The Prenatal Care of Women Who Give Birth to Children With Fetal Alcohol Spectrum Disorder: A Missed Opportunity for Prevention of Alcohol Exposed Pregnancies

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Abstract

Background: Prenatal care (PNC) may be effective in preventing alcohol consumption during pregnancy and decreasing the incidence of Fetal Alcohol Spectrum Disorder (FASD). This study investigates PNC utilization of women in Manitoba who have given birth to children with FASD (exposed) compared to women who gave birth to children without FASD (unexposed).

Methods: We linked population-level health, education and social services data to clinical data on FASD diagnosis to identify exposed (n=719) and unexposed (n=2107) women matched 1:3 on date of birth of index child, region of residence, and socioeconomic status. Regression modeling produced relative rates of specified outcomes. The revised Graduated Index of Prenatal Care Utilization was used to define the adequacy of PNC.

Results: Rates were higher among the exposed group for: inadequate PNC (aRR=1.65, 95% CI 1.34, 2.03), no PNC (aRR=2.36, 1.50, 3.72), and late initiation of PNC (1.66, 95% CI 1.39, 1.98). Despite many exposed women not receiving optimal PNC, 63% did access PNC.

Interpretation: Disparities exist in the receipt of PNC between women who give birth to children with FASD and women who do not. There is a need to educate women at risk for alcohol consumption during pregnancy about the importance of PNC. While a significant proportion of women in the exposed group did not receive optimal PNC, a substantial proportion did receive PNC and continued to drink during pregnancy. This represents an important opportunity for systematic screening of at-risk alcohol use and brief intervention programs to be delivered in health care settings delivering PNC.

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Despite universal education campaigns indicating the detrimental health effects of prenatal drinking, almost 11 percent of Canadian women report alcohol consumption during pregnancy[1]. Prenatal alcohol use can lead to the development of Fetal Alcohol Spectrum Disorder (FASD), which is a diagnostic term comprising range of effects associated with prenatal alcohol exposure[2]. Patients with FASD experience symptoms including: facial dysmorphology, growth restriction, central nervous system and neurodevelopmental abnormalities, as well as behavioural, emotional and social difficulties[2-4]. The incidence of FASD has been reported to be 2 to 5%[5] in the general population and up to 23% in high-risk populations in Canada[5-15].

FASD has been cited as the only preventable birth defect[2]. In Canada, where there is access to universal health care, it can be hypothesized that the incidence of FASD could be reduced through regular prenatal care (PNC). PNC is one of the most widely used preventative healthcare services in developed countries[16]. PNC has the potential to reduce the incidence of perinatal morbidity by identifying potential risks, treating physical and mental health conditions, and helping women to address social and behavioural factors that contribute to poor outcomes for both the mother and infant[16,17]. Physicians delivering PNC should routinely screen for alcohol use in pregnancy, and when identified, refer patients to treatment and support programs, and link women to community resources. Furthermore, PNC can also potentially help ameliorate the harmful effects of alcohol consumption during pregnancy by treating co-morbid health and mental disorders in women and educating women about proper nutrition and prenatal health.

PNC has been shown to be more effective if it begins in the first trimester of pregnancy and regular visits are continued throughout pregnancy[18]. The Society of Obstetricians and Gynaecologists of Canada's guidelines state that women should receive PNC visits every 4 to 6 weeks in early pregnancy, every 2 to 3 weeks after 36 weeks gestation[17,19].

No studies have investigated PNC utilization of women who have given birth to children with FASD using large population-based samples. Documenting whether these women receive adequate PNC is the first step in investigating the potential role primary health care settings can play in reducing alcohol exposed pregnancies. The objectives of this study were to: (1) compare PNC utilization among women whose child(ren) have FASD relative to women whose children do not have FASD; (2) compare characteristics of those with adequate versus inadequate care amongst women whose child(ren) have FASD.

Methods:

This study utilized the Manitoba Mothers and FASD Study (MBMomsFASD) cohort which is a retrospective cohort of women whose child(ren) were diagnosed with FASD in Manitoba; details about this cohort can be found elsewhere{Singal, #67}.

Data Sources: This study utilized de-identified administrative health, social and educational data from the Population Research Data Repository housed at the Manitoba Centre for Health Policy (MCHP) and clinical assessment data from the Manitoba FASD Centre, which is the only referral/diagnostic centre for FASD in the province. Table 1 provides a description of all databases used in this study. Rates of PNC utilization were obtained from the Hospital Discharge

Abstracts, and Medical/physician reimbursement claims. Data are de-identified and all files are linkable at the person-level through the use of an encrypted personal health number. The data in the Repository have been widely utilized for health research and the reliability and validity of the databases have been well established[20-26].

Study Population:

Group 1 (Exposed): Mothers whose children received a clinical diagnosis of FASD: Clinical data from the MB FASD Centre was used to ascertain all children and youth (birth to 21 years of age) in Manitoba who had been diagnosed with FASD between 1999 and 2012. This database was linked to administrative data from the MCHP Repository to identify these children's birth mothers. Only mothers who could be linked to their children, who had postal code information, and who were Manitoba residents registered to receive health care in the province and covered from their own birth till March 2012 were included.

Group 2 (Unexposed): Mothers whose children did not receive a diagnosis of FASD: Women whose children did not receive an FASD diagnosis from the MB FASD Centre, with no record of prenatal alcohol, whose children had no evidence of FASD from the Repository were matched to the exposed group of women on month of birth of the index child, socioeconomic status, and region of residence. Matching was done at a ratio of 3 unexposed women for 1 woman in our exposed group. To decrease the likelihood that the comparison women had children with undiagnosed FASD the following exclusion criteria were used: (1) women with any children assessed at the Manitoba FASD Centre; (2) women with children who had a diagnosis of FASD as recorded in hospital or physician claims data using the following ICD codes: a hospital visit with ICD 9CM code 760.71, ICD 10CCA code of 86.0 or a physician visit

with any ICD 9 code 760; (3) women who had children who had prescriptions for psychostimulants or risperidone; (4) women with children diagnosed with ADHD (due to high comorbidity of FASD and ADHD diagnoses [27,28]; (5) women involved in the InSight Mentoring program (a program that provides support for women with alcohol and substance abuse issues); (6) women with a history of substance abuse disorder (including alcohol) during pregnancy as indicated by the physician and hospital claims; (7) women whose newborn risk screen indicated they had used alcohol during pregnancy; and, (8) women whose children received special education funding indicating they had severe to profound disabilities.

Outcome Variables: The number and timing of PNC visits was estimated from hospital discharge abstracts and physician claims files. Medical claims files were used to identify PNC visits. Other forms of prenatal health services were not included such as attendance at community prenatal classes or Community Support Programs. Pregnancy trimesters were defined as: first - date of conception to 91 days; second - 92-189 days, and; third - 190 days to date of birth. The date of conception was calculated by subtracting the gestational age from the birthdate of the child. The following outcomes were calculated to investigate PNC utilization: (1) no care; (2) late initiation of PNC; (3) care initialized in 1st trimester; (4) care initialized in 2nd trimester; (5) care initialized in 3rd trimester; (6) low number of prenatal visits; (7) adequacy of PNC (See Table 2 for definitions of all outcomes).

Adequacy of PNC was assessed using the Revised Graduated Index of Prenatal Care Utilization (R-GINDEX), a validated and commonly used index to measure utilization of PNC[29]. The following three variables were required to utilize this index and were obtained from hospital and

physician records: (1) gestational age of newborn; (2) trimester that PNC began; (3) total number of prenatal visits during pregnancy. The R-GINDEX has six categories of care including: "no care", "inadequate care", "intermediate care", "adequate care", "intensive care" and "missing". This index is based on the full American College of Obstetricians and Gynaecologist's guidelines and has been utilized by various studies to evaluate PNC throughout North America[16,17,29,30]. To investigate characteristics of women who gave birth to a child(ren) with FASD and who had inadequate PNC we conducted a sub-analysis on our exposed women who had an R-GINDEX rating of inadequate or no PNC compared to women who had adequate, intensive or intermediate care.

Data Analysis: Adjusted relative rates (aRRs) of PNC utilization were modeled using generalized linear models (GLM) with a Poisson distribution, which is suitable for non-normally distributed data such as counts. All analysis tested for differences between groups and adjusted for covariates. Decisions regarding which covariates to exclude from the models were determined by frequency distributions and tests of significance. The following variables were included as covariates in each of the models: age of mother at birth of child, region of residence, receipt of income assistance and SES. SES was defined using area-level mean household income from census information and grouped into quintiles ranked from 1 (low) to 5 (high), , with approximately 20% of the population assigned to each quintile.[31]

A summary dataset for the total number of events (e.g. total number of mothers with inadequate PNC) was produced to model the rate of PNC utilization comparing the exposed and comparison groups. In a sub-analysis, Pearson's Chi-square tests ($p < 0.05$) were used to determine if there were significant differences in characteristics of exposed women who had received inadequate or

no prenatal care versus exposed women who had received other care (intermediate, adequate, intensive).

Results:

Our study groups consisted of women who were born from 1946 to 1992 with ages ranging from 14 to 46 years (Table 3). The majority of women were from an urban location. The groups were similar in age distribution, however, compared to the unexposed group, women with children with FASD tended to be slightly younger (mean age 24 versus 29, respectively). Exposed group women were also more likely to be lone parents, lower SES, with higher gravity, parity, and more mental disorders, physical disorders, and child and family services and justice system involvement compared to the unexposed group (see Table 3).

Prenatal Care Utilization: Twenty-eight percent of the exposed group had inadequate PNC, and 6% had no PNC versus only 14% and 2% of our comparison group, respectively. When adjusting for maternal age, region of residence, receipt of income assistance and SES, our exposed group had over one and a half times the rate of inadequate PNC (aRR = 1.65, 95% CI = 1.34, 2.03), and over 2 times the rate of no PNC versus our comparison group (aRR = 2.29, CI = 1.45, 3.62). Women in our exposed group also had higher rates of: PNC that was initiated in the 2nd trimester (aRR = 1.68, CI = 1.34, 2.08); late initiation of care (aRR = 1.66, CI =1.39, 1.98); low number of prenatal visits (aRR = 3.05, CI = 2.50, 3.72); intermediate PNC (aRR = 1.39, CI = 1.07, 1.65), and; inadequate/no PNC (aRR = 1.77, CI = 1.34, 2.03). Women in our exposed group had lower rates of adequate (aRR = 0.71, CI = 0.55, 0.93) and intensive PNC (aRR = 0.39, CI = 0.32, 0.44).

Characteristics of women who have given birth to children with FASD and who have inadequate or no PNC: There were no significant differences in demographic characteristics between women who had inadequate or no PNC versus women who received other types of PNC using bivariate analyses (Table 5), therefore no further multivariate analysis was conducted. There was a significant association between women diagnosed with a physical health condition or with prenatal psychological distress; women diagnosed with these disorders obtained more adequate levels of care versus those who were not already connected with the health care system.

Interpretation

The results of this study demonstrate that a substantial portion of women who give birth to children with FASD receive inadequate PNC. We found that over a third (35%) of women in our exposed group were ranked as having inadequate or no PNC at all, compared to just over 16% of women in our comparison group. In contrast, less than a third (29.8%) of our exposed group received adequate or intensive PNC, compared to two-thirds (66.2%) of our comparison group. Even when we adjusted for a number of factors that could contribute to use of PNC, large differences remained between women who gave birth to a child with FASD compared to those who did not.

Our results are consistent with the few previous studies in this area. Three studies have found that women who give birth to children with FASD receive less PNC compared to women in the general population, and generally begin PNC later in their pregnancy (Astley, Bailey, Talbot, & Clarren, 2000b; Coyne et al., 2008; Kvigne et al., 2003; Kvigne et al., 2008). However, these studies relied on self-report data, utilized small sample sizes, and were not conducted in Canada,

which precludes generalization to Canadian policy makers. The results of this study indicate the need for increased education of women of childbearing age with alcohol use and dependence issues about the importance of PNC.

While we were not able to identify specific characteristics associated with inadequate or no PNC among women who give birth to children with FASD, several reasons have been identified in the literature as to why women do not access PNC[32,33]. Patient issues include feeling stigmatized by drug and alcohol use and dependence[34,35], depression and mental disorders[35], or having negative attitudes towards PNC[34,36], or believing it unnecessary[34,36]. Women also identify lack of transportation to get to appointments, lack of child care and long waiting times as barriers to care[32,35-37]. Additional barriers include not having a regular health care provider before pregnancy, and negative attitudes of health care providers[36]. Future work should be done utilizing larger samples to investigate whether there are additional characteristics associated with inadequate or no PNC among women who give birth to children with FASD.

While we have identified an increased risk in obtaining inadequate PNC for women who give birth to children with FASD, 55% of women who have given birth to a child with FASD are indeed receiving adequate, intensive or intermediate PNC and consume heavy amounts of alcohol throughout their pregnancy. The results of this study therefore also identify that PNC may be a *missed opportunity for the prevention of FASD and drinking during pregnancy*. Research has demonstrated the effectiveness that brief intervention programs have had in primary care settings on reducing risky alcohol use[38]. These intervention strategies may be

effective in PNC settings as well and could help reduce the incidence of prenatal alcohol exposure and ultimately FASD.

Our study results indicate the need for further work that: (1) evaluates existing approaches and knowledge of PNC physicians regarding the screening, identifying, and treating of women at risk for alcohol consumption during pregnancy; (2) improves training of physicians providing PNC in screening for and management of at-risk drinking and alcohol use disorders during pregnancy; (3) develops community linkages with physicians providing PNC to ensure that women with alcohol use disorders receive addictions treatment and have access to appropriate community support programs; (4) highlights the importance of physicians delivering PNC to emphasize the detrimental consequences of alcohol consumption during pregnancy.

Strengths and Limitations: Studies investigating use of health care services among women with alcohol use and dependence commonly collect data from self-report surveys, which introduce non-response, recall, and interviewer bias. By utilizing administrative health data we have eliminated these sources of bias. Furthermore by utilizing clinical data from the Manitoba FASD Centre we have ensured that our case group comprises women whose children have undergone an accurate and comprehensive multidisciplinary assessment in a central tertiary-level provincial diagnostic clinic which follows the Canadian guidelines for the diagnosis of FASD[2]. However, the use of this sample is also a limitation as the use of a clinically referred FASD sample limits generalizability of findings, as women whose children are not referred to the clinic for assessment will be missed. Furthermore, while we have taken great care in excluding all mothers with possible prenatal alcohol exposure and children with a diagnosis of FASD, we

cannot be certain that there are no women in our comparison group that do not have un-reported prenatal alcohol use or undiagnosed children with FASD. However, this would serve to weaken rather than strengthen our findings. Additionally, the number and timing of PNC visits was estimated from administrative claims files, and as in all studies utilizing administrative databases, these estimates rely on the accuracy of physician coding. There may be missing PNC records in hospital or physician charts and healthcare providers who do not submit claims for PNC may be missed. However, MCHP data have been extensively validated for conducting this type of research[17,20,21,23-26].

Conclusion: Although women who give birth to children with FASD are at greater risk for inadequate PNC, a sizeable percentage of these women received adequate PNC and yet continued to consume alcohol during pregnancy. Further work must be done to: 1) uncover barriers and facilitators to accessing PNC for women with alcohol use and dependence issues. And; 2) evaluate current knowledge and practice of PNC providers regarding screening and preventing alcohol use during pregnancy in order to utilize PNC as an effective vehicle for the prevention of alcohol exposed pregnancies.

References

1. Walker MJ, Al-Sahab B, Islam F, Tamim H. The epidemiology of alcohol utilization during pregnancy: an analysis of the Canadian Maternity Experiences Survey (MES). *BMC pregnancy and childbirth.* 2011;11:52.
2. Chudley AE, Conry J, Cook JL, Loock C, Rosales T, LeBlanc N. Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis. *CMAJ : Canadian Medical Association journal = journal de l'Association medicale canadienne.* 2005;172:S1-S21.
3. Burd L, Cotsonas-Hassler TM, Martsolf JT, Kerbeshian J. Recognition and management of fetal alcohol syndrome. *Neurotoxicology and teratology.* 2003;25:681-8.
4. Pei J, Job J, Kully-Martens K, Rasmussen C. Executive function and memory in children with Fetal Alcohol Spectrum Disorder. *Child neuropsychology : a journal on normal and abnormal development in childhood and adolescence.* 2011;17:290-309.
5. May PA, Baete A, Russo J, et al. Prevalence and characteristics of fetal alcohol spectrum disorders. *Pediatrics.* 2014;134:855-66.
6. Astley SJ. Profile of the first 1,400 patients receiving diagnostic evaluations for fetal alcohol spectrum disorder at the Washington State Fetal Alcohol Syndrome Diagnostic & Prevention Network. *The Canadian journal of clinical pharmacology = Journal canadien de pharmacologie clinique.* 2010;17:e132-64.
7. Harris KR, Bucens IK. Prevalence of fetal alcohol syndrome in the Top End of the Northern Territory. *Journal of paediatrics and child health.* 2003;39:528-33.
8. Kowlessar D. *An examination of the effects of prenatal alcohol exposure on school-age children in Manitoba first nation community: A study of fetal alcohol syndrome prevalence and dysmorphology*. Winnipeg, Manitoba, Canada: Department of Human Genetics, University of Manitoba; 1997.
9. May PA, Blankenship J, Marais AS, et al. Approaching the prevalence of the full spectrum of fetal alcohol spectrum disorders in a South African population-based study. *Alcoholism, clinical and experimental research.* 2013;37:818-30.
10. May PA, Fiorentino D, Coriale G, et al. Prevalence of children with severe fetal alcohol spectrum disorders in communities near Rome, Italy: new estimated rates are higher than previous estimates. *International journal of environmental research and public health.* 2011;8:2331-51.
11. May PA, Fiorentino D, Phillip Gossage J, et al. Epidemiology of FASD in a province in Italy: Prevalence and characteristics of children in a random sample of schools. *Alcoholism, clinical and experimental research.* 2006;30:1562-75.
12. May PA, Gossage JP, Kalberg WO, et al. Prevalence and epidemiologic characteristics of FASD from various research methods with an emphasis on recent in-school studies. *Developmental disabilities research reviews.* 2009;15:176-92.
13. May PA, Gossage JP, Marais AS, et al. The epidemiology of fetal alcohol syndrome and partial FAS in a South African community. *Drug and alcohol dependence.* 2007;88:259-71.
14. Robinson GC, Conry JL, Conry RF. Clinical profile and prevalence of fetal alcohol syndrome in an isolated community in British Columbia. *CMAJ : Canadian Medical Association journal = journal de l'Association medicale canadienne.* 1987;137:203-7.

15. Williams RJ, Odaibo FS, McGee JM. Incidence of fetal alcohol syndrome in northeastern Manitoba. *Canadian journal of public health. Revue canadienne de sante publique.* 1999;90:192-4.
16. Alexander GR, Kotelchuck M. Assessing the role and effectiveness of prenatal care: history, challenges, and directions for future research. *Public health reports (Washington, D.C. : 1974).* 2001;116:306-16.
17. Heaman MI, Newburn-Cook CV, Green CG, Elliott LJ, Helewa ME. Inadequate prenatal care and its association with adverse pregnancy outcomes: a comparison of indices. *BMC pregnancy and childbirth.* 2008;8:15.
18. 2010 UDoHaHSHP. *Maternal, Infant, and Child Health*2000.
19. Canada SoOaGo. *SOGC Clinical Practice Guidelines: Healthy Beginnings: Guidelines for care during pregnancy and childbirth.* Ottawa: SOGC;1998.
20. Brownell MD, Roos NP, Roos LL. Monitoring health reform: a report card approach. *Social science & medicine (1982).* 2001;52:657-70.
21. Jutte DP, Roos LL, Brownell MD. Administrative record linkage as a tool for public health research. *Annual review of public health.* 2011;32:91-108.
22. Robinson JR, Young TK, Roos LL, Gelskey DE. Estimating the burden of disease. Comparing administrative data and self-reports. *Medical care.* 1997;35:932-47.
23. Roos LL, Gupta S, Soodeen RA, Jebamani L. Data quality in an information-rich environment: Canada as an example. *Canadian journal on aging = La revue canadienne du vieillissement.* 2005;24 Suppl 1:153-70.
24. Roos LL, Menec V, Currie RJ. Policy analysis in an information-rich environment. *Social science & medicine (1982).* 2004;58:2231-41.
25. Roos LL, Nicol JP. A research registry: uses, development, and accuracy. *Journal of clinical epidemiology.* 1999;52:39-47.
26. Roos LL, Jr., Nicol JP, Cageorge SM. Using administrative data for longitudinal research: comparisons with primary data collection. *Journal of chronic diseases.* 1987;40:41-9.
27. Burger PH, Goecke TW, Fasching PA, et al. [How does maternal alcohol consumption during pregnancy affect the development of attention deficit/hyperactivity syndrome in the child]. *Fortschritte der Neurologie-Psychiatrie.* 2011;79:500-6.
28. Infante MA, Moore EM, Nguyen TT, Fourligas N, Mattson SN, Riley EP. Objective assessment of ADHD core symptoms in children with heavy prenatal alcohol exposure. *Physiology & behavior.* 2014.
29. Alexander GR, Kotelchuck M. Quantifying the adequacy of prenatal care: a comparison of indices. *Public health reports (Washington, D.C. : 1974).* 1996;111:408-18; discussion 19.
30. Tayebi T, Hamzehgardeshi Z, Ahmad Shirvani M, Dayhimi M, Danesh M. Relationship between Revised Graduated Index (R-GINDEX) of prenatal care utilization & preterm labor and low birth weight. *Global journal of health science.* 2014;6:131-7.
31. *Profile of the population, 2001 Census.* ottawa (ON): Statistics Canada Data Liberation Initiative Table Name 95F0495XCB01002-Man.ivt.;2003.
32. Feijen-de Jong EI, Jansen DE, Baarveld F, van der Schans CP, Schellevis FG, Reijneveld SA. Determinants of late and/or inadequate use of prenatal healthcare in high-income countries: a systematic review. *European journal of public health.* 2012;22:904-13.

33. Heaman MI, Moffatt M, Elliott L, et al. Barriers, motivators and facilitators related to prenatal care utilization among inner-city women in Winnipeg, Canada: a case-control study. *BMC pregnancy and childbirth.* 2014;14:227.
34. Friedman SH, Heneghan A, Rosenthal M. Characteristics of women who do not seek prenatal care and implications for prevention. *Journal of obstetric, gynecologic, and neonatal nursing : JOGNN / NAACOG.* 2009;38:174-81.
35. Grella CE. Services for perinatal women with substance abuse and mental health disorders: the unmet need. *Journal of psychoactive drugs.* 1997;29:67-78.
36. Phillippi JC. Women's perceptions of access to prenatal care in the United States: a literature review. *Journal of midwifery & women's health.* 2009;54:219-25.
37. Beckmann CA, Buford TA, Witt JB. Perceived barriers to prenatal care services. *MCN. The American journal of maternal child nursing.* 2000;25:43-6.
38. Moyer A, Finney JW. Brief interventions for alcohol misuse. *CMAJ : Canadian Medical Association journal = journal de l'Association medicale canadienne.* 2015;187:502-6.

Table 1: Description of datasets used for analysis

Name of Dataset	Description of Dataset	Years of Data Used	Information retrieved
Population Registry	A registry maintained by Manitoba Health of all Manitobans eligible to receive health services since 1970 and includes demographic information and 6-digit residential postal code.	1970/71 to June 2013	Demographic information: region of residence
Canada Census Information	Social data based on the Statistics Canada Population Census. These data were used to determine area-level income, with Manitoba population divided into income quintiles according to average-level household income, composed of five possible income groupings with Q1 being the lowest and Q5 being the highest income quintile.	1996, 2001, 2006, 2013	Socioeconomic status information
Employment and Income Assistance Data	Data maintained by Department of Families that provide information on Manitoba residences who receive provincial employment and income Assistance.	1995/96 to 2012/2013	Receipt of income assistance
Babies First/Families First Screening Program data	Newborn risk screen data collected as part of a home visiting program conducted by Healthy Child Manitoba. The screen is filled out by Public Health Nurses on all families with newborns in Manitoba and captures data on biological, social and demographic risk factors and alcohol use during pregnancy.	2003 to 2013 = Families First 2000 to 2002 = Baby First	Alcohol and drug use during pregnancy Social isolation
Insight Program data	Includes data from an outreach program where mentors provide intensive support to women who are pregnant or have recently had a baby and use substances. This dataset includes information on women who have prenatal alcohol use	1999 to 2012/2013	Alcohol and substance use during pregnancy
Hospital Abstracts	Health data maintained by Manitoba Health consisting of all hospitalizations in Manitoba, including up to 16 ICD-9-CM diagnostic codes for discharges before April 1, 2004 and up to 25 ICD-10-CM diagnostic codes for discharges on or after April 1, 2004.	1984 to 2012/13	Physical and mental health diagnoses Antenatal hospitalizations Suicide attempts
Medical/Physician reimbursement claims	Health data maintained by Manitoba Health consisting of all ambulatory physician visits in Manitoba and include a single ICD-9 diagnostic code associated with each visit, coded to the third digit.	1984 to 2012/13	Physical and mental health diagnoses Physician visits Prenatal care
Prescription claims data: Drug Programs Information Network	Data maintained by Manitoba Health containing all prescription drug claims from the Drug Programs Information Network (DPIN, an electronic, on-line, point-of –sale prescription drug database that connects Manitoba Health and all pharmacies in Manitoba). Contains information on all prescription drugs dispensed in Manitoba.	1995/96 to 2012/13	Physical and mental health conditions
Manitoba FASD Centre data	Includes clinical assessments and diagnoses received under the FASD umbrella for all children referred to the MB FASD Centre	1999 to 2012/2013	FASD diagnosis Children diagnosed with FASD
Vital Statistics data	A longitudinal population-based registry maintained by Manitoba's Vital Statistics Agency that includes all Manitobans who have died since January 1970 to present and the cause of death.	1970 to 2012/2013	Cause of premature death Suicide completion
Education data: Enrolment, Marks and Assessments	Education data maintained by the Department of Education and Training that provides information on enrolment, marks, and high school completion, and special funding. Special education funding is provided to children with severe to profound disabilities.	1995/96 to 2012/2013	High school completion, level of special education funding
Child and Family Services Information System (CFSIS)	A data management system that supports case tracking and reporting of services provided to children and families as they pass through the Manitoba Child and Family services (CFS) System. This database includes information on children in care as well as information of families receiving protective and support services.	1992/1993 to 2012/2013	Involvement with child and family services

Table 2: Definitions of outcomes used to compare prenatal health care (PNC) utilization among women whose child(ren) have a diagnosis of FASD and women whose child(ren) do not have FASD

Outcome Measure	Definition
Late initiation of PNC	A woman was considered to have late initiation of prenatal care if her prenatal care began after the first trimester (date of conception to 91 days).
No care	A woman was considered to have no prenatal care if no prenatal care was initiated in the first, second, or third trimester.
Care initialized in first trimester	A women was considered to have care initialized in the first trimester if her first prenatal visits was in the first trimester (date of conception to 91 days).
Care initialized in 2nd trimester	A women was considered to have care initialized in the 2nd trimester if her first prenatal visits was in the second trimester (92-189 days).
Care initialized in 3rd trimester	A women was considered to have care initialized in the 3rd trimester if her first prenatal visits was in the third trimester (190 days to date of birth).
Low number of prenatal visits	A women was considered to have a low number of prenatal visits if she had less than five prenatal care visits prior to delivery.
Inadequate or no PNC	The proportion of women with no or inadequate prenatal care was determined using the R-GINDEX.
Quality of pre-natal care by the R-GINDEX	The Revised-Graduated Prenatal Care Utilization Index is a measure of the adequacy of prenatal care by a health care provider which identified six major categories of prenatal care: inadequate prenatal care, intermediate prenatal care, adequate prenatal care, intensive care, no care and missing information. Knowledge of three birth-related outcomes are required to calculate R-GINDEX: 1) the gestational age of the infant (date of pregnancy and birth) as calculated from the hospital abstract; 2) the trimester during which prenatal care began, using hospital abstracts and physician claims data. The ICD-9-CM tariffs that were included are: 8400, 8401, 8501, 8507, 8509, 8529, 8540, 8550; 3) the total number of prenatal visits during pregnancy as calculated from the hospital abstract and physician claims.
Inadequate PNC	The proportion of women with inadequate prenatal care was determined using the R-GINDEX.
Intermediate PNC	The proportion of women with intermediate prenatal care was determined using the R-GINDEX.
Adequate PNC	The proportion of women with adequate prenatal care was determined using the R-GINDEX.
Intensive PNC	The proportion of women with inadequate prenatal care was determined using the R-GINDEX. Women whose number of visits is approximately one standard deviation about the mean number of visits for each trimester of initiation and the gestational age at delivery were labelled as intensive care users. These women have an unexpectedly large number of PNC visits, which may indicate potential morbidity or complications.
No care	The proportion of women with no prenatal care was determined using the R-GINDEX. care initiated in any trimester
Missing information	The proportion of women with inadequate prenatal care was determined using the R-GINDEX. gest < 24 weeks and care began in trimester three Gest age <11 and care began in trimester 2 And no care initiated in any trimester – no visits If gestation age missing

Table 3: Characteristics of women whose children are diagnosed with FASD and a matched sample of women whose children do not have FASD

Characteristic	Exposed Cases N = 719	Comparison Group N = 2107
Maternal age at birth of index child		
Mean year, (SD)	24.59 (6.15)	29.24 (5.69)
Range	14 - 43	14 - 46
Maternal age at birth of index child		
< 18 years	75 (10.43)	26 (1.23)
18-24 years	330 (45.90)	442 (20.98)
25- 29 years	152 (21.14)	612 (29.05)
30-34 years	105 (14.60)	630 (29.90)
35 + and missing[1]	57 (7.79)	397 (18.84)
Missing	< s[2]	0
Maternal Age at first birth		
< 18 years	253 (35.19)	183 (8.96)
18-24 years	350 (48.68)	854 (40.53)
25- 29 years	62 (8.62)	585 (27.76)
30-34 years	34 (4.73)	324 (15.38)
35 + and missing[1]	20 (2.78)	161 (7.64)
Missing	< s[2]	0
History of teen pregnancy	253 (35.24)	183 (8.96)
Region of residence		
Rural	253 (35.19)	767 (36.40)
Urban	458 (63.69)	1340 (63.60)
Missing	8 (1.11)	0
Mean household income		
Q1	464 (64.53)	1392 (66.07)
Q2	106 (14.74)	310 (14.71)
Q3	59 (8.21)	166 (7.88)
Q4	39 (5.42)	117 (5.55)
Q5	33 (4.59)	96 (4.56)
Missing	18 (2.50)	26 (1.32)
Receipt of Income assistance five years before birth of the index child	218 (30.32)	41 (1.95)
SES		
Low (Q1)	464 (64.53)	1392 (66.07)
Middle (Q2 & Q3)	165 (22.95)	476 (22.59)
High (Q4 & Q5)	72 (10.01)	213 (10.11)
Missing	18 (2.50)	26 (1.23)
Married at the birth of child	69 (5.49)	1143 (90.93)
Gravidity		
0-3	354 (49.24)	1469 (69.72)
=>4	299 (41.59)	622 (29.52)
Missing	66 (9.18)	16 (0.76)
Parity		
0-3	347 (48.26)	1456 (69.10)
=>4	130 (10.08)	177 (8.40)
Missing	242 (33.66)	474 (22.50)
Involvement with child and family services five years before the birth of the child[3]	289 (40.19)	160 (7.59)
Diagnosis of psychiatric disorder five years before the birth of the child	597 (83.03)	1170 (55.52)
Substance abuse[4]	207 (28.79)	65 (3.08)
Personality Disorder[4]	21 (2.92)	15 (0.71)
Mood & Anxiety Disorder[4]	290 (40.33)	577 (27.38)
Schizophrenia[4]	< s[2]	7 (0.33)
Prenatal psychological distress[5]	540 (75.10)	1082 (51.35)
Postnatal psychological distress[6]	536 (74.55)	1074 (50.97)

[1] Number of missing women was < 6, therefore the number of missing women was combined with the "over 35 age group" to ensure privacy rules of MCHP data were adhered to.
[2]Crude rate suppressed if n<6
[3] Includes voluntary or involuntary involvement with child and family services of any children of the mother or the mother herself (if she was under the age of 18 at the time), including any support services or out of home placements.
[4]Diagnosis three years before the birth of the child
[5] Diagnosis 8 months before the birth of the child
[6] Diagnosis 12 months after the birth of the child

Table 4: Health care system use and prenatal care (PNC) of women who have given birth to a child with FASD compared to women who have not given birth to a child with FASD

	Study Cohort Crude Rate (%)		Adjusted RR (95% CI)
Outcome	**Women who gave birth to a child with FASD N = 719**	**Women who did not give birth to a child with FASD N = 2107**	**Women who gave birth to a child with FASD versus women who did not give birth to a child with FASD**
Trimester care was initiated			
First trimester	370 (51.46%)	1638 (77.74%)	**0.64 (0.56, 0.74)**
2nd trimester	176 (24.48%)	280 (13.29%)	**1.68 (1.34, 2.08)**
3rd trimester	50 (6.95%)	102 (4.84%)	1.21 (0.82, 1.79)
No care initiated[1]	45 (6.26%)	50 (2.37%)	**2.36 (1.50, 3.72)**
Missing information[2]	78 (10.85%)	37 (1.76%)	N/A
Late initiation of PNC	271 (42.28%)	432 (20.87%)	**1.66 (1.39, 1.98)**
Low number of PNC	253 (35.19%)	243 (11.53%)	**3.05 (2.50, 3.72)**
Quality of PNC care by the R-GINDEX			
Inadequate PNC	203 (28.23%)	296 (14.05%)	**1.65 (1.34, 2.03)**
Intermediate PNC	179 (24.90%)	329 (15.61)	**1.39 (1.07, 1.65)**
Adequate PNC	94 (13.07%)	389 (18.46%)	**0.71 (0.55, 0.93)**
Intensive PNC	120 (16.69%)	1006 (47.75%)	**0.39 (0.32,0.44)**
No care[1]	45 (6.26%)	50 (2.37%)	**2.29 (1.45, 3.62)**
Missing information[2]	78 (10.85%)	37 (1.76%)	N/A
Inadequate or no PNC[3]	248 (34.49%)	346 (16.42%)	**1.77 (1.34, 2.03)**

Note: Adjusted for: SES, receipt of income assistance, region of residence, age at birth of index child

[1]For women who we had gestational age

[2]Women who we did not have gestational age

[3]As defined from the R-GINDEX

Table 5: Characteristics of women who gave birth to a child with FASD who had inadequate/no prenatal care (PNC) versus women who gave birth to a child with FASD who had intermediate/adequate/intensive prenatal care

Characteristic	Women who gave birth to a child with FASD and had inadequate/no PNC N = 248	Women who gave birth to a child with FASD and had intermediate/adequate/ intensive PNC N = 393	P-value
Maternal age at birth of index child			
Mean year, (SD)	23.60 (5.59)	24.41 (5.59)	0.08
Range	14.00-41.00	14-41.00	
Maternal age at birth of index child			
< 18 years	25 (10.08%)	46 (11.70%)	
18-24 years	133 (53.63%)	178 (45.29%)	0.06
25- 29 years	53 (21.37%)	78 (19.85%)	
30-34 years	23 (9.27%)	65 (16.54%)	
35 + or missing[1]	14 (5.64%)	26 (6.62%)	
History of teen pregnancy	104 (42.11%)	239 (35.37)	0.09
Region of residence			
Rural or missing[1]	96 (40.32%)	125 (31.80%)	0.08
Urban	148 (59.68%)	268 (68.19%)	
Receipt of Income assistance five years before birth of the index child	71 (28.63%)	140 (35.62%)	0.07
SES			
Low (Q1)	170 (68.55%)	264 (67.18%)	0.20
Middle (Q2 & Q3)	55 (22.18%)	83 (21.12%)	
High (Q4 & Q5)	14 (5.65%)	38(9.67%)	
Missing	9 (3.63%)	8 (2.04%)	
Married at the birth of child	25 (10.08%)	43 (10.97%)	0.72
Gravidity			
0-3	125 (50.40%)	223 (56.74%)	0.29
4-9	115 (46.37%)	158 (40.20%)	
10-14 or missing[1]	8 (3.22%)	11 (2.80%)	
Parity			
0-3	141 (40.63%)	200 (57.64%)	0.96
>4	53 (21.78%)	73 (18.57%)	
Missing	54 (21.77%)	120 (30.53%)	
Involvement of child and family services 5 years before the birth of the child	89 (35.89%)	157 (39.95%)	0.30
Justice system involvement before birth	38 (15.32%)	48 (12.21%)	0.26
Mental disorder before birth of the child[2]	201 (81.05%)	339 (86.26%)	0.08
Prenatal psychological distress	176 (70.97%)	310 (78.88%)	**0.02**
Substance use disorder	73 (29.44%)	126 (32.06%)	0.48
Presence of a physical health condition[3] (diabetes, hypertension, total respiratory disease)	33 (13.31%)	83 (21.12%)	**0.01**

[1] Number of missing women was < 6, therefore the number of missing women was combined to ensure privacy rules of MCHP data were adhered to.
[2] Mental health disorder includes the following diagnoses: substance abuse disorder, prenatal psychological distress, personality disorder, mood and anxiety disorder, schizophrenia
[3] Physical health condition includes the following diagnoses: diabetes, hypertension, total respiratory disease