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Changes in the health of mothers of children with neurodevelopmental disabilities: An administrative data study

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ABSTRACT

Background: Using linked administrative health data, this study compared the health and healthcare service utilization between mothers of children with and without neurodevelopmental disabilities (NDD), before, during, and after the birth of a child.
Methods: The population (N = 25,388) was based on a cohort of children born in 2000 and who were, along with their mothers, continuously registered with the British Columbia's universal health insurance program between 2000 and 2007.
Results: Compared to mothers of children without NDD, mothers of children with NDD were more likely to have chronic conditions and higher service utilization before child birth. Mothers of children with NDD showed a smaller increase in physician visits in the year before birth but a greater increase in different prescription drugs in the year after birth. There was no further divergence (or convergence) in health and service utilization between the groups in the 7-year period post-birth.
Conclusions: Differences in health and healthcare service utilization between mothers of children with and without NDD existed before the birth of the child and did not diverge in the 7 years post-birth. Replication of these findings is warranted as well as follow-up analyses examining longer term outcomes for mothers beyond 7 years post-birth.

What this paper adds?

- Use of linked administrative health data provided an unprecedented opportunity to examine health and healthcare service utilization of mothers of children with NDD before, during, and after the birth of a child compared to mothers of children without NDD.
- Differences in health and healthcare service utilization between mothers of children with and without NDD existed before the birth of the child.
- Contrary to expectations, the birth of a child with NDD did not significantly alter maternal health and healthcare service utilization in the 7 years post-birth.

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- The findings raise questions about pre-existing differences in the population of mothers who give birth to a child with NDD.

1. Introduction

The terms neurodevelopmental disorders and disabilities (NDD/D; Miller, Mâsse, Shen, Schiariti, & Roxborough, 2013) or neurodisability (Morris, Janssens, Tomlinson, Williams, & Logan, 2013) refer to a group of neurological conditions that are associated with functional impairment starting in the developmental period. Although prevalence estimates for childhood NDD/D vary considerably because of a lack of an agreed definition (van der Lee, Mokkink, Grootenhuis, Heymans, & Offringa, 2007), it has been estimated that 93 million children aged 0–14 years worldwide live with such a disability (World Health Organization [WHO], 2011). The health and well-being of children are inextricably tied to the health and well-being of parents (American Academy of Pediatrics, 2003), and mothers are still most often the primary caregivers (Arim et al., 2012). Given this, the health of mothers of children with NDD requires attention to better understand the implications of caring for a child with NDD.

Indeed, healthcare service delivery models have shifted from primarily treating the child to more family-centered approaches (see King, Teplicky, King, & Rosenbaum, 2004 for a review). These newer models underline the importance of understanding and promoting caregiver health in the context of childhood disability to improve care for families of children with disabilities. It is well-documented that caring for a child with NDD can place additional demands on time, energy, and finances beyond those of caring for a healthy child (Brehaut et al., 2004; Burton & Phipps, 2009; Goudie, Narcisse, Hall, & Kuo, 2014; Stoddard-Dare, DeRigne, Quinn, & Mallett, 2015). While many parents cope well with these challenges, sometimes additional demands can amount to a significant caregiving burden (Goudie et al., 2014). A great deal of research has shown that caring for a child with NDD can lead to psychological health problems for parents themselves, such as higher rates of distress and depression (Brehaut et al., 2004, 2009; Gallagher & Hannigan, 2014; Lach et al., 2009) as well as physical health problems, including chronic conditions such as back problems and migraine headaches (Brehaut et al., 2004, 2009; Lach et al., 2009). Importantly, these health effects do not appear to be limited to specific NDD conditions, nor they are limited only to the most severe cases (Brehaut et al., 2009). This highlights that children with diverse medical conditions as well as their parents may have common needs and experience similar health consequences. Overall, the range of health problems that parents of children with NDD experience constitutes a major public health concern, yet little is known about the changes in the health of parents of children with NDD at the population level.

The present study is informed by a conceptual framework that integrates risk-resilience and stress process models to describe various effects on the health of parents of children with health problems (see Raina et al., 2004). More specifically, this comprehensive model describes the interactions among contextual variables (e.g., socioeconomic status), child characteristics (e.g., NDD), caregiver strain (e.g., demands of caregiving), and coping factors (e.g., social support). In this study, we used this model to guide our research questions and identify constructs that can be operationalized in administrative data (e.g., socioeconomic background, child NDD, maternal health). In addition, we used a non-categorical approach (Stein & Jessop, 1982) to identify child NDD (i.e., diverse conditions with similar consequences) because this approach has been shown particularly useful for public health and policy (Miller et al., 2013; Stein, Bauman, Westbrook, Coupey, & Ireys, 1993). Finally, we focused on maternal health because in our previous population-based work, we identified that in 90% of cases, the primary caregiver was the biological mother (Brehaut et al., 2009).

Much of the work to date has been limited to clinical or survey studies that have provided cross-sectional snapshots of caregiver health (Brehaut et al., 2004; Gallagher & Hannigan, 2014; Lach et al., 2009) whereas, only a few population-based, longitudinal survey studies have been conducted. Brehaut et al. (2011) found more depressive symptoms and poorer overall self-reported health among parents of children with health problems compared to health of those of healthy children, problems that persisted over a 10-year period. Smith and Grzywacz (2014) reported that parenting a child with special health needs was associated with greater activity limitations and depressive symptoms for parents 10 years later. Still, many questions remain from a public health standpoint. First, we do not know if these health problems translate into high healthcare service utilization. Do mothers of children with NDD use healthcare services more than mothers of children without NDD? Do they have more doctor visits? More specialist visits? Are they taking more prescription drugs? Second, we know little about the pattern of change in maternal health prior to and after the birth of a child with NDD. For example, are mothers of children with NDD more likely to be diagnosed with chronic conditions or have higher healthcare service use in the years before the birth of their child with NDD, after the birth, or both?

The purpose of the present study was to compare the health of mothers of children with NDD to that of mothers of children without NDD, using provincially linked administrative longitudinal health data that included data before the birth of the child with NDD. Overall, using administrative data in this study provided an unprecedented opportunity to understand patterns of maternal health and healthcare service utilization before and after the birth of a child with NDD to inform research, practice, and policy to improve the health of families of children with NDD (Miodrag & Hodapp, 2010).

2. Methods

2.1. Population and data source

The population for this study ($N = 25{,}388$) was based on a cohort of children born in 2000 and who were, along with their mothers, continuously registered with the British Columbia's (BC) universal health insurance program between 2000 and 2007. In BC, medical coverage is administered through the Medical Services Plan (MSP) and drug coverage through PharmaCare. The birth cohort was selected in 2000 in order to allow for four years of maternal health information prior to the child's birth and to allow for seven years of post-birth follow-up. Since the focus of this study was on maternal health over time, only mothers who were

continuously registered between 1996 and 2007 were included in the analyses (81% of all mothers of children born in 2000).

This study used data from four separate administrative data holdings provided through Population Data BC (PopData):[1]

1) The *MSP Payment Information File* (British Columbia Ministry of Health [creator], 2012a): medical services provided by fee-for-service practitioners to people covered by BC's universal health insurance program.
2) The *Discharge Abstract Database (DAD)* (Canadian Institute for Health Information [creator], 2012): hospital discharges, transfers, and in-hospital deaths of patients from all acute-care hospitals.
3) *PharmaNet* (British Columbia Ministry of Health [creator], 2012b): prescription data for drugs and medical supplies (for example, insulin pumps, orthotics) dispensed by pharmacies, regardless of payer.
4) The *Consolidation File* (MSP Registration and Premium Billing) (British Columbia Ministry of Health [creator], 2012c): population demographic data prepared for research use by PopData.

All data from PopData are linked using encrypted, randomly assigned identifiers that match personal health numbers across databases, and thereby provide individual level data that are de-identified.

2.2. Data access

Data access was approved by Data Stewards at the BC Ministry of Health, and ethics approval was granted by the Ottawa Health Science Network Research Ethics Board, where the research was carried out. The encrypted data files were made accessible to the research team on a secure research environment through PopData. All inferences, opinions, and conclusions drawn in this study are those of the authors, and do not reflect the opinions or policies of the Data Stewards.

2.3. Mother-child linkage

Children were linked to mothers based on the MSP contract number, which is the same for all family members. Only children linked to one mother were included (90% of cases; children could be linked to more than one mother in cases of parental separation and/or new family formation). Some mothers (˜1% of the sample) were linked to more than one child because they had more than one child born in 2000. If mothers were linked to two or more children, linkage priority was given to children with NDD (i.e., the mother was linked first to the child with NDD (if they had one) and then to the child without NDD), otherwise a random selection was made.

2.4. Child neurodevelopmental disorders and disabilities (NDD)

For each year between 2000 and 2006, NDD diagnosis based on the International Classification of Diseases, Ninth Revision (ICD-9), as indicated in the MSP (physician claims) and DAD (hospital separations) files, was assessed for children in the study sample. Diagnosis of NDD was examined in the cohort from birth to age 7 to allow for diagnoses at school age (see Pringle, Colpe, Blumberg, Avila, & Kogan, 2012). Miller et al.'s (2013) definition of NDD/D, in which diagnostic information is aligned with predetermined functional domains (e.g., cerebral palsy aligned with functional limitation in the motor domain), was applied (see Appendix A for a list of diagnostic codes and functional domains). This approach previously used with administrative data (Arim et al., 2017) allowed us to harmonize diagnosis information, which relates to health conditions, with functional domains to align with contemporary conceptualizations of disability (Miller & Rosenbaum, 2016; WHO, 2001).

2.5. Maternal health outcomes

In keeping with previous survey-based findings regarding differences in maternal health according to child health groups (see Brehaut et al., 2004, 2009 for examples), as well as to make use of the breadth of administrative data available in the current study, three health outcomes were selected: presence of a chronic condition, number of physician visits, and number of different classes of prescription drugs. These outcomes were assessed yearly from 1996 to 2007, covering the time period from four years before the child's birth until seven years afterwards, with the specific timing of each year based on the month of birth of the child (e.g., for a child born in July 2000, the year before birth would be considered July 1999 through June 2000). Maternal health outcomes are described in detail in Appendix B, with exclusion criteria presented in Appendix C.

2.6. Temporal predictors

Four temporal predictors were included in our models to assess how maternal health changed over time. The first temporal predictor coded *time* as 0–11, with an increase of one representing one year. Two additional dichotomous temporal predictors were included, one indicating the *year before birth* and another indicating the *year after birth*, as we observed that maternal health outcomes changed in a specific way during these periods based on our initial visual exploration of data. The fourth temporal predictor was

[1] http://www.popdata.bc.ca/data

called *time post-birth* and assessed time since the birth of the child (coded as 0 before the birth of the child, with an increase of one representing one year). Time post-birth assessed whether the slope in the maternal health outcome variables changed after the birth of the child. It also enabled us to examine whether the divergence (or convergence) in maternal health outcomes differed for mothers of children with NDD compared to those without NDD.

2.7. Covariates

Three variables were used as covariates. Because age is directly linked to health, *maternal age* in the baseline year, as indicated in the Consolidation File, was included. Two time-varying socioeconomic status indicators, namely, *receipt of premium subsidy* for which eligibility is based on net family income, and *residence in lowest-income neighbourhood quintiles*, as indicated in the MSP and Consolidation File, respectively, were also examined because it is well-established that socio-economic disadvantage is associated with an increased risk of health problems (Mikkonen & Raphael, 2010). Neighbourhood income quintiles are an aggregated socio-economic status indicator that divides the provincial population into five income groups based on postal codes. PCCF + software (Wilkins, 2010) was used to assign Canadian census geographies and income quintiles to MSP contract-holders. Finally, *presence of another child with NDD* who was born between 1996 and 2000 was also considered. About 8% (n = 140) of mothers of children with NDD who were born in 2000 had another child with NDD born between 1996 and 2000 (i.e., an older sibling with NDD), compared with 4% (n = 833) of mothers of children born in 2000 without NDD. Mothers of children without NDD who had another child with NDD born between 1996 and 2000 were excluded from the final sample for data analysis in order to avoid confounding effects in the comparison group. Mothers of children with NDD who had another child with NDD born between 1996 and 2000 were not excluded from the final sample because the focus of the analysis was on the comparison of health outcomes between mothers of children with and without NDD.

2.8. Analysis

Descriptive statistics for all study variables in the baseline year (3–4 years before the birth of the child) were examined separately for mothers of children with NDD and those without NDD. Due to the large sample size, very small differences emerged as statistically significant ($p < .05$). Given this, effects sizes (Cohen's d) were computed to determine the size of the differences between the groups with established criteria for small (0.20–0.49), medium (0.50–0.79), large (0.80–1.29), and very large (1.30 or greater) effect sizes for differences in means (Cohen, 1988; Rosenthal, 1996), and small (7–17 points), medium (18–29 points), large (30–44 points), and very large (45 points or greater) for differences in percentages with odds ratios being used for percentages outside the 15%–85% range (Rosenthal, 1996). Next, multilevel modeling for individual change (Singer & Willet, 2003) was used to examine the change in maternal health over time for mothers of children with NDD as compared to mothers of children without NDD. A logistic multilevel model for individual change was examined for the binary health outcome (i.e., presence of a chronic condition) and linear multilevel models were examined for continuous health outcomes (i.e., the number of physician visits and the number of different prescription drug classes). All analyses were conducted using SAS software version 9.4 for Windows (SAS Institute, Inc., Cary, North Carolina).

A two-level multilevel model for individual change was estimated for each health outcome, with blocks of covariates entered in a sequential fashion. A final model was estimated after excluding statistically non-significant effects of level 2 predictors on the rate of change for all temporal predictors. Only the final model is presented but results from all models are available from the authors upon request.

3. Results

Descriptive statistics for maternal demographic and health characteristics in the baseline year (before cohort child's birth) separately for mothers of children with NDD and those without NDD are presented in Table 1. Mothers of children with NDD had a higher number of different prescription drug classes (2.49 vs. 1.96) and were more likely to be hospitalized for acute-care (4.11% vs. 2.92%) compared to mothers of children without NDD. Differences in effect sizes were small indicating small but meaningful real-world implications.

Parameter estimates from the final model examining the changes in each of the three maternal health outcomes after accounting for the effects of maternal age, receiving a premium subsidy, and residing in a lowest-income neighbourhood quintile are presented in Table 2. Figs. 1–3 depict the changes in each of the three maternal health outcomes per year for both groups in the presence of all temporal predictors and covariates that were statistically significant in the final model.

Regarding the change in the predicted proportion of mothers with a diagnosed chronic condition (Fig. 1), in the baseline year, mothers of children with NDD were more likely to have been diagnosed with a chronic condition compared to mothers of children without NDD (OR = 1.36, Table 2). Although the likelihood declined gradually for both groups over time, the relative difference remained consistent until the birth of the child. The likelihood of being diagnosed with a chronic condition increased in the year before the child's birth (OR = 1.15) and in the year after birth (OR = 1.31) for both groups of mothers. However, the increases in the likelihood did not differ between groups. In the period from the child's 1 st to 7th birthdays, the likelihood of being diagnosed with a chronic condition stabilized for mothers in both groups (and this stabilization in the likelihood did not differ between groups).

Regarding the change in the predicted number of physician visits (Fig. 2), in the baseline year, mothers of children without NDD were predicted to have, on average, about eight physician visits per year. Mothers of children with NDD were predicted to have a higher number of physician visits at baseline than mothers of children without NDD (1.84 more visits per year; Table 2). There was

Table 1
Maternal demographic and health characteristics in the baseline year (3–4 years before the birth of child), by child health group.

Baseline characteristics	Mothers of children with NDD n = 1,847	Mothers of children without NDD n = 22,708
Demographic characteristics		
Age, *M(SD)*	26.39 (5.87)	26.42 (5.55)
Premium subsidy, %	39.85	35.27
Lowest-income quintile neighbourhood, %	25.55	23.17
Health characteristics		
Number of physician visits (excluding pregnancy/birth and lab/x-ray visits), *M(SD)*	10.26 (11.41)	8.46 (9.22)
Number of different prescription drug classes, *M(SD)*	2.49 (2.75)	1.96 (2.22)[S]
Chronic condition, %	37.74	31.87
Acute-care hospitalization, %	4.11	2.92[S]

Note. Comparisons without an effect size are effectively negligible (e.g., effects sizes are less than 0.20 for differences in means or less than 7 points for differences in percentages).
[S]small effect size compared to "without NDD" group.
[M]medium effect size compared to "without NDD" group.
[L]large effect size compared to "without NDD" group.
[XL]very large effect size compared to "without NDD" group.

Table 2
Parameter estimates from the final models for maternal health outcomes (N = 24,555).

	Final Model Presence of a chronic condition		Final Model Number of physician visits	Final Model Number of different prescription drug classes
	Estimate (SE)	OR[CI]	Estimate (SE)	Estimate (SE)
Level 1 fixed effects				
Baseline (3-4 years pre-birth)	−1.02 (0.02)***		8.23 (0.05)***	1.86 (0.01)***
Time (in years, from 3–4 years pre-birth to 6–7 years post-birth)	−0.05 (0.01)***	0.95[0.93–0.96]	0.01 (0.02)	0.01 (0.01)*
Year before birth (1 in the year before birth, 0 all other)	0.14 (0.02)***	1.15[1.10–1.20]	0.71 (0.06)***	0.05 (0.01)***
Year after birth (1 in the year after birth, 0 all other)	0.27 (0.02)***	1.31[1.26–1.36]	2.01 (0.05)***	0.20 (0.01)***
Time post-birth (in years, 0 until birth of child, then from 0–1 years post-birth to 6–7 years post-birth)	0.06 (0.01)***	1.06[1.04–1.08]	−0.26 (0.03)***	0.06 (0.02)***
Received premium subsidy	0.29 (0.01)***	1.33[1.30–1.37]	1.23 (0.04)***	0.31 (0.01)***
Lowest-income quintile neighbourhood	0.04 (0.01)**	1.04[1.01–1.07]	0.01 (0.04)	0.05 (0.01)***
Level 2 fixed effects				
Predicting: Baseline				
Mothers of children with NDD	0.31 (0.03)***	1.36[1.28–1.45]	1.84 (0.16)***	0.52 (0.04)***
Age of mother (centred on 26 y, in 10 s)	0.15 (0.02)***	1.17[1.13–1.20]	1.08 (0.09)***	−0.04 (0.02)
Predicting: Time				
Mothers of children with NDD	**X**	**X**	**X**	**X**
Age of mother (centred on 26 y, in 10 s)	**X**	**X**	−0.31 (0.03)***	−0.05 (0.01)***
Predicting: Year before birth				
Mothers of children with NDD	**X**	**X**	−0.34 (0.16)*	**X**
Age of mother (centred on 26 y, in 10 s)	**X**	**X**	0.30 (0.10)**	**X**
Predicting: Year after birth				
Mothers of children with NDD	**X**	**X**	**X**	0.10 (0.04)*
Age of mother (centred on 26 y, in 10 s)	**X**	**X**	0.25 (0.09)**	0.06 (0.02)*
Predicting: Time post-birth				
Mothers of children with NDD	**X**	**X**	**X**	**X**
Age of mother (centred on 26 y, in 10 s)	**X**	**X**	0.19 (0.05)***	0.05 (0.01)***
Random effects				
Baseline (3–4 years pre-birth)	1.19 (0.02)***		33.87 (0.37)***	2.45 (0.03)***
Time			0.06 (0.01)***	0.02 (0.03)***
Time post-birth			0.73 (0.02)***	0.03 (0.00)***
Residual			39.19 (0.12)***	2.73 (0.01)***

Note. * $p < .05$. ** $p < .01$. *** $p < .001$. OR[CI] = odds ratio[confidence interval]. **X** indicates that the variable was not statistically significant in the model and thus excluded from the final model.

almost no change in the predicted number of yearly physician visits for both groups over time. However, in the year before the child's birth, mothers in both groups experienced an increase in the average number of physician visits, although the increase was smaller for mothers of children with NDD (0.37 additional visits vs. 0.71, respectively; Table 2). In the year after the child's birth, mothers in

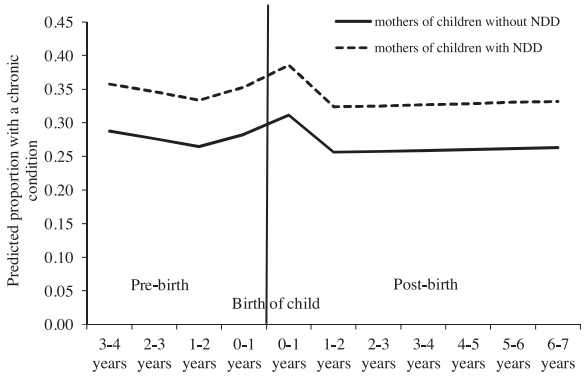

Fig. 1. Differences in the proportion with a chronic condition between mothers of children with and without NDD.
Note. Predicted probability estimate from multilevel model that included covariates for time, year before birth, year after birth, time post-birth, premium subsidy, low-income quintile neighbourhood, and age of mother.

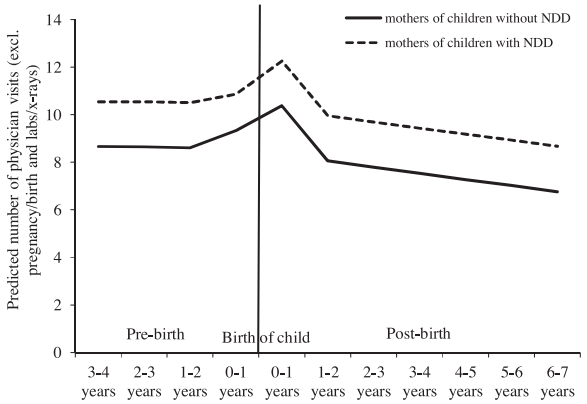

Fig. 2. Differences in the number of physician visits (excluding pregnancy/birth and lab/x-ray visits) between mothers of children with and without NDD.
Note. Model estimates from multilevel model that included covariates for time, year before birth, year after birth, time post-birth, premium subsidy, low-income quintile neighbourhood, and age of mother.

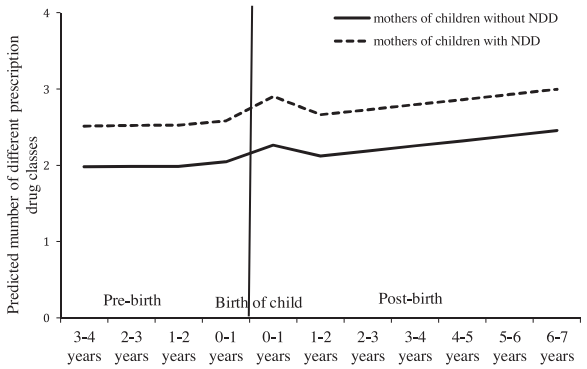

Fig. 3. Differences in the number of different prescription drug classes between mothers of children with and without NDD.
Note. Model estimates from multilevel model that included covariates for time, year before birth, year after birth, time post-birth, premium subsidy, low-income quintile neighbourhood, and age of mother.

both groups experienced an increase in physician visits (about two more visits per year; but this increase did not differ between groups). In the six year period from the child's 1st to 7th birthdays, mothers in both groups experienced a decrease in the number of physician visits (0.25 fewer visits each year from a predicted mean of about 10 visits per year to a predicted mean of about 7 visits per year, and this decrease did not differ between groups).

Regarding the change in the predicted number of different prescription drug classes (Fig. 3), in the baseline year, mothers of

children without NDD were predicted to be prescribed, on average, about two different drug classes per year. Mothers of children with NDD were predicted to be prescribed more classes of drugs at baseline than mothers of children without NDD (2.38 vs. 1.86; Table 2). This pattern was stable over time. However, in the year before the child's birth, mothers in both groups had a slight increase of 0.05 more different prescription drug classes per year (but this increase did not differ between groups). In the year after the child's birth, mothers in both groups had an increase of 0.20 of a unit in the number of different prescription drug classes per year, and this difference was greater for mothers of children with NDD compared to those without NDD (an increase of 0.30 vs. 0.20). This increase translates to a predicted mean from 1.98 to 2.26, on average, for mothers of children without NDD and from 2.52 to 2.91 for mothers of children with NDD. For descriptive purposes, we also examined the highest drug classes in the year after the birth of the child. In the year 2001, the top three drug classes were (1) beta-lactam antibacterials, penicillins, (2) anti-inflammatory and antirheumatic products, non-steroids, and (3) opioids for mothers in both groups (opioids were the second highest drug class for mothers of children without NDD whereas it was the third highest for mothers of children with NDD). In the six year period from the child's 1st to 7th birthdays, mothers in both groups had an increase in the number of different prescription drug classes (0.07 more different prescription drug classes each year from a predicted mean of 2.26 different drug classes to a predicted mean of 2.46 different drug classes per year, but this increase was not different between groups).

4. Discussion

The present study aimed to use provincially linked administrative health data to shed light on health and healthcare service utilization of mothers of children with NDD compared to mothers of children without NDD during the periods before, during, and after the birth of the child. To our knowledge, this is the first study that used linked administrative health data to examine health and healthcare service utilization specifically of mothers of children with NDD and the first to include data for the mothers prior to child birth. There are several methodological strengths of using administrative data as compared to survey data, including reduced burden of data collection, reduced respondent bias (e.g., recall), and consistent response rates over time (Virnig & McBean, 2001). As routinely collected, administrative data provide great potential for comprehensive, comparative, and cost-effective longitudinal analyses that other forms of data cannot match. In addition, administrative data allows for detecting small yet meaningful differences with the use of effect sizes that have both clinical and practical significance, particularly for a subgroup such as caregivers of children with NDD. However, research on the quality of administrative data is still sparse (Smith et al., 2017). Despite several approaches that are in place in Canada to optimize quality of administrative data (see Eastwood, Denny, Kelly, & Quan, 2018), little is known about physician diagnostic practices over time and how closely administrative data definitions match theoretical constructs of interest given that administrative data lack information about functional limitations and severity. In particular, there is a need for validation studies for case ascertainment in the paediatric population (Shiff, Jama, Boden, & Lix, 2014). This limitation of administrative data should be kept in mind when interpreting the findings of this study. Overall, this study demonstrated the feasibility of using administrative data to evaluate changes in maternal health and healthcare service utilization before and after birth of a child with NDD. The findings indicated that mothers of children with NDD were more likely to have chronic conditions and higher service utilization, but these differences were exhibited before the child's birth. In addition, mothers of children with NDD showed a smaller increase in physician visits in the year before birth but a greater increase in different prescription drugs in the year after birth compared to mothers of children without NDD. There was no further divergence (or convergence) in health and service utilization between the groups in the 7-year period post-birth.

A strength of the present study was that it allowed us to focus on a landmark life events for mothers such as the birth of the child with NDD and to have a large 10-year study period from 3 to 4 years pre-child birth to 6–7 years post-child birth. Additionally, it allowed us to examine health outcomes based on objective measures (i.e., not survey based self-report), as well as to include a comparison group to better understand the changes in the health of mothers of children with NDD. Future research can replicate this study by focusing on different landmarks event such as the timing of the diagnosis of the child with NDD, distinguishing among different sub-domains of child NDD (e.g., motor, social etc.) and broadening maternal health conditions for a more refined understanding on the associations between child NDD and maternal health.

One similar study (Ray, Croen, & Habel, 2009) examined the health conditions and service utilization of mothers of children diagnosed with attention-deficit and hyperactivity disorder (ADHD) in the year before and two years after the birth of the child, with results comparable to our findings. They found that mothers of children with ADHD were more likely to use healthcare services and be diagnosed with a number of medical conditions than mothers of children without ADHD in the year before and two years after the birth of the child. Our study provides further support for these results, showing increased use both before and after the birth period. The results highlight the need to further examine the individual and environmental factors associated with the differences in maternal health and healthcare service utilization for mothers of children with NDD.

Several important findings emerged from our study. First, we found that mothers of children with NDD were more likely to have chronic conditions and higher healthcare service utilization than mothers of children without NDD well before the birth of the child. This finding highlights the importance of pre-existing characteristics in accounting for differences in health and healthcare service utilization and in understanding the role of caring for a child with NDD in maternal health. While it is beyond the scope of this paper to engage in a discussion about pre-existing health characteristics of mothers and children born with NDD, our finding emphasizes that the health and healthcare service utilization of mothers prior to the birth of their child is an important health determinant and the birth of a child with NDD does not appear to change the pattern in the 7 years post-birth. Future research is needed to further disentangle factors such as genetics (see Mitchell, 2011) and other environmental factors such as access to healthcare in order to better understand these birth differences in the health of mothers of children with NDD.

Mothers in both groups experienced an increase in healthcare service utilization one year before and after the birth of the child, even after excluding pregnancy- or birth-related visits and lab or x-ray visits. However, these increases in healthcare service utilization were different between mothers of children with and without NDD (although differences were short-lived). Specifically, in the year before the birth of the child, mothers of children without NDD showed a greater increase in physician visits than mothers of children with NDD. This may be partially due to the exclusion of all pregnancy and birth related visits so remaining visits may have been due to other circumstances such as consultations. Future research may shed light on this issue by comparing diagnoses related to pregnancy and child birth in physician claims data between mothers of children with and without NDD before the child's birth.

In the year after the birth, mothers of children with NDD showed a greater increase in the number of different prescription drugs compared to mothers of children without NDD. While our findings are in line with Smolina, Hanley, Mintzes, Oberlander, and Morgan (2015) who reported increases in the average number of drugs dispensed during pregnancy and postpartum in BC for a cohort of women who gave birth, they also reveal the need for monitoring the patterns and determinants of prescription drug use, particularly for mothers of children with NDD. Future research may examine associations between prescription drug use during pregnancy and postpartum and health risks for both mothers and children.

There was no further divergence (or convergence) in health and healthcare service utilization between mothers of children with and without NDD in the 7-year period post-birth. These findings do not contradict previous research suggesting that parenting a child with special health needs is associated with adverse health effects. Indeed, these findings support that the health differences between mothers of children with and without NDD can be observed at any point in time. However, our findings also highlight that these differences exist before the birth of the child with NDD and remain over time without further differentiation. Taken together, these findings highlight the importance of supporting the needs of parents of children with NDD and developing family-centered intervention/prevention programs for parents of children with NDD.

While the likelihood of having a chronic condition was stable for mothers in both groups in the 7-year period post-birth, mothers in both groups showed a decrease in physician visits but an increase in the number of different prescription drugs. These results may suggest fewer health effects of caregiving over time and an eventual adaptation particularly for mothers of children with NDD. This effect has been reported by others (Hsieh, Huang, Lin, Wu, & Lee, 2009). However, it may also be possible that these results reflect tendencies of mothers to seek care for themselves while receiving care for their children. If this is the case, then maybe administrative health data are a blunt tool to detect the kinds of differences one can expect between mothers of children with and without NDD. In fact, previous research has reported similarities in patterns of healthcare service utilization for mothers and their children (Minkovitz, O'Campo, Chen, & Grason, 2002). Future research may disentangle mothers' and children's healthcare service utilization by examining whether or not they see the same or different physicians, information not available to us for the current study.

We should also note that our findings regarding the outcomes in the baseline year are within the range of reported national trends. For example, the average number of physician visits in Canada ranged between 6 and 8 visits since 1996 (Organization for Economic Co-operation & Development (OECD), n.d.), and was 8.5 for mothers in both groups in the present study. Similarly, 33% of Canadians reported having one or more chronic conditions in a population-based health survey data (Broemeling, Watson, & Prebtani, 2007), and we found a similar proportion (32%) for mothers in both groups.

Despite the previously noted strengths, several limitations of this study should be acknowledged. First, mothers were identified at the first registration of the children with the MSP, and thus, we did not know whether mothers were co-resident and the main caregiver of the child during the full study period. Future research may determine co-residence using postal code information in the Consolidation File, which was not available to us in this study. Second, the group of children without NDD included both healthy children and those with other health conditions that were not NDD. Given this, the differences between the groups of mothers may have been underestimated in this study. Future studies are needed to replicate this study to determine if the health differences are larger with a comparison group of mothers with healthy children. Indeed, recently, our team compared the health of mothers of children with health problems to that of mothers of healthy children and found similar results with one exception that is, the health of the two groups of mothers further diverged after the birth of a child with health problems (Brehaut et al., 2018). Moreover, child health may not be stable over time. Thus, future studies may wish to consider child health group as a time-varying predictor of maternal health. Third, our findings are based on individuals with continuous access to healthcare services that are covered by public health insurance. Thus, individuals with limited or irregular access to healthcare services such as those living in rural and remote areas and newly arrived immigrants may have been underrepresented. In addition, out-of-pocket fees for services and non-subsidized services are not captured. Equally important, identification of child NDD as well as maternal health outcomes in administrative data may be impacted by various other factors other than access to services, including mothers' attitude to health and physician practices. Fourth, the possibility of systematic over-or under-diagnosis, either for children or mothers should also be acknowledged as a limitation of administrative data. It is possible that associations between children's and their mother's health might have been introduced by family physicians who treat both the child and the mother. In these cases, increased service utilization may reflect physician practices rather than poorer health. Future research is needed on administrative data diagnostic information and actual health status, condition severity, and functional limitations as well as to shed light on differences in physicians' practices when they treat multiple members of the same family. Finally, our analyses are based on a single birth cohort born in 2000. Although a similar pattern of results was observed with another cohort, replication of this study with different data and birth cohorts as well as examining maternal health beyond 7 years post-birth would be warranted. Future research could also examine other aspects of health, such as mental health, although these administrative data do not necessarily capture services paid out of pocket. Overall, this study demonstrated that administrative data can provide a unique research opportunity to examine differences in health and healthcare service utilization of mothers of children with NDD compared to mothers of children without NDD, in the periods before and after birth. Contrary to expectations, the birth of a child with NDD did not significantly alter maternal health. Differences in health and healthcare service

utilization between mothers of children with and without NDD existed before the birth of the child raising questions for future research about underlying differences.

5. Conclusions

Using provincial linked administrative health data, this study found that mothers of children with NDD were more likely to have been diagnosed with a chronic condition and had higher healthcare service utilization, including higher physician visits and more different prescription drugs compared to mothers of children without NDD. This pattern was apparent prior to the birth of the child as well as post-birth. This pattern generally remained with some divergence in the year before and in the year after the birth of the child. There was no further divergence (or convergence) in health and healthcare service utilization between mothers of children with and without NDD in the 7-year period post-birth. Future research is warranted to replicate these findings, focus on different landmark events, distinguish among different sub-domains of child NDD, investigate differences farther into the future, and examine other aspects of health, such as mental health, before and around the birth of child with NDD.

Declarations of interest

None.

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Appendix A. List of diagnostic codes to identify children with NDD

	Definition[a] NDD/D domain	Diagnostic codes ICD-9 codes
1.	Motor	Infantile cerebral palsy (343), spina bifida (741), lack of coordination (781.3), muscular dystrophies and other myopathies (359)
2.	Speech	Other speech disturbance (784.5), problems with voice production (v41.4), aphasia (784.3), developmental speech or language disorder (315.3)
3.	Learning-cognition	unspecified (problems with scholastic skills, 315.9), problems with learning (v40.0), fetal alcohol syndrome (760), reading disorder (315.0), other symbolic dysfunction (784.6), down syndrome (758), symptoms and signs involving cognitive functions and awareness (799.5), unspecified mental retardation (319), hyperkinetic syndrome of childhood (314)
4.	Social	Pervasive developmental disorders (299) (largely autism and its variants)
5.	Sensory	Deafness (389), blindness and low vision (369), problems with special senses and other special functions (v41)
6.	Neuropsychological	Epilepsy (345), combined vocal and multiple motor tic disorder (307.23)

Note. [a] Both physician claims and hospital discharge information was used as some health conditions are more likely to be captured in hospital separations rather than physician claims data (e.g., newborns with FASD). In line with other studies using administrative data to identify individuals with neurological conditions (e.g., Arim et al., 2017; Tu et al., 2014), for children to be classified in the NDD group, two physician service codes or one hospitalization code between birth and six years of age were used for a given NDD diagnostic code for children who were registered with the Medical Services Plan their lifetime between 2000 and 2006. NDD = Neurodevelopmental disorders. NDD/D = Neurodevelopmental disorders and disabilities. ICD-9 = International Classification of Diseases, Ninth Revision.

Appendix B. Description of maternal health outcomes

Variable	Description	Data file
Chronic condition	A mother was considered to have a chronic condition if she was diagnosed with at least one of the following medical conditions (ICD-9 codes) in each year: allergy (287.0, 477, 995.27 or 995.3), arthritis (714), asthma (493), back problem (724), bronchitis (490, 491, 492, 466.0, 506.0), cancer (140-208,235-239), diabetes (249, 250), hearing problem (388, 389), heart disease (393-398, 401-405,410-414, 415-417,420-429), herpes (054, 771.2), hypertension (401, 796.2), injury (E800.0-E999), migraine (346), sinusitis (473), ulcer (531, 532), glaucoma (365), and cataracts (368).	MSP

Number of physician visits excluding pregnancy or birth and lab and x-ray visits per year	A physician visit was based on number of unique records by date and specialty, excluding pregnancy or birth related visits and lab and x-ray visits. For pregnancy or birth related visits, the following ICD-9 codes: 630 to 677, 760 to 779, V20 to V28, and PopData codes: 30B, 31B, 32B, 33B, 34B, 35B, 36B, 37B, 38B, 34A, 23B, 08A, 12B, 15B, 16B, 10B, 18B, 11B, 19B were excluded. For lab visits, ICD-9 codes: 630 to 633 and PopData code L01; for x-ray visits, ICD-9 codes: 634 to 639 and PopData code X01 were excluded. Appendix C includes a list of these codes and their definition.	MSP
Number of different prescription drug classes, excluding birth control	Each drug identification number has a World Health Organization Anatomical Therapeutic Chemical (ATC) classification code assigned by Health Canada (WHO Collaborating Centre for Drug Statistics Methodology, 2018). The ATC structure divides active substances into groups according to the organ or system on which they act and their therapeutic, pharmacological, and chemical properties. The number of different third level ATC codes was used to define number of different drug classes because third level ATC codes represent major therapeutic or pharmacological subgroups. Prescriptions for systemic use hormonal contraceptives (code G03 A) were excluded.	PharmaNet

Note. ICD-9-CM = International Classification of Diseases, Ninth Revision, Clinical Modification. PopData = Population Data BC. MSP = Medical Services Plan. DAD = Discharge Abstract Database.

Appendix C. Visits excluded from the number of physician visits maternal health outcome

ICD-9 code	Definition	PopData code	Definition
630-633	Ectopic and molar pregnancy	L01	Laboratory codes
634-639	Other pregnancy with abortive outcomes	X01	X-ray codes
640-648	Complications mainly related to pregnancy	08 A	Healthy Newborn Care
650-659	Normal delivery, and other indications for care in pregnancy, labour and delivery	10B	Sterilization – Female
660-669	Complications occurring mainly in the course of labour and delivery	11B	Consultation Re Sterilization – Female
670-677	Complications of the puerperium	12B	Genetic Counselling – Female
760-763	Maternal cause of perinatal morbidity and mortality	15B	Artificial Insemination
764-779	Other conditions originating in the perinatal period	16B	Insertion/Removal of IUD
V20	Health supervision of infant or child	18B	Prenatal Care
V21	Constitutional states in development	19B	Hypertrophy of Breast, Mammary Gland, Nipple Arising During Pregnancy
V22	Normal pregnancy	23B	Erosion and Inflammation Of Cervix (Uteri) Arising During Pregnancy
V23	Supervision of high-risk pregnancy	30B	Leukorrhea, Vaginal Discharge Not Otherwise Specified Arising During Pregnancy
V24	Postpartum care and examination	31B	Contraceptive Advice
V25	Encounter for contraceptive management	32B	Hypertensive Disease Arising During Pregnancy
V26	Procreative management	33B	False Labour
V27	Outcome of delivery	34A	Pregnancy, Examination Pregnancy Unconfirmed
V28	Antenatal screening	34B	Premature Rupture of Membranes
		35B	Threatened Abortion
		36B	Pregnancy, Examination Pregnancy Unconfirmed
		37B	Premature Rupture of Membranes
		38B	Threatened Abortion

Note. ICD-9 = International Classification of Diseases, Ninth Revision. PopData = Population Data BC.

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