ORIGINAL ARTICLE
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Emergency Department Use in Children with Cerebral Palsy: A Data Linkage Study

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ABSTRACT: ***Objective:*** To describe the pattern of emergency department (ED) consultations in children with cerebral palsy (CP) compared to controls and factors predictive of ED consultations. ***Methods:*** This retrospective cohort study linked data from the *Registre de la paralysie cérébrale du Québec* (REPACQ) and provincial administrative health databases. The CP cohort was comprised of children enrolled in REPACQ born between 1999 and 2002. REPACQ covers 6 of 17 Quebec health administrative regions. Region-, age-, and gender-matched controls were identified from administrative health databases in a 20:1 ratio. The primary outcome was high use of ED services (≥4 ED visits during the study period). Relative risk (RR) and 95% confidence interval (CI) were calculated. ***Results:*** In total, 301 children with CP were linked to administrative data and 6040 peer controls were selected. Ninety-two percent (92%) of the CP cohort had at least one ED visit in the study period, compared to 74% among controls (RR 1.24, 95% CI 1.19–1.28). Children with CP were more likely than their peers to have high ED use (RR 1.40; 95% CI 1.30–1.52). Factors predictive of high ED use were comorbid epilepsy (RR 1.23; 95% CI 1.04–1.46) and severity of motor impairment (RR 1.14; 95% CI 0.95–1.37). ***Conclusion:*** Children with CP are more likely to present to the ED than their peers, resulting in increased use of ED services. Coordinated care with improved access to same-day evaluations could decrease ED use. Health system factors and barriers should be investigated to ensure optimal and appropriate use of ED services.

RÉSUMÉ : Enfants atteints d'infirmité motrice cérébrale et utilisation des services des urgences : étude sur le couplage de données. ***Objectif*** : L'étude visait à décrire l'usage des services des urgences (SU) chez les enfants atteints d'infirmité motrice cérébrale (IMC) comparativement celui enregistré chez des témoins, et à dégager des facteurs prévisionnels de consultations au SU. ***Méthode*** : Il s'agit d'une étude de cohorte, rétrospective, dans laquelle ont été couplées des données provenant du *Registre de la paralysie cérébrale du Québec* (REPACQ) à celles provenant de bases de données administratives de la province. La cohorte d'IMC se composait d'enfants nés entre 1999 et 2002, et inscrits au REPACQ, lequel couvre 6 régions sociosanitaires sur 17 au Québec. La recherche de témoins appariés selon l'âge, le sexe et les régions repose sur des bases de données clinico-administratives, dans un ratio de 20 pour 1. Le principal critère d'évaluation était l'utilisation élevée des SU (≥ 4 consultations au SU durant la période à l'étude). Ont été calculés le risque relatif (RR) et l'intervalle de confiance (IC) à 95 %. ***Résultats*** : Il y a eu en tout couplage de données administratives à 301 enfants atteints d'IMC et sélection de 6040 témoins appariés. Ainsi, 92 % des enfants dans la cohorte d'IMC comptaient au moins 1 consultation au SU durant la période à l'étude contre 74 % dans le groupe témoin (RR : 1,24; IC à 95 % : 1,19-1,28). Les enfants atteints d'IMC étaient plus susceptibles d'aller souvent aux SU que les témoins (RR : 1,40; IC à 95 % : 1,30-1,52). Les facteurs prévisionnels d'une forte utilisation des SU étaient l'épilepsie concomitante (RR : 1,23; IC à 95 % : 1,04-1,46) et la gravité des troubles moteurs (RR : 1,14; IC à 95 % : 0,95-1,37). ***Conclusion*** : Les enfants atteints d'IMC sont plus susceptibles d'aller au SU que les témoins appariés, d'où utilisation accrue des soins offerts. Un moyen de diminuer le recours aux SU serait la coordination des soins associée à un meilleur accès aux services de santé pour des consultations le jour même. Pour ce faire, il faudrait se pencher sur les facteurs liés au système de santé et aux obstacles afin d'assurer un usage optimal et approprié des SU.

Key words: Cerebral palsy, Emergency, Pediatric neurology, Neurodevelopmental disorders

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Introduction

Cerebral palsy (CP) – defined as a spectrum of permanent and nonprogressive motor disorders resulting from congenital or acquired disturbances to the developing brain – is the most common cause of childhood physical disability: prevalence has been estimated at 2.0 per 1000 births.[1] It is heterogeneous by definition: multiple causes exist and clinical phenotypes – with regard to the distribution of motor dysfunction, severity, and associated comorbidities – vary immensely.[2] Children with disabilities have previously been shown to have increased rates of emergency department (ED) visits compared to their healthy peers.[3] Furthermore, increased CP severity (i.e. non-ambulant) and complexity, including comorbidities such as epilepsy, have been shown to be associated with a higher frequency of ED presentations.[4]

The contribution of socioeconomic disparities to healthcare use among children with CP remains largely unknown. Findings from past and current Canadian literature strongly support a trend

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toward increased ED visits for nonurgent issues in patients of low socioeconomic status.[5]

Focused coordinated care models have already been shown to decrease the use of ED services in individuals with complex medical needs; however, there is no data specific to children with CP.[6] Improved understanding of factors predictive of ED use in this population would be helpful to inform families and health-care professionals as to specific areas of focus and improvement to optimize ongoing coordinated care. This, in turn, would have the potential to optimize the use of ED services by these children and their families.

With this in mind, the primary objective of this study was to compare the frequency of any ED visit and the frequency of high ED use in children with CP to that of general population controls. The secondary goal was to explore the association between ED use in children with CP and sociodemographic and clinical features. We hypothesized that more frequent ED use is associated with lower socioeconomic status, limited access to a primary care physician, and specific clinical variables including spastic quadriparesis CP subtype, nonambulatory motor function, and CP-related comorbidities.

Methods

Study Design and Setting

For this data linkage study, data were drawn from both a provincial population-based CP registry and provincial administrative health databases. This study was conducted at the Research Institute of the McGill University Health Centre. Institutional Research Ethics Board (REB) approval was obtained from the McGill University Health Centre REB and the REBs of all participating institutions. Approval to access nominal data for data linkage was also obtained from the Commission d'accès à l'information.

Data Sources

The *Registre de la paralysie cérébrale du Québec* (hereafter called the Registry) is a population-based registry of children with CP from Quebec. Covering 6 of the 17 administrative health regions in Quebec, the Registry represents over half of the province's pediatric population. Enrollment in the Registry requires that children be at least 2 years of age and fulfill international consensus criteria for CP[7] and when possible, 5-year follow-up data are also obtained. A comprehensive profile is obtained for each participant enrolled in the Registry including sociodemographic data, pre-, peri-, and neonatal CP risk factors, CP-related comorbidities, and functional outcomes. For this study, registered cases included were those born between January 1, 1999 and December 31, 2002. For these patients, data up to December 31, 2012 (i.e. until the age of 10–13 years) were extracted retrospectively and reviewed. Data drawn from the Registry included CP subtype (spastic hemiplegic, spastic diplegic, spastic tri/quadriplegic or other [ataxic, hypotonic, and dyskinetic]), gross motor function (Gross Motor Classification System (GMFCS), categorized as I–III (ambulant with little motor impairment) and IV–V (non-ambulant), and comorbidities such as cognitive, visual and sensorineural auditory impairment, feeding and communication difficulties, and epilepsy.

Children residing in the province of Quebec for more than 3 months are registered with the *Régie de l'assurance maladie du Québec* (RAMQ) and eligible for universal health coverage. The RAMQ maintains a computerized database of physician billing claims, which include the primary diagnosis for each visit (International Classification of Diseases [ICD], Ninth Revision [ICD-9-CM]), the specialty of the submitting physician, and the patient's date of birth, and sex. Claims also include the first three digits of the patient's postal code (i.e. forward sortation area). Age at CP diagnosis was defined as the age of the first CP code (ICD-9 343.x) entered in the RAMQ database. The specificity of the CP diagnostic code within this administrative health database has been previously demonstrated as good by our group.[8]

Control Group

A large sample of population-based controls (general population) was selected from the RAMQ database from across the province of Quebec as children from the same age, gender, and administrative region who never received a diagnostic code of CP.

Sociodemographic Factors

Forward sortation area was used to classify participant's region of residence according to Statistics Canada categorization of population centers (i.e. rural areas, small (1000–29,000), medium (30,000–99,999), and large (>100,000) population centers).[9] Proxies for socioeconomic status were also obtained from the RAMQ database and included eligibility for the provincial public drug plan and parental eligibility for unemployment benefits. Material and social deprivation indices were also calculated.[10] The deprivation indices span five categories, with quintile 1 (Q1) representing the least deprived and quintile 5 (Q5) representing the most deprived. The material deprivation index is calculated by integrating, in the population aged 15 years and over, the proportion of individuals without a high school diploma or equivalent, the employment-to-population ratio, and the average income. The social deprivation index, on the other hand, is calculated by integrating the proportion of individuals living alone, the proportion of the population who are separated, divorced, or widowed, and the proportion of single-parent families. These indices, which are based on data from dissemination areas – the smallest available geographic units in the Statistics Canada national census – have previously been used by our group in the population of children with CP.[11]

Emergency Room Visits

Four categories were used to describe ED visits in both the cohort of children with CP and the control group: 0 ED visits, 1 ED visit, ≥2 ED visits, and ≥4 ED visits (i.e. high ED use) at any time during the study period.

Data Linkage

A file containing participant Registry identification numbers, RAMQ insurance numbers, name, and sex was sent to the RAMQ for data linkage. Once data linkage was complete, the resulting dataset was de-identified to ensure participant confidentiality.

Analysis

All analyses were conducted using SAS9.4 (SAS Institute Inc., Cary, North Carolina). Descriptive statistics were run to obtain a profile of children with CP in Quebec and healthy controls. Relative risk (RR) and 95% confidence intervals (CIs)

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were calculated where appropriate. Chi-square tests were performed to identify differences between the CP cohort and the healthy controls for categorical variables.

Results

We identified 312 children with CP, of which 301 were successfully linked to administrative health databases (96%). There were no differences between children with CP whose registry data was successfully or unsuccessfully linked to administrative health records (Supplemental Table 1). More than half of the children in the CP cohort were male (56%). The mean age at diagnosis was 3.6 years old (standard deviation [SD] 3.0 years). Spastic hemiplegia was the most common subtype (28%), with spastic CP subtypes making up 74% of the CP cohort. The majority of the CP cohort (60%) had a GMFCS of I–III. Communication difficulties (54%), epilepsy (34%), and cognitive impairment (32%) were the most frequently reported comorbidities.

Most children with CP had at least one ED visit (92%), with 84% having two or more and 66% having four or more during the study period (Table 1). In children with CP, there were no factors that predicted those with at least one ED visit, except for the social deprivation index, whereby children with a worse social deprivation index were more likely to visit the ED at least once during the study period (RR 1.09 CI 95% 1.03–1.15). Children with CP were more likely to have at least two ED visits if they had a worse social deprivation index (RR 1.15 CI 95% 1.05–1.26), lived in a small–medium population center (RR 1.13 CI 95% 1.02–1.24), were non-ambulant GMFCS (RR 1.12 CI 95% 1.02–1.24), had a spastic triplegic or quadriplegic CP subtype (RR 1.13 CI 95% 1.03–1.25), or had comorbid epilepsy (RR 1.12 CI 95% 1.02–1.24). Factors predictive of high ED use in patients with CP were having comorbid epilepsy (RR 1.23 95% CI 1.04–1.46) and the presence of two or more comorbidities (RR 1.34, 95% CI 1.10–1.62).

ED Use Compared to Peers

The cohort of children with CP was comparable to peer controls with regard to their sociodemographic profiles, including deprivation index profiles, admissibility to the public drug plan, and the proportion of parents receiving unemployment benefits.

Ninety-two percent (92%) of the cohort of patients with CP had at least one ED visit in the study period, compared to 74% among controls (RR 1.24 95% CI 1.19–1.28) (Table 2). There was no difference in the age of the first ED visit between the children with CP and their peers. Children with CP were more likely to have high ED use compared to their peers (RR 1.40 95% CI 1.30–1.52).

The top reasons for ED visits for children with CP were respiratory illnesses (26%), injuries and poisoning (11%), and diseases of the nervous system (10%) (Supplemental Table 2). ED presentations related to seizures and epilepsy made up 80% of the ED visits for nervous system disorders and 8% of all ED visits in patients with CP. The most frequent respiratory system diagnostic code was for acute respiratory infections (40%), whereas the most frequent one for sensory organs was for suppurative and unspecified otitis media (61%) (Supplemental Table 2). In peer controls, the main reasons for ED visits were diseases of the respiratory system (28%) including acute respiratory infections (52%), injury and poisoning (18%) including open wounds (38%) and fractures (26%), diseases of the sense organs (11%) including otitis media (66%) and disorders of the external ear (12%), and diseases of the digestive system (6%) including enteritis and colitis (45%).

Children with CP were more likely to have ED visits related to diseases of the nervous system (RR 9.14 95% CI 7.78–10.75) (Table 3) compared to the control cohort. In both cohorts, a large number of ER visits were classified with vaguely defined terms, including "symptoms, signs and ill-defined conditions" and "other". For children with CP, the most common diagnoses in this category were pyrexia of unknown origin (56%) and abdominal pain (18%), with similar results observed in controls.

Discussion

This study sought to evaluate the use of ED services in patients with CP in Quebec in comparison to age-matched controls without CP and the factors that increase the burden of ED visits in children with CP. As hypothesized, children with CP have greater ED use than their peers, notably with regard to increased likelihood of high ED use. This study also shows that reasons for ED consultation vary between groups; children with CP present to the ED with neurological issues, related to seizures and epilepsy, more often than their peers.

Children with CP who have a more severe motor disability profile, a lower SES, and a higher number of associated comorbidities have a higher likelihood of frequent ED visits; respiratory infections and neurological issues seem to contribute to this. Notably, comorbid epilepsy seems to be an important factor in increasing ED visits. GMFCS status had been previously shown to be strongly associated with CP subtype and comorbidity, which is also the case in this study.[12]

An improvement in coordinated interdisciplinary care with access to same-day evaluations on an outpatient basis for children with CP and medical complexity, mostly with regard to management of respiratory illness and neurological issues such as epilepsy, could potentially reduce the burden that the frequent ED visits represent for these patients, their families, and the healthcare system as a whole. Concerning sociodemographic factors, administrative efforts to reduce the impact of low SES on children with CP and their families could also help reduce the burden of ED visits.

Our findings are comparable to those from the Australian CP Register. In their study using administrative health data collected from two tertiary care hospitals in Melbourne cross-linked to registry data, Meehan et al. showed that ED use was higher in children with more severe and complex CP, with the majority of ED presentations being in the context of respiratory, neurological, and gastrointestinal issues.[4] The similarities between these two studies, undertaken in two vastly different jurisdictions, reinforce the external validity of our results, at least within developed, occidental countries.

The strengths of our approach include having a population-based sample of children with CP who have a confirmed diagnosis and rich phenotypic profile captured within the registry. We also have a large population-based control cohort without CP, which limits the possibility of referral bias compared to studies exploring ED use at a single center. Although there is no standardized linkage process in place in Quebec with a unique

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Table 1: Profile of CP cohort ED visits

	CP cohort	0 ED visits	≥1 ED visit	≥2 ED visits	≥4 ED visits
	n (% column)	*n* (% row)	*n* (% row)	*n* (% row)	*n* (% row)
Total	*n* = 301	24 (8.0)	277 (92.0)	252 (83.7)	199 (66.1)
Deprivation index (material)					
Q4–Q5	83 (27.6)	4 (4.8)	79 (95)	74 (89)	60 (72)
Q1–Q3	193 (64.1)	15 (7.8)	178 (92)	159 (82)	123 (64)
Unknown	25 (8.3)				
Relative risk (95% CI)[a]		0.62 (0.21–1.81)	1.03 (0.97–1.10)	1.08 (0.98–1.20)	1.13(0.96–1.34)
Deprivation index (social)					
Q4–Q5	101 (33.5)	2 (2.0)	99 (98)	93 (92)	73 (72)
Q1–Q3	175 (58.1)	17 (9.7)	158 (90)	140 (80)	110 (63)
Unknown	25 (8.3)				
Relative risk (95% CI)[a]		0.20 (0.048–0.86)	1.09 (1.03–1.15)	1.15 (1.05–1.26)	1.15 (0.97–1.36)
Parents receive unemployment benefits					
Yes	75 (24.9)	5 (6.7)	70 (93.3)	68 (90.7)	48 (64.0)
No	96 (31.9)	5 (5.2)	91 (94.8)	80 (83.3)	65 (67.7)
Unknown	130 (43.2)				
Relative risk (95% CI)		1.28 (0.38–4.26)	0.98 (0.91–1.06)	1.09 (0.97–1.22)	0.95 (0.76–1.18)
Access to primary care					
Yes	284 (94.3)	20 (7.0)	264 (93.0)	240 (84.5)	193 (68.0)
No	17 (5.6)	4 (23.5)	13 (76.4)	12 (70.6)	6 (35.3)
Relative risk (95% CI)		0.30 (0.12–0.78)	1.22 (0.93–1.59)	1.20 (0.88–1.63)	1.93 (1.01–3.68)
Age at diagnosis					
≥5 years old	37 (12.3)	2 (5.4)	35 (94.6)	32 (86.5)	22 (59.5)
<5 years old	264 (87.7)	22 (8.3)	242 (91.7)	220 (83.3)	177 (67.0)
Relative risk (95% CI)[b]		0.65 (0.16–2.65)	1.03 (0.95–1.12)	1.04 (0.90–1.19)	0.89 (0.67–1.17)
Region					
Other	56 (18.6)	2 (3.6)	54 (96.4)	52 (92.8)	40 (71.4)
Large urban population center	228 (75.7)	17 (7.5)	211 (92.5)	188 (82.5)	149 (65.4)
Unknown	17 (5.6)				
Relative risk (95% CI)[c]		0.48 (0.11–2.01)	1.04 (0.98–1.11)	1.13 (1.02–1.24)	1.09 (0.90–1.32)
GMFCS					
IV–V	70 (23.3)	2 (2.9)	68 (97.1)	64 (91.4)	51 (72.9)
I–III	182 (60.4)	17 (9.3)	165 (90.6)	148 (81.3)	116 (63.7)
Unknown	49 (16.3)				
Relative risk (95% CI)[d]		0.30 (0.072–1.29)	1.07 (1.01–1.14)	1.12 (1.02–1.24)	1.14 (0.95–1.37)
CP subtype					
Spastic tri/quadriplegia	82 (27.2)	4 (4.9)	78 (95.1)	75 (91.5)	59 (72.0)
Other	170 (56.5)	15 (8.8)	155 (91.1)	137 (80.6)	108 (63.5)
Unknown	49 (16.3)				
Relative risk (95% CI)[e]		0.55 (0.19–1.61)	1.04 (0.97–1.12)	1.13 (1.03–1.25)	1.13 (0.95–1.35)
Epilepsy					
Yes	102 (33.9)	6 (5.8)	96 (94.1)	92 (90.2)	76 (74.5)
No	152 (50.5)	13 (8.6)	139 (91.4)	122 (80.3)	92 (60.5)
Unknown	47 (15.6)				
Relative risk (95% CI)		0.69 (0.27–1.75)	1.03 (0.96–1.10)	1.12 (1.02–1.24)	1.23 (1.04–1.46)

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Table 1: *(Continued)*

	CP cohort	0 ED visits	≥1 ED visit	≥2 ED visits	≥4 ED visits
	n (% column)	*n* (% row)	*n* (% row)	*n* (% row)	*n* (% row)
Cognitive impairment					
Yes	97 (32.2)	5 (5.2)	92 (94.8)	83 (85.6)	71 (73.2)
No	113 (37.5)	10 (8.8)	103 (91.2)	96 (85.0)	70 (61.9)
Unknown	91 (30.2)				
Relative risk (95% CI)		0.58 (0.21–1.65)	1.04 (0.97–1.12)	1.01 (0.90–1.13)	1.18 (0.98–1.43)
Multiple comorbidities					
Two or more	133 (44.2)	6 (4.5)	127 (95.5)	116 (87.2)	99 (74.4)
None to one	115 (38.2)	13 (11.3)	102 (88.7)	92 (80.0)	64 (55.6)
Unknown	53 (17.6)				
Relative risk (95% CI)		0.40 (0.16–1.02)	1.08 (1.00–1.16)	1.09 (0.97–1.22)	1.34 (1.10–1.62)

[a]Q4–Q5 vs. Q1–Q3, [b]≥5 years old vs. <5 years old, [c]large population center vs. other, [d]GMFCS IV–V vs. I–III, [e]spastic tri/quadriplegic CP vs. other.

Table 2: ED use in children with CP and controls

	CP cohort with ≥1 ED visits	Control cohort with ≥1 ED visits	RR (95% CI)
	n = 301	*n* = 6040	
Total	277 (92.0%)	4493 (74.4%)	1.24 (1.19–1.28)
Age at first ED visit *n* (%)			
0–5 years	273 (98.6)	4350 (96.8)	1.02 (1.00–1.03)
6–12 years	4 (1.4)	143 (3.2)	
Number of visits *n* (%)			
≥4 visits	199 (71.8)	2301 (51.2)	1.40 (1.30–1.52)
<4 visits	78 (28.2)	2192 (48.8)	

Table 3: Primary diagnostic category for CP and control cohorts ED admissions

Primary diagnostic category *n* (%)	All ED visits	CP cohort ED visits	Control cohort ED visits	
	n = 28013	*n* = 2735	*n* = 25278	RR (95% CI)
Respiratory system	7889 (28.2)	719 (26.3)	7170 (28.4)	0.93 (0.87–0.99)
Symptoms, signs, and ill-defined conditions	3254 (11.6)	374 (13.7)	2880 (11.4)	1.20 (1.09–1.33)
Injury and poisoning	4928 (17.6)	292 (10.7)	4636 (18.3)	0.58 (0.52–0.65)
Nervous system	553 (2.0)	275 (10.1)	278 (1.1)	9.14 (7.78–10.75)
Sensory organs	3149 (11.2)	238 (8.7)	2911 (11.5)	0.76 (0.67–0.86)
Digestive system	1698 (6.1)	179 (6.5)	1519 (6.0)	1.09 (0.94–1.23)
Musculoskeletal system	432 (1.5)	30 (1.1)	402 (1.6)	0.69 (0.48–1.00)
Other	4584 (16.4)	427 (15.6)	4157 (16.4)	—
Missing	1526 (5.4)	201 (7.3)	1325 (5.2)	—

identifier, as is available in other countries, we were still able to successfully link 96% of our cohort from the Registry to administrative healthcare databases.

One of the limitations of this study is the reliance ICD-9-CM codes to analyze the reason for presentation to the ED, which may overlook some specific details and result in vague, unclassified reasons for the visit. This was certainly the case in our study, given that a large number of ED visits were classified within the categories of "symptoms, signs and ill-defined conditions" and "other". However, this applied to both the CP cohort and controls

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in similar proportions and does not influence the applicability of our results. Important information could still be obtained despite this caveat. Another limitation is the use of government administrative data, which may lack specificity. However, the rich and complete data included in the Registry, as well as the linkage with administrative health databases, enable us to increase the accuracy of the data, which reduces the risk of bias in this regard. This integrative method has previously been shown to be highly specific.[8]

Conclusion

Children with CP have a greater need for urgent and semi-urgent assessments of health problems than their peers. Although the ED is the appropriate place for some of these consultations, improved coordinated care, access to same-day assessment, and adequate administrative policy efforts could help optimize the care of children with CP and alleviate their burden of ED visits.

Future studies are needed to demonstrate the impact of specific interventions with regard to optimization of outpatient care of patients with CP on ED visits and overall costs, as well as longer-term follow-up to understand healthcare utilization patterns in teens and young adults during transition of care.

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Statement of Authorship

MO led the study design and conceptualization, data acquisition, interpretation of data, and drafting and revising the manuscript. OF contributed to the interpretation of data and drafting and revising the manuscript. PN contributed to the data analysis and interpretation and drafting and revising the manuscript. MD contributed to the data analysis and revision of the manuscript. LK, NP, and MS contributed to the acquisition of data, interpretation of the data, and revision of the manuscript for intellectual content.

Supplementary Material

To view supplementary material for this article, please visit https://doi.org/10.1017/cjn.2020.217.

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