.55 (0.14)**	**0.25 (0.13-0.49)**
20-24	**−0.31 (0.10)**	**−0.22 (0.10)**	0.61 (0.36-1.05)
≥ 25	Ref	Ref	Ref
Out-of-home care	−0.38 (0.22)	**−0.45 (0.21)**	**0.09 (0.02-0.46)**
Income assistance	**−0.38 (0.13)**	**−0.37 (0.12)**	**0.36 (0.20-0.64)**
Premorbid psychiatric morbidity	−0.18 (0.16)	−0.30 (0.17)	0.59 (0.26-1.35)
Intercurrent psychiatric morbidity	−0.13 (0.19)	−0.001 (0.19)	1.17 (0.40-3.46)

Values in bold are statistically significant. ChildCRD: childhood-onset chronic rheumatic disease; LAI: Language Arts Achievement Index; MAI: Math Achievement Index; OR: odds ratio; SEFI-2: Socioeconomic Factor Index version 2.

results and young adult socioeconomic outcomes had also been demonstrated in another population study from Manitoba.[27]

Education is human capital and is considered an investment for future earnings, explaining a significant variance in adult incomes.[41] Young adults with rheumatic diseases have challenges in establishing employment and they experience increased job insecurity.[11,45,46] Employment not only has implications for socioeconomic achievements but could affect the health of chronically ill individuals through access to healthcare benefits. Among young adults with rheumatic conditions, those with higher education and more mentally demanding work were better able to retain employment during the difficult economic conditions of the coronavirus disease 2019 (COVID-19) pandemic.[47] Therefore, identifying patients with ChildCRDs at risk of poor educational outcomes and successfully intervening with supports could have far-reaching implications on their future employment and on their adult socioeconomic and health outcomes.

We aimed to predict future grade 12 academic performance so that we could identify children at risk early, in order to help them obtain timely supportive educational resources. Therefore, we focused only on factors that occurred early in the disease course or within defined periods before the tests so that we could strongly advocate for educational support for patients with risk factors at those times. We did not examine the entire disease course and, therefore, we did not capture all possible flares. However, previous ChildCRD studies have shown that disease patterns were often established within the first 3 years after diagnosis, well within the period of time in which we developed our severity indicator.[37,48] We have presumed that healthcare utilization by patients with ChildCRDs was related to their underlying disease severity. We acknowledge that healthcare utilization is an imperfect measure of disease severity; other factors may also influence use, such as individual/parental health beliefs, psychological characteristics, mental health, social structure, and ease of access to healthcare resources.[22] Ethnicity is associated with education performance and attainment.[49,50] However, ethnicity information is not available in the administrative data that were used for this study. We could not directly adjust for family and specific community contextual factors. However, the SEFI-2 included items that could partially adjust for the community context.

In conclusion, youths with ChildCRDs with the most severe early disease had worse language arts and math grade 12 standards test results compared to those with mild disease, independent of sociodemographic and psychiatric morbidities. As

sociodemographic factors have effects that could be greater than the effects of disease severity, a good understanding of the social risk factors of patients with ChildCRDs is important. By recognizing early disease severity patterns, high-risk sociodemographic predictors, and psychiatric predictors, pediatric rheumatologists could identify children at risk earlier and advocate for their educational support as early as possible to improve educational outcomes. Pediatric rheumatologists can play an important role in helping youths and their families engage with their teachers, peers, and school authorities to better understand and support youths with ChildCRDs.

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PLAIN LANGUAGE SUMMARY

A plain language summary of this article (text or graphical) is included as online supplementary material.

ONLINE SUPPLEMENT

Supplementary material accompanies the online version of this article.

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