USE OF HEALTH, EDUCATION, AND SOCIAL SERVICES BY INDIVIDUALS WITH FETAL ALCOHOL SPECTRUM DISORDER

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ABSTRACT

Background
Fetal Alcohol Spectrum Disorder (FASD) is the leading cause of intellectual disability in western society, presenting a significant burden on health, education and social services. Quantifying the burden of FASD is important for service planning and policy and program development.

Objective
To describe the health, education and social service use of individuals with FASD to provide an indication of the burden of service use of the disorder.

Methods
Using a matched-cohort design health, education and social service data were linked with clinical records on individuals 6+ years diagnosed with FASD between 1999/2000-2009/10 (N=717). Matching was 2:1 with a general population (gPop) and asthma group by age, sex and area-level income. Adjusted rates and relative risks were calculated using Generalized Linear Models.

Results
Hospitalizations were higher in the FASD compared to gPop (adjusted relative risk=3.44 (95% confidence interval=2.29, 5.17)) and asthma (2.87 (1.94, 4.25)) groups, whereas for physician visits and overall prescriptions, the FASD group differed from only the gPop group (1.58 (1.34, 1.84); 1.44 (1.22, 1.72), respectively). Antibiotics, pain killers and anti-psychotics were similar across groups whereas antidepressants and psychostimulants were higher in the FASD group (antidepressants: FASD vs. gPop 8.76 (2.82, 27.21); FASD vs. asthma 2.10 (1.15, 3.83); psychostimulants: FASD vs. gPop 5.78 (2.89, 11.57); FASD vs. asthma 2.47 (1.37, 4.47)). Attention-deficit\hyperactivity disorder was higher in the FASD than the gPop and asthma groups (6.41 (3.29, 12.49); 3.12 (1.97, 4.93), respectively). Education and social service use was higher for the FASD than either of the other groups for all measures (FASD vs. gPop and FASD vs. asthma, respectively for: grade repetition 3.06 (1.58, 5.94); 3.48 (1.79, 6.78); receipt of any special education funding 9.22 (6.23, 13.64); 6.10 (4.14, 8.99); family receipt of income assistance 1.74 (1.33, 2.27); 1.89 (1.45, 2.47); child in care 13.19 (5.84, 29.78);10.70 (4.80, 23.88); and receipt of child welfare services 5.70 (4.21, 7.71); 4.94 (3.67, 6.66)).

Conclusion
The health, education and social service utilization burden of individuals with FASD is substantial, greater than that of individuals in the general population and with chronic illness (i.e., asthma). The findings highlight the need for multisystem supports for those with FASD, and comprehensive prevention programs**.**

Key Words: *FASD, health service utilization, social services, administrative data, special education*

Use of Health, Education and Social Services by Individuals with Fetal Alcohol Spectrum Disorder

Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term comprising the range of effects associated with all levels of prenatal exposure to alcohol.[1] Prenatal alcohol exposure has been identified as the leading cause of mental retardation in the western world.[2] People with FASD are at high risk to develop secondary disabilities, such as depression, anxiety, substance abuse, and frequently experience poor social outcomes including judicial system involvement and educational failure.[3,4] Consequently, the social, psychological, and economic costs for affected individuals and their communities persist throughout the lifetime.[5]

With current prevalence estimates of at least 1 in 100 and possibly as high as 2 to over 6%[6,7] in school age children, FASD poses a significant burden to health, education and social services.[8,9] Furthermore, there is complexity to understanding the multiple factors which influence neurodevelopmental outcome and disability including socioeconomic status, availability of appropriate education supports, and presence of other health conditions. An accurate understanding and quantification of the current service utilization burden of this disorder is important for planning supportive services across sectors and for the development of social policy and prevention programs. There is currently a dearth of information available on the specific utilization of health and other services by individuals with FASD.[10]

This study attempted to fill the gap in information on service utilization by individuals with FASD. Existing data sets were used to determine the types of services that are used by individuals with FASD, and how their utilization differs from individuals without the disorder. Our specific objective was to examine the relative risks of health, education and social service utilization for individuals identified as FASD, to provide an indication of the burden of service use of the disorder.

METHODS

Data Sources

This study combined de-identified administrative claims data on health, education and social service use from the Population Health Research Data Repository housed at the Manitoba Centre for Health Policy (MCHP) with clinical assessment data from the Manitoba FASD Centre, which is the only referral centre for FASD in the province of Manitoba. The specific data files used in analyses were:

1) Hospital discharge abstracts, which contain information on all hospitalizations in Manitoba, including up to 16 ICD-9-CM diagnostic codes for discharges before April 1, 2004 and up to 25 ICD10 diagnostic codes for discharges on or after April 1, 2004;

2) Medical claims, which contain information on ambulatory physician visits in Manitoba and include a single ICD-9 diagnostic code associated with each visit, coded to the third digit;

3) Prescription claims, which include all prescription medications dispensed within Manitoba, except those dispensed to hospital inpatients;

4) Population registry, which is a registry of all Manitobans eligible to receive health services and includes demographic information and 6-digit residential postal code for geocoding;

5) Canada Census information, which was used to determine area-level income, with the Manitoba population divided into urban and rural income quintiles according to average area-level household income, comprising 11 possible income groupings – five each for urban and rural areas, and one for those with income information not available;

6) Income assistance which includes information on all individuals and families receiving provincial Employment and Income Assistance;

7) Child welfare records, which include information from Child and Family Services on all Manitoba residents receiving services, including in-home services and out-of-home placements;

8) Education data, including information on enrolment and special education funding. Special education funding is provided to children with

severe to profound disabilities and was categorized as; emotional/behavioural, multiple handicap, and other (e.g., autism spectrum disorder, blindness, deafness);

9) Manitoba FASD Centre clinical data, which includes clinical assessments and diagnoses received, i.e., diagnoses under the FASD umbrella (see definition below), normal, other diagnoses (e.g., genetic diagnoses) and deferred status (for individuals who will be reassessed at a later time).

Although data are anonymized, all files are linkable at the person-level through the use of an encrypted personal heath number. The success of database linkage at MCHP is very high and the reliability and validity of the databases have been well documented.[11-19]

Study Population

The study population consisted of individuals diagnosed with FASD at the Manitoba FASD Centre between fiscal year April 1, 1999 and March 31, 2010. A matched cohort design was employed. The FASD cohort ranged in age from 6 to 34 years in calendar year 2009, with 89.5% of the cohort under the age of 20 in 2009. Children under 6 years of age were not included in the study because we wanted to match the FASD cohort to a cohort with a chronic illness that would be associated with increased health care utilization. Asthma was chosen due to its relatively high prevalence in children and young adults, however it is difficult to distinguish in administrative records from transient wheeze in children younger than 6 years and thus comparisons at younger ages were limited.[20,21]

Only those individuals with FASD who could be linked to the Manitoba population registry (i.e., were Manitoba residents registered to receive health care in Manitoba) and covered from the start of the study period or their birth through the end of the study period were included (n=717). There were 71 individuals in the FASD Centre dataset who could not be linked to the registry (over 90% of whom resided outside of Manitoba, e.g., northwestern Ontario or Nunavut). FASD was defined as one diagnosis of any of the following conditions: Fetal Alcohol Syndrome (FAS) (8.2%), Partial FAS (32.0%), Alcohol Related Neurodevelopmental Disorder (ARND) (59.8%), or Alcohol Related Birth Defects (ARBD) (0.0%).

Two different matched comparison groups were selected: a "general population" group; and a chronic condition group. The general population group was chosen by selecting all individuals of the same age in 2009 as the FASD study population, with the following exclusions: 1) any individuals assessed at the Manitoba FASD Centre between April 1, 1999 and March 31, 2010; 2) any individual who had a hospitalization code for FASD (ICD-9-CM=760.71, ICD10-CA=Q86.0) anytime between 1984/95 and 2008/09; and, 3) any individual who was identified as having asthma (see definition below). From this group, 2 matches for each FASD individual were randomly selected from all potential matches. Matching was done according to age (in years), sex, and income quintile. Income information was derived from the 2006 Canada Census and applied to each individual according to residential postal code at time of matching.

The chronic condition group was chosen by selecting individuals with asthma; asthma was defined as:[20,22] 1) 1+ hospitalizations with ICD-9 diagnosis code 493x (including all subtypes of asthma) or ICD-10 diagnosis code J45x (including all subtypes of asthma) in any diagnosis field over 2 years of data. Hospital claims between 1999/00 and 2008/09 were searched; or 2) 1+ physician claims with ICD-9 diagnosis code of 493 over 2 years of data. Physician visits between 1999/00 to 2008/09 were searched; or 3) 1+ Rx for Asthma drugs over 2 years of data. 1999/00 to 2007/08 drug claims were searched (2008/09 were not available at time of analysis). A listing of asthma medications used in this definition is available from the authors on request. From this group, 2 matches for each FASD individual were randomly selected from all potential matches, matched by age, sex and income quintile. Thus the final study population numbers were: FASD=717, general population=1,434, and asthma=1,426 (we were not able to find 2 unique asthma matches for every FASD child). Table 1 shows the demographic comparisons of the FASD and matched cohorts. A listing of each of the health, social services and educational outcomes analyzed

in the study as well as a description of these measures and the years of data used for each in the analyses can be found in Table 2.

TABLE 1 Demographic Comparisons of FASD, General Population, and Asthma Cohorts

	Cohort		
	FASD	General Population	Asthma
N	717	1434	1426
Age as of Dec. 2009 (years)			
Mean (SD)	13.35 (4.71)	13.35 (4.71)	13.38 (4.70)
Median	13	13	13
Range	age 6 - 34	age 6 - 34	age 6 - 34
Sex (%)			
Male	66.5%	66.5%	66.9%
Female	33.5%	33.5%	33.1%
Income Quintile (%)			
income not found	10.2%	10.2%	9.7%
rural 1 (lowest rural)	21.5%	21.5%	21.7%
rural 2	3.8%	3.8%	3.8%
rural 3	3.3%	3.3%	3.4%
rural 4	3.5%	3.5%	3.5%
rural 5 (highest rural)	2.5%	2.5%	2.5%
urban 1 (lowest urban)	37.5%	37.5%	37.7%
urban 2	9.2%	9.2%	9.3%
urban 3	4.3%	4.3%	4.3%
urban 4	3.1%	3.1%	3.1%
urban 5 (highest urban)	1.1%	1.1%	1.1%

TABLE 2 Outcome measures used to compare health and social service utilization for FASD, general population and asthma groups

Outcome Measure	Description	Years
Overall Hospitalization Rate:		
number of hospitalizations per person	rate of hospitalizations for any reason except birth, over a 3-year period, per 100 person years	2007/08-2009/10
number of hospitalizations per person, childbirth-related excluded	rate of hospitalizations for any reason except birth and childbirth-related, over a 3-year period, per 100 person years	2007/08-2009/10
at least one hospitalizations per person	rate of subjects hospitalized at least once, except birth, over a 3-year period, per 100 person years	2007/08-2009/10
Physician Visit Rate	total number of ambulatory visits to a physician over a 3-year period, per person	2007/08-2009/10
Prescription Drug Use:		
overall (least 1 prescription)	rate of at least 1 prescription for any drug over a 1 year period, per 100 person years	2005/06
antibiotic	rate of at least 1 antibiotic prescription over a 1 year period, per 100 person years	2005/06
antidepressant	rate of at least 1 antidepressant prescription over a 1 year period, per 100 person years	2005/06
Psychostimulant	rate of at least 1 Psychostimulant prescription over a 1 year period, per 100 person years	2005/06
narcotic analgesic	rate of at least 1 narcotic analgesic prescription over a 1 year period, per 100 person years	2005/06
NSAID (non-steroidal anti-inflammatory)	rate of at least 1 NSAID prescription over a 1 year period, per 100 person years	2005/06
antipsychotic	rate of at least 1 antipsychotic prescription over a 1 year period, per 100 person years	2005/06
Attention deficit hyperactivity disorder (ADHD)	persons with ADHD (as per hospital, physician & drug data) during fiscal year 2005/06, per 100 person years	2005/06

TABLE 2 Cont'd - Outcome measures used to compare health and social service utilization for FASD, general population and asthma groups

Outcome Measure	Description	Years
Family Receipt of Income Assistance	rate of children in family receiving Income Assistance (for at least 1 month) over years: 1995-2009	1995/96-2008/09
Involvement with Child & Family Services:		
Children in Care (up to age 17 years)	rate of being in out of home care, for at least 1 month at any time during the study period, per 100 person years	1995/96-2008/09
protection/support	rate of having received protection or support services (child welfare services), for at least 1 month at any time during the study period, per 100 person years	1995/96-2008/09
Grade Repetition	rate of students in grades K - 8 who were retained in a grade at least once in academic years: 03/04-07/08	2003/04-2007/08
Special Education Funding for:		
-Emotional Behavioural Disorder (EBD)	rate of students receiving special funding for Emotional/Behavioural Disorders, for at least 1 school year, per 100 person years	1997/98-2008/09
-Multiple Handicapped	rate of students receiving special funding for Multiple Handicaps, for at least 1 school year, per 100 person years	1997/98-2008/09
-Other	rate of students receiving special needs funding for "other" condition, for at least 1 school year, per 100 person years	1997/98-2008/09
-Any level I or II Funding	rate of students receiving any special needs funding, for at least 1 school year, per 100 person years	1997/98-2008/09

TABLE 3 Covariates used in modeling, by outcome

		Covariates							
Outcome:	Model distribution* and fit**	cohort	sex	age group	income	region of residence	In Care	cohort X age grp	cohort X sex
hospitalizations	NB (1.033)	yes	yes	yes	yes	yes	no	yes	no
hospitalizations, excluding pregnancy-related	NB (1.012)	yes	yes	yes	yes	yes	no	yes	no
at least 1 hospitalization	NB (0.934)	yes	yes	yes	yes	no	no	yes	no
Physician visits	NB (1.202)	yes	yes	yes	yes	yes	yes	yes	no
Prescription medications									
- Any medication	P (0.917)	yes	yes	yes	no	no	yes	yes	no
- Antibiotics	P (0.916)	yes	yes	yes	no	no	yes	yes	no
- Anti-Depressants	P (1.247)	yes	yes	no	yes	no	no	no	*yes*
- Psychostimulants	NB (1.214)	yes	yes	yes	no	no	yes	yes	no
- Narcotics	P (0.943)	yes	yes	no	yes	no	yes	no	*yes*
- NSAIDs	P (0.929)	yes	yes	yes	no	no	yes	yes	no
- Antipsychotics	NB (1.310)	yes	yes	yes	no	no	no	yes	no
ADHD	NB (0.922)	yes	yes	no	yes	yes	yes	no	*yes*
Income Assistance	NB (0.952)	yes	yes	yes	yes	yes	yes	yes	no
Children in Care	NB (0.858)	yes	yes	yes	yes	yes	no	yes	no
Protection/Support Services	NB (1.252)	yes	yes	yes	yes	yes	no	yes	no
Grade Repetition	P (0.903)	yes	yes	no	no	yes	no	no	*yes*
Special Needs Funding:									
- EBD	NB (0.906)	yes	no	yes	yes	yes	yes	yes	no
- Multiple Handicap	NB (0.948)	yes	yes	yes	yes	no	no	yes	no
- All others	NB (0.981)	yes	yes	yes	yes	no	no	yes	no
- All Special Needs	NB (1.190)	yes	yes	yes	yes	yes	yes	yes	no

* Model distributions was either Negative Binomial (shown in table as "NB") or Poisson (shown in table as "P).

**Model fit given by deviance value divided by the degrees of freedom

TABLE 4 Service utilization for FASD, general population and asthma groups,
Adjusted Rates per 100 Person Years, individuals 6 years and older

	Crude Rates per 100 Person Years			Adjusted Rates per 100 Person Years (95% CI)			Adjusted Relative Risk (95% CI)	
Indicator	**FASD**	**General Population**	**Asthma**	**FASD**	**General Population**	**Asthma**	**FASD versus General Population**	**FASD versus Asthma**
Overall Hospitalization Rate-during most recent 3 yrs								
number of hospitalizations per person all	9.30	3.16	3.48	10.87 (7.24, 16.33)	3.16 (2.60, 3.72)	3.78 (2.51, 5.69)	**3.44 (2.29, 5.17)**	**2.87 (1.94, 4.25)**
number of hospitalizations per person, childbirth excluded	8.61	2.93	3.25	10.19 (6.65, 15.37)	2.93 (2.39, 3.47)	3.50 (2.30, 5.33)	**3.45 (2.27, 5.25)**	**2.89 (1.93, 4.33)**
at least one hospitalizations per person	4.07	2.31	2.53	4.06 (2.97, 5.57)	2.31 (1.84, 2.80)	2.61 (1.95, 3.49)	**1.76 (1.28, 2.41)**	**1.56 (1.15, 2.11)**
Physician Visit Rate - during most recent 3 years (per person)	3.68	2.12	3.07	3.33 (2.84, 3.91)	2.12 (2.05, 2.18)	3.10 (2.64, 3.64)	**1.58 (1.34, 1.84)**	1.08 (0.93, 1.25)
Prescription Drug Use: (ages 0-19)								
overall (kids with at least 1 prescrip in 2005/06)	69.63	45.96	69.24	66.35 (55.84, 78.82)	45.96 (42.14, 49.77)	69.77 (68.99, 70.62)	**1.44 (1.22, 1.72)**	0.95 (0.81, 1.12)
antibiotic	37.37	31.87	47.18	38.98 (31.13, 48.80)	31.87 (28.70, 35.05)	46.58 (39.65, 54.73)	1.22 (0.98, 1.55)	0.84 (0.68, 1.04)
antidepressant	3.83	0.66	1.82	5.76 (1.86, 17.95)	0.66 (0.20, 1.11)	2.75 (0.89, 8.50)	**8.76 (2.82, 27.21)**	**2.10 (1.15, 3.83)**
Psychostimulant	26.61	2.78	5.75	13.97 (8.22, 23.72)	2.78 (1.80, 3.76)	5.36 (4.97, 5.80)	**5.78 (2.89, 11.57)**	**2.47 (1.37, 4.47)**
narcotic analgesic	1.46	1.89	2.81	1.91 (0.77, 4.72)	1.89 (1.12, 2.67)	3.08 (1.72, 5.53)	1.01 (0.40, 2.50)	0.62 (0.27, 1.44)
NSAID	7.47	2.72	5.87	9.21 (4.99, 16.98)	2.72 (1.79, 3.65)	7.36 (4.40, 12.32)	**3.39 (1.84, 6.25)**	1.25 (0.78, 2.00)
antipsychotic	11.00	0.99	2.16	6.92 (1.52, 31.51)	0.99 (0.40, 1.59)	3.70 (0.80, 17.18)	7.01 (.54, 31.91)	1.87 (0.53, 6.67)
Attention deficit\hyperactivity disorder (per 1000)	27.61	3.68	6.29	23.57 (12.10, 45.97)	3.68 (2.55, 4.81)	7.56 (6.12, 9.33)	**6.41 (3.29, 12.49)**	**3.12 (1.97, 4.93)**
Family Receipt of Income Assistance (per 100)	28.67	17.32	17.17	30.10 (23.00, 39.39)	17.32 (16.53, 18.12)	15.92 (12.14, 20.87)	**1.74 (1.33, 2.27)**	**1.89 (1.45, 2.47)**
Involvement with Child & Family Services:								
Children in Care (CIC) (up to age 17 years)	40.50	4.29	5.89	56.53 (25.03, 127.65)	4.29 (3.88, 4.70)	5.29 (2.34, 11.93)	**13.19 (5.84, 29.78)**	**10.70 (4.80, 23.88)**
protection/support	22.20	5.79	6.85	33.02 (24.40, 44.67)	5.79 (5.32, 6.27)	6.68 (4.92, 9.08)	**5.70 (4.21, 7.71)**	**4.94 (3.67, 6.66)**
Grade Repetition (all ages) (per 100) (2003/04-07/08)	11.11	3.12	2.65	9.55 (4.92, 18.53)	3.12 (1.59, 4.65)	2.74 (1.22, 6.16)	**3.06 (1.58, 5.94)**	**3.48 (1.79, 6.78)**
Special Education Funding for:								
- Emotional Behaviour Disorder	8.56	1.34	1.39	8.42 (4.72, 15.03)	1.34 (1.12, 1.57)	2.05 (1.11, 3.79)	**6.27 (3.51, 11.19)**	**4.10 (2.32, 7.27)**
- Multiple Handicapped	9.30	0.97	1.87	9.83 (5.59, 17.26)	0.97 (0.78, 1.16)	2.04 (1.14, 3.68)	**10.11 (5.76, 17.77)**	**4.81 (2.83, 8.17)**
-Other	14.13	1.21	0.92	15.40 (9.36, 25.33)	1.21 (1.00, 1.43)	1.26 (0.72, 2.21)	**12.67 (7.70, 20.85)**	**12.22 (7.46, 20.01)**
-Any level I or II Funding	31.74	3.87	4.71	35.63 (24.07, 52.74)	3.87 (3.48, 4.25)	5.84 (3.86, 8.83)	**9.22 (6.23, 13.64)**	**6.10 (4.14, 8.99)**

Bolded values are significant at p<0.05.

Analyses

Crude and adjusted rates were produced for each indicator for each study population group (FASD, general population, asthma). Adjusted rates were modeled using generalized linear model (GLM), suitable for non-normally distributed data such as counts. Covariates used for adjustment included cohort (FASD, general population, asthma), sex, age group (6-10, 11-15, 16+), income quintile, region of residence, whether an individual was in out-of-home care, and interactions between cohort and sex and cohort and age group. Standard criteria for assessing goodness of fit for general least squares regression models were used to determine best fit. In each case if the computed deviance value divided by the degrees of freedom (df) for the regression model fell between 0.85 and 1.35 the model was deemed appropriate or a good fit. Depending on which yielded the best fit (deviance/df closest to 1.00), either a Poisson or negative binomial distribution was used. Because the study population had varying years of follow-up, we calculated rates according to person years at risk, using the population registry. All analyses tested for differences between groups and adjusted for additional covariates depending on model fit. Decisions regarding which covariates to exclude from these models were determined by frequency distributions, model fit statistics and tests of significance of the covariates. 95% confidence intervals (CIs) were used for adjusted rates and relative risks. Model distributions and fit values, as well as covariates used to adjust rates in models for each of the indicators are listed in Table 3.

The study protocol was approved by the University of Manitoba Health Research Ethics Board (H2010:060), the Manitoba Health Information Privacy Committee, Manitoba Family Services and Labour, Manitoba Education, Manitoba Entrepreneurship, Training and Trade, and the Healthy Child Manitoba Office.

RESULTS

Table 4 provides crude and adjusted rates for the FASD cohort and the two matched comparison cohorts, as well as relative risks comparing the FASD group to the two matched cohorts. As shown in the table, the FASD group had over three times as many hospitalizations as the general population group, and almost three times as many hospitalizations as the asthma group. Because pregnancy and childbirth related hospitalizations can be a common reason for hospitalization, we also ran the hospitalization analysis excluding these, and found similar results. The FASD group also had over one-and-a-half times the risk of at least one hospitalization compared to the other two groups. Comparing the total number of hospitalizations to the results with at least one hospitalization suggests that the FASD group was more likely to be hospitalized multiple times, evidenced by the drop in relative risks when looking at those with at least one hospitalization. The most common reason for hospitalization (not shown in table) differed across the groups: for FASD it was mental disorders, for asthma it was respiratory disorders and for the general population it was injury.

The FASD group had about one and a half times the physician visits compared to the general population group, but there was no difference in number of physician visits between the FASD and asthma groups. Prescriptions for antibiotics did not differ across the three groups, nor did prescriptions for narcotic analgesics or antipsychotics. The FASD group had over 8 times the likelihood of being prescribed psychostimulants and almost 6 times the likelihood of being prescribed antidepressants compared to the general population group. For these same medications the difference between the FASD group and the asthma group was over two-fold. The FASD group was over 6 times more likely to be diagnosed with attention-deficit\hyperactivity disorder (ADHD) than the general population group, and over 3 times more likely than the asthma group.

With respect to social service utilization, the FASD group was almost twice as likely to be living in a family receiving income assistance compared to the two comparison groups. The FASD group was over 10 times more likely to be in out-of-home care than the other two groups, and over 5 times more likely than the general population group and almost 5 times as likely as the asthma group to be receiving child welfare services.

For education services, the FASD group was over 3 times more likely to repeat a grade than the

two comparison groups. The FASD group was over 9 times more likely to receive special education funding for special needs compared to the general population group, and over 6 times more likely compared to the asthma group. For all categories of special education funding the FASD group had significantly higher rates than the other two groups, ranging from over 4 times to almost 13 times higher.

CONCLUSION

This is the first paper describing utilization of health and social services in individuals with confirmed FASD diagnoses in comparison with both a chronic disease group (represented by individuals with asthma) and a general population cohort, and as such also presents unique data regarding the relative burden of this prevalent disorder. The burden of this disorder in terms of health, education and social service use is considerable. Popova et al.[10] recently published a study of health care utilization and costs of FAS in Canada, however they relied on identification of FAS through health care utilization data and correctly point out that these data likely undercount those with FAS. Furthermore, they focused specifically on FAS diagnoses rather than including other diagnoses that fall under the FASD umbrella, which also leads to an underestimate of the burden of this disorder. While this study population is broader than Popova et al.'s, it is a clinically referred and diagnosed group, and therefore likely also represents an underestimation of the complete burden of utilization and service need in this population of affected individuals.

The specific data provided in this study describe clear evidence of the complex medical and social needs of individuals with FASD as demonstrated by their significant degree of multiple service utilization, above and beyond that seen even in individuals with a chronic illness. Thus, for example, hospitalization rates were three times higher for the cohort with FASD compared to both the healthy and asthmatic cohorts; even when pregnancy- and childbirth-related hospitalizations were removed from the analyses, there was a minimal impact on these differences, suggesting that these types of hospitalizations were not driving the differences observed. The importance of hospitalization data as an identifiable, measureable, and clinically important outcome is well established. Our cohort with FASD was in fact far more likely to experience multiple hospitalizations, evidenced by the drop in relative risks between the FASD group and the other two groups when we examined those who had been hospitalized at least once rather than total hospitalizations. This is a significant measure of the morbidity of this group as well as their health care utilization.

Antidepressant and psychostimulant prescriptions were significantly higher for the FASD group compared to the two other cohorts, reflecting the higher burden of behavioural and mental health disorders in this population. It was not surprising that the neurobehavioural disorder, ADHD, was 6 times higher in the FASD group than in the general population group and 3 times higher than in the chronic illness/asthmatic group. While this is consistent with previous literature, including the diagnostic guidelines, these findings highlight the significant burden of FASD, particularly if one considers the possibility that at least some of the individuals with ADHD included in the general population may represent an undiagnosed FASD population, thus actually attenuating our findings.

Higher service utilization for individuals with FASD was not confined to the health sector, but occurred across multiple service sectors including social services and education. Rates of income assistance were almost twice as high in the FASD group compared to both the general population and asthma groups, despite matching by area-level income. Rates of placement in out-of-home care were significantly and substantially higher in children and youths with FASD, representing an over 10-fold increase, consistent with previous literature demonstrating elevated involvement with child welfare services amongst this population.[23] Not surprisingly given both the high rates of behavioural disorders and high rates of children in care, rates of social service supports to families with individuals with FASD were also significantly higher.

Previous research demonstrates that youths with FASD also significantly underperform in school,[24-26] and our results suggest that they

struggle throughout their educational experience at significantly higher rates than both the general population and the chronic disease group, with rates of grade repetition that were over 3 times higher. Their significantly higher rate of special education funding is a reflection of both their increased cognitive and behavioural needs and represents a significant additional cost to the system.

One limitation of this study is the use of a clinically referred FASD sample, as opposed to a population-based sample, thereby limiting generalizability of the findings. The use of this clinically referred sample is also a strength, however, as the individuals included have undergone a complete multidisciplinary assessment in a central tertiary-level provincial clinic following the Canadian guidelines for diagnosis of FASD.[2] Because the need for assessment is greater than the capacity of the clinic, it is possible that some individuals in the matched cohorts may have had FASD, a further limitation of this study; however this would serve to attenuate rather than strengthen our findings. Future work to develop algorithms for identifying individuals with FASD through a combination of data sources would be beneficial not only for providing population-based assessments of utilization of services, but also for estimating prevalence of this condition. This study was also limited by the databases available to study; specifically, the future addition of justice data would provide extremely useful outcome data in this population and is in the process of being added to the MCHP Data Repository. Additionally, tracking other factors such as geographic location and ethnicity may provide additional information related to intervention and preventive services. Such expanded, population-based datasets would allow for outcome modeling, examining, for example, educational and social services outcomes by age of diagnosis, and allowing for the study of use of services both before and after the diagnosis is made, to determine the impact of diagnosis on service use.

This paper provides population based evidence of the significant and complex medical, behavioural, educational, and social needs of individuals diagnosed with FASD. Individuals with FASD consistently utilize significantly greater number of health, social and education services, not only compared to the general population, but also to a chronic disease cohort (asthma). The data in this study also represent an opportunity for intervention and prevention. The influences of poverty, violence, and family breakdown are comorbid in this population and must be considered in the interpretation of data, though there was an attempt to control for some of this through area-level income matching. This is a clearly vulnerable population that requires multiple levels of service intervention. These data support the need for ongoing research in the FASD population to relate early diagnosis to new models of cross-disciplinary service delivery and outcomes. Prevention efforts must address the complex and interrelated causes of alcohol use within the social determinants of health.

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