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Mental health of parents of children with a developmental disability in British Columbia, Canada

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ABSTRACT

Background There is evidence in the literature that parents of children who have a developmental disability experience an increased risk of mental health problems.

Methods This study used population-level administrative data from the Ministry of Health, British Columbia, Canada, to assess the mental health of parents of children who have a developmental disability compared with the mental health of parents of children who do not have a developmental disability. Population-level and individual explanatory variables available in the data were included in the models.

Results At a population level, the study found strong evidence that parents of children who have a developmental disability experience higher odds of depression or other mental health diagnoses compared with parents of children who do not have a developmental disability. Age of the parent at birth of the child, income and location of healthcare services were all associated with outcomes.

Conclusion Parents of children who have a developmental disability may be in need of programmes and services that support their mental health.

experienced by these parents include: reduced income,^{13 14} reduced employment¹⁵ and neighbourhood distress.¹⁶ Using self-reports by parents, several population-level studies have found that mental health issues of parents of children who have a DD may be explained by socioeconomic factors rather than solely by the presence of a child with a DD.^{17–19} Other studies have shown that individual and family variables may also have an impact on the mental health of parents of children who have a DD.¹ These variables include: the sex of the parent,²⁰ stigma experienced²¹ and severity of the disability,²² among other factors.

This study used population-level administrative data to investigate the mental health of parents who have a child who has a DD in the province of British Columbia (BC), Canada, from 1990 to 2014. Administrative data have many benefits for studying disability-related issues and address several of the weaknesses of previous studies. The data used create the capacity to form large cohorts of people with rare diagnoses, rather than having to pool disabilities in order to achieve large enough numbers. These data do not rely on self-reports, provide information on the prevalence of DD, include data on demographics, can provide large comparison groups, reduce selection bias and include some of the individual variables that may affect outcomes. This is the first known study to use population-level administrative data to study parents of children with a DD. The specific question investigated in this study is whether the mental health of parents who have a child with a DD differs from the mental health of parents who have a child who does not have a DD.

METHODS

Data for this study were obtained from Population Data BC (PopData), a service that provides access to and linkages among a number of different administrative databases in BC, Canada. Linkages are formed by PopData identifying the same person across multiple data sets. Researchers receive deidentified data with unique study IDs that enable individual-level analysis across files without revealing identities. Health data are available for the entire population of BC with the exception of people who have never registered with the provincial medical plan, data from alternative funding arrangements for health professionals (eg, salaried physicians and nurse practitioners) and data from on-reserve First Nations health services. Linkage rates for PopData have been reported as above 95%.²³ For this study, three databases held by PopData BC were linked.

INTRODUCTION

There is a considerable amount of literature regarding the effects of having a child with a developmental disability (DD) on the mental health of parents (see Marquis *et al* for a review¹). Studies have found both an increase in mental health problems among these parents^{2–4} and no difference in mental health between parents of children with a DD and parents of children without a DD.^{5 6} These mixed results may be due to methodological issues, there are many challenges involved in studies of the effects of DD and involved in comparing the results of these studies. Challenges include: varying definitions of DD used¹; lack of accurate data on the incidence and prevalence of DD making it difficult to determine if accurate samples have been obtained^{7 8}; combining of physical disabilities and DD to obtain adequate sample sizes¹; small sample sizes^{9–11}; reliance on convenience sampling^{9 10}; failure to account for the large number of potential confounders (including both social determinants of health such as income and individual variables such as type of DD)¹; lack of adequate control groups¹⁰; and lack of large, population-based studies.¹²

Parents of a child who has a DD commonly experience the effects of social determinants of poor health, as well as individual characteristics and experiences that may produce and interact with these inequities.¹ Social determinants



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- ▶ A *central consolidation file* containing demographic information on all individuals in BC including information on birth date and sex of each individual within the province and neighbourhood income quintiles from census data.^{24 25}
- ▶ The *Medical Services Plan (MSP)* payment file which contains administrative information for all fee-for-service care provided by physicians in BC including the date of each visit to a physician, the diagnostic code (International Classification of Diseases Ninth Revision; ICD-9), the *health authority (HA)* and *health service delivery areas* where the visit occurred, and the subsidy code indicating whether payments to the physician were subsidised through provincial programmes and the amount of the subsidy.²⁶
- ▶ The *hospital separation file* with information on all hospitalisations, including the date of admission and discharge and related diagnostic codes (ICD-9 and ICD-10).²⁷

Defining the cohorts

The study groups consisted of four cohorts of parents: parents of children with a DD born between 1990 and 1995; parents of children with a DD born between 2000 and 2005; parents of children born between 1990 and 1995 without a DD; and parents of children born between 2000 and 2005 without a DD. For each parent data were examined from the date of birth of the child until 2014 (end date of the data collection). These groups were chosen to represent a large proportion of the population within distinct time periods (to reduce cohort effect), but still

provide numbers of observations that were manageable for data manipulation.

Identification of children with a DD was done using the algorithm developed by Lin *et al.*²⁸ Children aged 0–19 were identified by ICD-9 codes in MSP files and by ICD-9 and ICD-10 codes in hospital separation files (see online supplementary appendix A for a list of the codes). Identification required at least two occurrences of the ICD-9 codes identifying DD in MSP data or at least one occurrence of DD identified by ICD-9 or ICD-10 codes in hospital separation data.

Linking parents and children was done using MSP contract numbers which are shared within families. The term ‘parents’ not ‘care-givers’ was used in this study, because MSP numbers are associated between parents and children within families, but are not associated between children and other caregivers, such as foster parents. However, the term ‘parents’ may include step-parents as well as biological parents.

Primary outcomes

The primary outcomes of depression and mental health diagnoses were selected based on prior research showing that among a range of conditions considered, depression and mental health problems were most significantly associated with having a child with a DD.²⁹ Depression and mental health problems were identified using diagnostic codes in the physician and hospital files (see online supplementary appendix B).

Table 1 Descriptive statistics

Variable	Parents of children who have a DD who were born 1990–1995	Parents of typical children who were born 1990–1995	Parents of children who have a DD who were born 2000–2005	Parents of typical children who were born 2000–2005
Total number of parents with postbirth data	16 659	596 545	11 294	344 800
Number of mothers (n (per cent of total parents))	9378 (56.30)	316 390 (53.04)	5957 (52.74)	180 918 (52.47)
Number of fathers	7281	280 155	5337	163 882
Mean number of children in the family (n (SD))	1.06 (0.24) Range 1–5	1.12 (0.41) Range 1–7	1.32 (0.47) Range 1–5	1.22 (0.46) Range 1–5
Mean age at birth of reference child				
Mothers (n (SD))	30.01 (5.98)	30.31 (5.50)	31.31 (6.14)	30.37 (5.39)
Fathers (n (SD))	32.29 (6.69)	32.67 (6.17)	33.80 (6.59)	32.91 (5.94)
Income quintile of the reference child at birth				
Lowest (n (%))	1169 (27.10)	57 527 (22.08)	1193 (25.16)	49 542 (21.77)
Second (n (%))	914 (21.19)	55 449 (21.28)	1017 (21.47)	48 413 (21.28)
Third (n (%))	812 (18.82)	53 388 (20.49)	957 (20.21)	46 452 (20.42)
Fourth (n (%))	759 (17.59)	50 919 (19.54)	849 (17.93)	44 057 (19.36)
Highest (n (%))	660 (15.30)	43 264 (16.61)	720 (15.20)	39 074 (17.17)
Mothers with a postbirth diagnosis of depression (n (%))	6999 (74.63)	193 370 (61.12)	3721 (62.46)	93 708 (51.80)
Mothers with a postbirth diagnosis of a mental health problem (other than depression) (n (%))	6133 (65.40)	159 100 (50.29)	3022 (50.73)	70 193 (38.80)
Fathers with a postbirth diagnosis of depression (n (%))	3987 (54.76)	119 271 (42.57)	1986 (37.21)	49 737 (30.35)
Fathers with a postbirth diagnosis of a mental health problem (other than depression) (n (%))	3551 (48.77)	106 815 (38.13)	1724 (32.30)	43 265 (26.40)

DD, developmental disability.

Explanatory variables

Variables used in the model were selected based on findings in the literature¹ and data available in the administrative data bases. Variables used were: sex of parent²⁰; sex of reference child³⁰; age of parent at birth of reference child³¹; number of children in the family³²; receipt of an MSP subsidy³³; neighbourhood income quintile³⁴; and HA³⁵ in which the person lived. Number of children in the family was measured at the last contact in the data. Neighbourhood income is measured in quintiles and individual MSP subsidy is a binary measure (receipt of a subsidy or no subsidy received). Receipt of an MSP subsidy is a measure of low income. The variable HA refers to the location where health services are provided. Health services vary across the province of BC, with access to an increased number and wider variety of services in southern (more urban) locations compared with northern locations.

Analyses

Following descriptive analysis, multiple logistic regressions were used to examine the binary outcome of having versus not having a diagnosis of depression or a mental health problem at any time after the birth of the reference child. *SAS proc logistic*³⁶ for binary data ('yes' or 'no' for having a diagnosis of depression or another mental health problem at any time after the birth of the reference child) was used for all logistic regression analyses. Proc logistic fitted logistic regression models and estimated parameters by *maximum likelihood* using a *Fisher's Scoring* algorithm. Individuals with missing observations were automatically deleted during model formation. Patterns of missing data were examined. For each of the cohorts 83%–91% of the data were complete. Missing data are primarily the result of missing postal codes when data were entered into the administrative database. Postal codes are used to determine income quintiles and HA. In all the cohorts in this study, the variables HA and neighbourhood income quintile had the most missing data. Cohorts of parents with children with a DD had the same pattern of missing data as parents of children without a DD.

Due to the size of the data, the *probability level (alpha)* was set at $p < 0.01$ for entry of the variables into the model and as a criterion for the variable to be retained in the model. ORs were produced for each variable as well as *Wald confidence limits* computed using the profile likelihood function. ORs for the continuous variable of age at birth of child can be interpreted as the odds of having a diagnosis for every year increase in age. ORs for the categorical variables are calculated in comparison to the reference category. Highest income quintile was used as the reference value for the variable of income quintile, male as the reference for sex and no subsidy as the reference for receipt of an MSP subsidy.

RESULTS

Descriptive statistics (table 1) showed differences in the number of parents in the lowest and highest income quintiles at birth of the reference child. Parents with a child with a DD were found more often in the lowest income quintile and less frequently in the highest income quintile relative to comparison groups. In the 1990–1995 and the 2000–2005 cohorts, both fathers and mothers of children with a DD had a higher occurrence of at least one depression or mental health diagnosis compared with mothers and fathers of children who did not have a DD.

In this study the number of postbirth diagnoses reported for either depression or another mental health problem was high for parents of typical children and for parents of children who have a DD. These numbers are higher than cross-sectional prevalence reported for populations elsewhere in the literature.³⁷ However, recent reports of lifetime prevalence of depression or mental illness in Canada^{38 39} and elsewhere^{40 41} estimate that between 20% and 50% of the total population may experience a mental health problem and hypothesise that previous studies may have underestimated lifetime prevalence. These recent estimates are similar to the estimates found in this study (table 1) for parents of typical children (26%–61%).

With all other variables held constant, mothers and fathers of children who have a DD had significantly higher odds of having

Table 2 Predictors of a depression diagnosis OR (CI)

Variable	Depression diagnoses of mothers of children born 1990–1995 (n=270 736)	Depression diagnoses of fathers of children born 1990–1995 (n=253 632)	Depression diagnoses of mothers of children born 2000–2005 (n=160 201)	Depression diagnoses of fathers of children born 2000–2005 (n=154 614)
Parent of child with a DD versus parent of child without a DD	1.755 (1.671 to 1.844)	1.600 (1.524 to 1.680)	2.235 (2.103 to 2.376)	1.637 (1.541 to 1.739)
Parent's age at birth of the child	1.015 (1.014 to 1.017)	1.013 (1.012 to 1.014)	0.992 (0.990 to 0.994)	1.003 (1.002 to 1.005)
Sex of the child (female vs male)	N.S.	N.S.	N.S.	N.S.
Number of children in the family	0.403 (0.382 to 0.425)	0.620 (0.596 to 0.645)	N.S.	N.S.
Income quintile				
Lowest versus highest	1.057 (1.031 to 1.084)	1.119 (1.091 to 1.148)	0.953 (0.923 to 0.983)	1.060 (1.024 to 1.099)
Second versus highest	1.080 (1.053 to 1.108)	1.108 (1.080 to 1.136)	1.010 (0.979 to 1.043)	1.096 (1.059 to 1.135)
Third versus highest	1.057 (1.030 to 1.084)	1.072 (1.045 to 1.099)	1.020 (0.989 to 1.053)	1.044 (1.008 to 1.081)
Fourth versus highest	1.070 (1.043 to 1.097)	1.061 (1.035 to 1.088)	1.023 (0.991 to 1.056)	1.010 (0.976 to 1.046)
Receipt of an MSP subsidy versus no subsidy	0.851 (0.835 to 0.868)	0.926 (0.906 to 0.946)	N.S.	1.062 (1.024 to 1.097)
Health authority				
Interior versus Vancouver Coastal	1.811 (1.764 to 1.859)	1.535 (1.496 to 1.575)	1.748 (1.690 to 1.807)	1.516 (1.461 to 1.572)
Fraser versus Vancouver Coastal	1.355 (1.328 to 1.383)	1.266 (1.239 to 1.293)	1.348 (1.315 to 1.382)	1.247 (1.212 to 1.283)
Island versus Vancouver Coastal	1.743 (1.698 to 1.789)	1.506 (1.467 to 1.546)	1.662 (1.608 to 1.717)	1.440 (1.389 to 1.494)
Northern versus Vancouver Coastal	1.605 (1.553 to 1.659)	1.306 (1.264 to 1.350)	1.389 (1.328 to 1.452)	1.254 (1.194 to 1.317)

DD, developmental disability; MSP, Medical Services Plan; N.S., not significant.

Table 3 Predictors of a mental health diagnosis OR (CI)

Variable	Mental health diagnoses of mothers of children born 1990–1995 (n=270 736)	Mental health diagnoses of fathers of children born 1990–1995 (n=253 632)	Mental health diagnoses of mothers of children born 2000–2005 (n=160 201)	Mental health diagnoses of fathers of children born 2000–2005 (n=154 614)
Parent of child with a DD versus parent of child without a DD	1.792 (1.713 to 1.874)	1.527 (1.455 to 1.603)	2.143 (2.0248 to 2.265)	1.634 (1.539 to 1.736)
Parent's age at birth of the child	1.013 (1.011 to 1.014)	1.012 (1.010 to 1.013)	0.996 (0.994 to 0.997)	N.S.
Sex of the child (female vs male)	N.S.	N.S.	N.S.	N.S.
Number of children in the family	0.433 (0.409 to 0.458)	0.627 (0.602 to 0.652)	0.964 (0.939 to 0.989)	N.S.
Income quintile				
Lowest versus highest	1.057 (1.032 to 1.084)	1.130 (1.101 to 1.160)	0.993 (0.962 to 1.026)	1.106 (1.066 to 1.148)
Second versus highest	1.039 (1.014 to 1.065)	1.093 (1.066 to 1.122)	1.005 (0.973 to 1.038)	1.111 (1.072 to 1.152)
Third versus highest	1.023 (0.998 to 1.048)	1.072 (1.045 to 1.099)	1.037 (1.004 to 1.071)	1.087 (1.049 to 1.128)
Fourth versus highest	1.044 (1.019 to 1.070)	1.055 (1.029 to 1.083)	1.047 (1.013 to 1.082)	1.016 (0.980 to 1.054)
Receipt of an MSP subsidy versus no subsidy	0.878 (0.861 to 0.895)	N.S.	N.S.	1.115 (1.079 to 1.153)
Health authority				
Interior versus Vancouver Coastal	1.568 (1.530 to 1.608)	1.411 (1.375 to 1.449)	1.399 (1.352 to 1.448)	1.319 (1.269 to 1.370)
Fraser versus Vancouver Coastal	1.507 (1.477 to 1.537)	1.452 (1.421 to 1.483)	1.328 (1.294 to 1.363)	1.377 (1.337 to 1.418)
Island versus Vancouver Coastal	1.821 (1.777 to 1.868)	1.587 (1.546 to 1.630)	1.677 (1.622 to 1.734)	1.468 (1.414 to 1.525)
Northern versus Vancouver Coastal	1.187 (1.150 to 1.225)	1.081 (1.045 to 1.119)	0.905 (0.863 to 0.949)	0.842 (0.796 to 0.890)

DD, developmental disability; MSP, Medical Services Plan; N.S., not significant.

a diagnosis of depression compared with mothers and fathers of children who did not have a DD in both the 1990–1995 cohorts and the 2000–2005 cohorts (table 2).

Generally for mothers and fathers in both comparison cohorts, not being in the highest income quintile was associated with slightly increased odds of a depression diagnosis (the exception was for the lowest income mothers for comparisons between mothers of children born 2000–2005). Receiving an MSP subsidy was associated with variable odds of a depression diagnosis (lower, non-significant or slightly higher depending on the cohort and sex of the parent). To examine any possible relationship between income quintile and subsidy, models were fitted separately for each of the two variables. Excluding income quintile from the model did not affect the results for subsidy and excluding subsidy from the model did not affect the results for income quintile.

For both comparison cohorts, compared with living in the urban Vancouver Coastal HA, living in any other HA increased odds of a diagnosis of depression for mothers and fathers.

Very similar results were found for diagnoses of a mental health problem (table 3). Mothers and fathers of children who have a DD had significantly higher odds of having a diagnosis of a mental health problem than mothers and fathers of children who did not have a DD. In both cohorts being in a lower income quintile generally slightly increased odds of a mental health diagnosis compared with being in the highest income quintile. Compared with living in the Vancouver Coastal HA, living in any other of the four HAs increased odds of a mental health diagnosis.

CONCLUSION

There is evidence in the literature that having a child with a DD can have an effect on the mental health of parents. However, much of the evidence is conflicting.¹ In addition, methodological issues, particularly issues of small sample size and convenience sampling, have limited the generalisability of findings.^{9 10} The purpose of this study was to use population-level health

administrative data to explore the relationship between parent mental health and having a child with a DD. Using anonymised administrative data ensured a large sample, and reduced problems of loss to follow-up,⁴² confidentiality,⁴³ recruitment⁴⁴ and selection bias.⁴⁵ This is the first time in Canada that administrative health data have been used to study the mental health of parents of children who have a DD.

This study found that at the population level in BC both mothers and fathers had significantly higher odds of a diagnosis of depression or another mental health problem following birth of their child with a DD, compared with mothers and fathers of children who did not have a DD.

Similar to other studies that found lower incomes among families with a child with a DD,⁴⁶ in this study, a greater proportion of parents of children who have a DD were in the lowest neighbourhood income quintiles compared with parents of children who do not have a DD. Many previous studies have also found a negative relationship between income level and poor mental health among parents in families with a child with disabilities.^{18 47–49}

Using a population-level measure of income (neighbourhood income quintile) this study found that the effect of having a child with a DD crossed all income levels. When comparing parents of children with a DD to parents of children without a DD, and with income held constant, significant differences in odds of depression and mental health problems remained. However, using an individual measure of income (receipt of an MSP subsidy) showed variable results. The findings in this study may differ from those in the literature due to both the difference in size between the samples used and to the differing measures of income used. Most of the studies cited used individual measures of socioeconomic status including such variables as items the parent would like to purchase but could not afford.^{18 49} The variables used in this study (receipt of an MSP subsidy and particularly neighbourhood income quintile) may not be as sensitive as other measures of income.

Findings regarding income are important in discussions regarding the relative importance of income or socioeconomic status versus psychosocial factors in explaining outcomes of stress or poor mental health. This study found that income had some effect on mental health, but it also showed that income did not explain the entire effect on mental health. Other variables such as child behaviour, social exclusion and stigma could play important roles, however it was not possible to measure these in this study.

Limitations

This study relies on administrative data used for physician billing purposes. As a result, the data cannot account for potentially important individual variables such as ethnicity, marital status, child behaviour and parenting styles. As well, positive impacts of parenting a child with a DD are not recorded in the data. In addition, health service utilisation is an indirect measure of health status, although the consistency of findings in this study strongly suggests that the relationship between having a child with a DD and experiencing depression or other mental health issues is not spurious.

The data analysed in this paper were based on ICD-9 and ICD-10 diagnostic codes used by physicians in the province of BC. These codes predate the definition of DD provided by the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5).⁵⁰ The researchers had no control over the diagnosis and definitions used by individual physicians and therefore cannot ascertain that the subjects within this study were diagnosed with DD as defined by the DSM-5.

The accuracy and completeness of administrative health data is dependent on physician coding.^{51–53} Inaccuracies in reporting and coding by physicians are beyond the control of the researchers. There is also evidence that the quality and completeness of physician coding is greater for three-digit ICD-9 codes than for four and five-digit codes.⁵⁴ This study used some four and five-digit ICD-9 codes to identify particular disabilities. Due to issues of coding, there may have been under-representation of some disabilities including fetal alcohol syndrome (FAS) and some of the rarer disabilities such as Prader-Willi syndrome. However, the estimate of prevalence of children who have a DD in BC found in this study and reported in a paper by Marquis *et al*⁵⁵ was equal to or higher than the prevalence reported elsewhere in the literature.⁸

Large data sets may be associated with large sample size fallacy.^{56–58} Therefore, as recommended in the literature,^{57,58} this study stratified the samples, reported ORs and CIs and assessed the results in comparison to related literature.

Prebirth diagnoses of depression and mental health diagnoses were not included in the analyses. This was due to the differences in observation times in the prebirth time period. Births occurred over a number of years and parents were of varying ages at the birth of their child, so there were varying amounts of time in which a prebirth diagnosis of depression or a mental health problem could be made. Mental health diagnoses include some conditions, such as schizophrenia, that are not likely causally related to the birth of the child with a DD, but are included here for consistency in categorisation with other studies.

In conclusion, this study provides strong evidence that at the population level mothers and fathers of children with a DD experience greater odds of depression or other mental health problems compared with mothers and fathers of children without a DD. The findings also highlight the complexity of studying families and the many variables which may affect the mental

health outcomes of parents. These results point to the importance of conducting research which accounts for the complexities of families and to the importance of developing programmes and services for families of children with a DD that support the mental health of parents.

What is already known on this subject

- There is conflicting evidence about the effects of having a child with a developmental disability on the mental health of parents. Differences among studies may be due to methodological issues, particularly small sample sizes. Large population-based studies are needed in this area.

What this study adds

- This study provides population-based evidence that having a child with a developmental disability is associated with increased odds of parents having depression or another mental health problem.

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Data availability statement Data may be obtained from a third party and are not publicly available.

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