Postpartum Acute Care Utilization Among Women with Intellectual and Developmental Disabilities

Hilary K. Brown, PhD1–3 Virginie Cobigo, PhD, C.Psych.,3,4 Yona Lunsky, PhD, C.Psych.,2,3,5 and Simone Vigod, MD, MSc, FRCPC1–3

Abstract

Background: Women with intellectual and developmental disabilities have high rates of pregnancy complications. However, their postpartum health is largely unknown. We compared risks for postpartum hospital admissions and emergency department visits among women with and without intellectual and developmental disabilities. 

Methods: We conducted a population-based study using linked Ontario (Canada) health and social services administrative data to identify singleton live births to women with (N=3,803) and without intellectual and developmental disabilities (N=378,313) (2002–2012). Outcomes were hospital admissions and emergency department visits in the 42 days following delivery discharge. We classified these as medical or psychiatric depending on the recorded primary discharge diagnosis. 

Results: Women with intellectual and developmental disabilities, compared to those without, had increased risk for postpartum hospital admissions overall (2.4% vs. 1.2%; adjusted hazard ratios [aHR]: 1.76, 95% confidence interval [CI]: 1.43–2.17) and for psychiatric reasons (0.8% vs. 0.1%; aHR: 10.46, 95% CI: 6.96–15.70), but not for medical reasons. They also had increased risk for postpartum emergency department visits overall (16.6% vs. 7.9%; aHR: 1.85, 95% CI: 1.71–2.01) and for both medical (15.8% vs. 7.8%; aHR: 1.80, 95% CI: 1.66–1.96) and psychiatric reasons (1.3% vs. 0.1%; aHR: 5.66, 95% CI: 4.17–7.69). 

Conclusions: High rates of postpartum hospital admissions and emergency department visits among women with intellectual and developmental disabilities demonstrate that this group may be vulnerable to acute complications or inadequate preventive care after childbirth. Providing enhanced health services during the postpartum period, in the form of longer or more frequent visits or specialized supports, could optimize their outcomes following delivery. 

Keywords: epidemiology, health disparities, postpartum

Introduction

Intellectual and developmental disabilities are neurodevelopmental disorders that are characterized by cognitive and adaptive limitations1 and that affect 1 in every 100 adults. Examples are autism, fetal alcohol syndrome, and Down syndrome. Historically, institutionalization and involuntary sterilization limited childbearing among women with intellectual and developmental disabilities. However, these practices are no longer common in most industrialized countries. Therefore, reproductive health is becoming an increasingly important issue for this population. In fact, the fertility rate of young women with intellectual and developmental disabilities is now comparable to that of young women without intellectual and developmental disabilities. Women with intellectual and developmental disabilities experience multiple social and health disparities, including high rates of poverty, chronic medical conditions, mental illness, and substance-related disorders. Emerging evidence suggests that they are at increased risk for serious pregnancy complications (e.g., preeclampsia/eclampsia, venous thromboembolism, stillbirth, preterm birth). Moreover, we recently showed that more than half of pregnant women with intellectual and developmental disabilities have a co-occurring

1Women’s College Research Institute, Women’s College Hospital, Toronto, Canada. 
2Department of Psychiatry, University of Toronto, Toronto, Canada. 
3Institute for Clinical Evaluative Sciences, Toronto, Canada. 
4School of Psychology, University of Ottawa, Ottawa, Canada. 
5Centre for Addiction and Mental Health, Toronto, Canada.
mental illness. Although these pre-existing and pregnancy-related issues could put women with intellectual and developmental disabilities at increased risk for postpartum complications, their medical and psychiatric health following delivery is largely unknown. The postpartum period is a time of significant physiological and psychological change for new mothers. Maternal hospital admissions and emergency department visits following delivery discharge are indicators of serious postpartum morbidity and are associated with high economic cost, family burden, and interruption of early parenting.

Our objective was to compare the risks for postpartum medical and psychiatric hospital admissions and emergency department visits among women with and without intellectual and developmental disabilities.

Materials and Methods

Study design and setting

This was a population-based study conducted in Ontario, Canada. Ontario has over 13 million residents and ~140,000 births per year. In Ontario, over 98% of deliveries, including those attended by a midwife, occur in hospital. All prenatal, delivery, and postpartum care provided in or outside of hospital by physicians and midwives is delivered at no cost to the patient. The current study period covered live births with an estimated date of conception between April 1, 2002 and March 31, 2012.

Data sources

Our data were obtained from the Institute for Clinical Evaluative Sciences, a nonprofit, independent organization that holds databases containing administrative, sociodemographic, and clinical data gathered routinely through healthcare encounters of Ontario residents. Person-level data were linked across databases using a unique encoded identifier and were analyzed at the Institute for Clinical Evaluative Sciences. To identify the study groups, we used the Canadian Institute for Health Information Discharge Abstract Database (hospitalizations), the Ontario Mental Health Reporting System (psychiatric hospitalizations), the National Ambulatory Care Reporting System (emergency department visits), and the Ontario Health Insurance Plan database (primary care visits) as well as linked information on Ontario Disability Support Program recipients from the Ontario Ministry of Community and Social Services. We identified live births using the MOMBABY dataset, which is a linked maternal-newborn dataset derived from the Canadian Institute for Health Information Discharge Abstract Database. The outcomes and covariates were derived using the databases described above as well as the Registered Persons Database (maternal date of birth, postal code).

Data abstractors enter information into these databases as part of government-mandated reporting. Standardized diagnostic codes are used to record clinical information. The Canadian Coding Standards for the International Statistical Classification of Diseases and Related Health Problems 10th revision is used for hospital databases, and physician billing claim codes are used for the Ontario Health Insurance Plan database. Rigorous evaluations of Institute for Clinical Evaluative Sciences databases have shown that sociodemographic information, primary diagnostic codes, and physician billing claim codes are reliable and valid.

Study sample

Our study is part of a larger research program that aims to describe the health of all Ontario adults with intellectual and developmental disabilities. Using linked health and social services administrative data, all individuals aged 18 to 64 years with intellectual and developmental disabilities in Ontario were identified as of April 1, 2009. Individuals were classified as having intellectual and developmental disabilities if they had relevant diagnostic codes recorded in health administrative data since database inception (≥2 physician visits or ≥1 emergency department visit or hospitalization since 1992, 2000, and 1988, respectively) or in documentation for the Ontario Disability Support Program. We used a conceptual definition that reflects Ontario legislation and common clinical definitions; diagnoses included pervasive developmental disorders (e.g., autism), fetal alcohol syndrome, and chromosomal or autosomal anomalies. A full list of codes is available in Supplementary Table S1 (Supplementary Data are available online at www.liebertpub.com/jwh). For this study, we identified, among women with intellectual and developmental disabilities aged 18 to 49 years, all singleton live births (≥20 weeks’ gestational age) with a conception date between April 1, 2002 and March 31, 2012 (N = 3,803 births). For comparison, we included a random 20% sample of singleton live births to Ontario women without intellectual and developmental disabilities with a conception date during the study period (N = 378,313 births). The size of the comparison group allowed us to maximize power and limit computing requirements.

Outcomes

Our primary outcomes were (1) hospital admissions and (2) emergency department visits without hospital admission from 0 to 42 days following delivery discharge. When there was more than one hospital admission or emergency department visit, we captured the first encounter for the main analyses. We classified encounters as medical or psychiatric based on the primary discharge diagnosis. Psychiatric encounters included those for the following International Statistical Classification of Diseases and Related Health Problems 10th revision codes: F00.X-F99.X, G30.X, G31.X, and R54.X (i.e., schizophrenia and psychotic disorders, mood disorders, anxiety disorders, behavioral disorders, personality disorders, dementia, and substance-related disorders). We also described the three most common reasons for medical and psychiatric encounters, the total number of medical and psychiatric encounters within 42 days of delivery discharge, and the total number of days spent in hospital within 42 days of delivery discharge.

In secondary analyses, we divided the outcome window into two critical time periods: 0–7 days following delivery discharge (corresponding to the early postpartum period) and 8–42 days following delivery discharge (corresponding to the late postpartum period), as recommended by the World Health Organization.

Covariates

Consistent with conceptual models of postpartum morbidity, we measured the following confounders using validated algorithms where available: maternal age, parity,
neighborhood income quintile and region of residence (based on residential postal code), preexisting diabetes mellitus, chronic hypertension, thyroid disease, epilepsy, and mental illness (including substance-related disorders). To describe health during pregnancy, we measured gestational diabetes, gestational hypertension, preeclampsia/eclampsia, venous thromboembolism, antepartum hemorrhage, other serious obstetric morbidity (i.e., placental infarction, placental abruption, obstetric embolism, uterine rupture, or septic shock), and caesarean section.

**Statistical analyses**

Descriptive analyses of baseline characteristics included frequencies and percentages. Differences between groups were ascertained using standardized differences, which are not affected by sample size. Standardized differences > 0.10 were considered to be clinically meaningful. We ascertained the occurrence of first hospital admission or emergency department visit within 42 days of delivery discharge. We then used Cox proportional hazards models to estimate unadjusted and adjusted hazard ratios (aHR) and 95% confidence intervals (CI), which take into account the timing of the occurrence of first hospital admission or emergency department visit. Due to the inclusion of more than one delivery to the same mother during the study period, we used a robust sandwich covariance matrix estimate to account for clustering. Multivariable models controlled for maternal age, parity, neighborhood income quintile, region of residence, prepregnancy health conditions, and year of delivery. In line with methodological guidelines, variables that could explain the association between maternal disability status and postpartum hospital admissions and emergency department visits (i.e., pregnancy complications and delivery mode) were not included in the main multivariable models. This allowed us to isolate the effect of maternal disability status on the risks for postpartum hospital admissions and emergency department visits while not over-adjusting for its mechanisms. We did, however, add these pathway variables to multivariable models in a second step to test their impact on results. We did not match women with and without intellectual and developmental disabilities on confounders because unadjusted comparisons are useful for clinical and policy planning and because adjusted comparisons enable assessment of the impact of confounding variables on results.

We used SAS 9.2 (SAS Institute Inc., Cary, NC) for the analyses. This study was approved by the institutional review board at the Sunnybrook Health Sciences Centre (Toronto, Canada; Institute for Clinical Evaluative Sciences logged study 2014-0900-522-000).

**Results**

**Baseline characteristics**

During the study period, there were 3,803 live births to 2,539 women with intellectual and developmental disabilities and 378,313 live births to 259,179 women without intellectual and developmental disabilities. Women with intellectual and developmental disabilities were more likely than those without to be less than 20 years of age at delivery (11.6% vs. 2.8%, standardized difference: 0.35),

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Intellectual and developmental disabilities (N = 3,803)</th>
<th>No intellectual and developmental disabilities (N = 378,313)</th>
<th>Standardized difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maternal age</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;20 years</td>
<td>440 (11.6)</td>
<td>10,643 (2.8)</td>
<td>0.35</td>
</tr>
<tr>
<td>≥35 years</td>
<td>467 (12.3)</td>
<td>78,588 (20.8)</td>
<td>-0.23</td>
</tr>
<tr>
<td>Primiparous</td>
<td>1,719 (45.2)</td>
<td>168,023 (44.4)</td>
<td>0.02</td>
</tr>
<tr>
<td>Neighborhood income quintile (Q)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quintile 1 (lowest)</td>
<td>1,502 (39.7)</td>
<td>83,276 (22.1)</td>
<td>0.39</td>
</tr>
<tr>
<td>Quintile 2</td>
<td>868 (23.0)</td>
<td>75,400 (20.0)</td>
<td>0.07</td>
</tr>
<tr>
<td>Quintile 3</td>
<td>618 (16.4)</td>
<td>77,169 (20.5)</td>
<td>-0.11</td>
</tr>
<tr>
<td>Quintile 4</td>
<td>434 (11.5)</td>
<td>78,316 (20.8)</td>
<td>-0.26</td>
</tr>
<tr>
<td>Quintile 5 (highest)</td>
<td>358 (9.5)</td>
<td>62,320 (16.6)</td>
<td>-0.21</td>
</tr>
<tr>
<td>Rural dwelling</td>
<td>541 (14.2)</td>
<td>39,030 (10.3)</td>
<td>0.12</td>
</tr>
<tr>
<td>Preexisting diabetes mellitus</td>
<td>108 (2.8)</td>
<td>5,775 (1.5)</td>
<td>0.09</td>
</tr>
<tr>
<td>Chronic hypertension</td>
<td>98 (2.6)</td>
<td>9,240 (2.4)</td>
<td>0.06</td>
</tr>
<tr>
<td>Thyroid disease</td>
<td>290 (7.6)</td>
<td>29,928 (7.9)</td>
<td>-0.01</td>
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<tr>
<td>Epilepsy</td>
<td>173 (4.6)</td>
<td>2,293 (0.6)</td>
<td>0.27</td>
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<tr>
<td>Mental illness</td>
<td>2,027 (53.3)</td>
<td>108,874 (28.8)</td>
<td>0.50</td>
</tr>
<tr>
<td>Gestational diabetes</td>
<td>122 (3.2)</td>
<td>15,886 (4.2)</td>
<td>-0.05</td>
</tr>
<tr>
<td>Gestational hypertension</td>
<td>60 (1.6)</td>
<td>6,072 (1.6)</td>
<td>0.00</td>
</tr>
<tr>
<td>Preeclampsia/eclampsia</td>
<td>63 (1.7)</td>
<td>3,984 (1.1)</td>
<td>0.37</td>
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<tr>
<td>Venous thromboembolism</td>
<td>42 (1.1)</td>
<td>2,431 (0.6)</td>
<td>0.05</td>
</tr>
<tr>
<td>Antepartum hemorrhage</td>
<td>234 (6.2)</td>
<td>17,315 (4.6)</td>
<td>0.05</td>
</tr>
<tr>
<td>Other serious obstetric morbidity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caesarean section</td>
<td>1,078 (28.4)</td>
<td>103,726 (27.4)</td>
<td>0.02</td>
</tr>
</tbody>
</table>
0.39), and to live in a rural area (<10,000 residents per km²) (14.2% vs. 10.3%, standardized difference: 0.12). They were also more likely to have epilepsy (4.6% vs. 0.6%; standardized difference: 0.27), mental illness (53.3% vs. 28.8%; standardized difference: 0.50), and preeclampsia/eclampsia (1.7% vs. 1.1%; standardized difference: 0.37) (Table 1).

Study outcomes

Women with intellectual and developmental disabilities, compared to those without, had increased risk for postpartum hospital admissions at 0–42 days following delivery discharge in unadjusted and adjusted analyses (2.4% vs. 1.2%; 5.9 vs. 2.8 admissions per 10,000 person-days; aHR: 1.76, 95% CI: 1.43–2.17). Women with and without intellectual and developmental disabilities had similar risks for postpartum hospital admissions for medical reasons, overall (1.6% vs. 1.1%; 3.9 vs. 2.7 admissions per 10,000 person-days; aHR: 1.25, 95% CI: 0.97–1.62) and at 0–7 days (aHR: 1.17, 95% CI: 0.82–1.67) and 8–42 days (aHR: 1.39, 95% CI: 0.99–1.95) following delivery discharge (Fig. 1). The most common reasons for medical hospital admissions at 0–42 days among women with and without intellectual and developmental disabilities were puerperal infection/sepsis, cholelithiasis, and postpartum hemorrhage (Table 2). There were two or more medical hospital admissions among 0.2% of women with and 0.1% of women without intellectual and developmental disabilities; the median total number of days spent in hospital was three for women with and two for women without intellectual and developmental disabilities (Table 2).

Women with intellectual and developmental disabilities, compared to women without, had increased risk for postpartum hospital admissions for psychiatric reasons, overall (0.8% vs. 0.1%; 2.0 vs. 0.2 admissions per 10,000 person-days; aHR: 10.46, 95% CI: 6.96–15.70) and at 0–7 days (Fig. 1). Unadjusted and adjusted hazard ratios for medical and psychiatric hospital admissions among women with and without intellectual and developmental disabilities.

FIG. 1. Unadjusted and adjusted hazard ratios for medical and psychiatric hospital admissions among women with and without intellectual and developmental disabilities.
The most common reasons for psychiatric hospital admissions at 0–42 days among women with and without intellectual and developmental disabilities were schizophrenia/psychosis, postpartum depression, and bipolar disorder (Table 2). The median total number of days spent in hospital was seven for women with and five for women without intellectual and developmental disabilities (Table 2).

Women with intellectual and developmental disabilities, compared to women without, had increased risk for postpartum emergency department visits at 0–42 days following delivery discharge in unadjusted and adjusted analyses (16.6% vs. 7.9%; 44.0 vs. 19.8 visits per 10,000 person-days; aHR: 1.85, 95% CI: 1.71–2.01).

Women with intellectual and developmental disabilities, compared to women without, had increased risk for psychiatric emergency department visits overall (1.3% vs. 0.1%; 3.1 vs. 0.3 visits per 10,000 person-days; aHR: 5.66, 95% CI: 4.17–7.69) following delivery discharge (Fig. 2). The most common reasons for psychiatric emergency department visits among women with and without intellectual and developmental disabilities were postpartum depression, anxiety disorder, and other mood disorders (Table 3). There were two or more psychiatric emergency department visits among 0.2% of women with and 0.01% of women without intellectual and developmental disabilities (Table 3).

In a second step, we added potential pathway variables (i.e., pregnancy complications and delivery mode) to the multivariable models. These variables did not change the results for any of the outcomes examined.

### Discussion

**Summary of findings**

Women with intellectual and developmental disabilities, compared to those without, had nearly double the risk for postpartum hospital admissions overall, driven by a 10-fold higher rate of admissions for psychiatric reasons. The top three reasons for medical and psychiatric admissions were similar in both groups. Women with intellectual and developmental disabilities also had nearly double the risk for postpartum emergency department visits overall, driven by a two-fold higher rate of visits for medical reasons and a seven-fold higher rate of visits for psychiatric reasons. It is important to note that, despite important differences between women with and without intellectual and developmental disabilities, absolute rates of acute care utilization for psychiatric reasons were low in both groups.

**Context of existing literature**

Little is known about postpartum health among women with intellectual and developmental disabilities. Our findings...
build on a Swedish study, which suggested that this population requires ongoing care following delivery, as indicated by high rates of discharge to another facility versus home. We also show that previously observed psychiatric problems during pregnancy among women with intellectual and developmental disabilities extend into the postpartum period. Finally, our results are consistent with literature showing high rates of hospital admissions and emergency department visits among adults with intellectual and developmental disabilities in general. However, ours is the first study to examine these issues in the postpartum period specifically for this population.

Explanation for findings

We hypothesized that women with intellectual and developmental disabilities would have higher rates of postpartum hospital admissions and emergency department visits due to their social and health risk factors. Women with intellectual and developmental disabilities in our cohort were more likely to live in poverty and to have preexisting health problems including epilepsy and mental illness. Their risks for hospital admissions and emergency department visits were somewhat attenuated after controlling for these and other confounders. However, the elevated risks for psychiatric hospital admissions as well as medical and psychiatric emergency department visits remained statistically significant in adjusted analyses. Addition of pregnancy complications and caesarean section to multivariable models did not change results.

It is possible that other factors, unmeasurable in administrative data, explain our findings. Women with intellectual and developmental disabilities are often unable to access appropriate healthcare services; they have difficulty describing their symptoms, and their healthcare providers report feeling unprepared for managing their complex health needs.
medical and social needs. These issues may result in a delay in recognizing postpartum medical or psychiatric concerns in this population, leading to more severe complications than if symptoms were managed effectively earlier. Other factors related to maternal stress may also play a role. Between 40% and 60% of children born to women with intellectual and developmental disabilities are removed by the child welfare system, and studies have shown that many women with intellectual and developmental disabilities experience significant anxiety and distress due to fear of losing their infant following delivery. Even for women with intellectual and developmental disabilities who retain custody of their infant, the postpartum period may be a particularly stressful time as the mother adjusts to her new role and navigates obstetric, pediatric, and social services. High rates of postpartum hospital admissions and emergency department visits in particular among women with intellectual and developmental disabilities could reflect ongoing physical and mental health concerns due to these stressors. It is also possible that the acute care utilization patterns observed in this study are a function of the generally high rates of hospitalizations and emergency department visits among adults with intellectual and developmental disabilities. However, given the increased vulnerability of women who have recently given birth, the trends observed in this study denote the need for particular attention directed to the support of postpartum women with intellectual and developmental disabilities.

### Strengths and limitations

Our cohort of women with intellectual and developmental disabilities is the largest and most comprehensive identified in the literature to date. By using linked health and social services administrative data, we achieved more complete ascertainment of disability status than is possible using health administrative data alone or clinical samples. Nevertheless, there are some limitations that are inherent in the use of administrative data. Although we linked health and social services administrative data to maximize our ascertainment of intellectual and developmental disabilities, some women may have been misclassified. This issue is not unique to our study, and the prevalence of intellectual and developmental disabilities in Ontario identified by our research group is consistent with international estimates. The definition of intellectual and developmental disabilities encompasses a heterogeneous group of conditions potentially associated with variations in risk. However, we felt it was important to retain a definition with clinical and policy relevance rather than examining specific diagnoses separately. Although we controlled for known confounders and conducted sensitivity analyses with pathway variables, there may be other variables related to disability severity, lifestyle factors (e.g., smoking), living situation (e.g., independent or with family), life stressors (e.g., child custody issues), social support (e.g., presence of social workers and family members), and healthcare accessibility that we could not account for. Despite the overall size of the cohort, the number of women with psychiatric admissions was small, resulting in wide CI. Results should be interpreted with caution. Our study is situated in a Canadian context, where women with and without intellectual and developmental disabilities have universal healthcare access and may not be generalizable to other settings. For example, risks for hospitalizations and emergency department visits may be exacerbated in contexts where there are additional barriers to care, including lack of health insurance.

### Conclusions

Our findings suggest the need to improve postpartum follow-up of women with intellectual and developmental disabilities to prevent and monitor for complications. In Ontario, women typically receive one postpartum visit within 6 weeks of childbirth. This may be inadequate for supporting the complex needs of women with intellectual and developmental disabilities. It may be advisable to use anticipatory guidance prenatally to ensure that women with intellectual and developmental disabilities have a plan for...
managing the postpartum period. Such a plan should involve coordination between health and social services so that women are adequately supported between medical appointments. Moreover, women with intellectual and developmental disabilities may require enhanced health services during the postpartum period, including longer or more frequent visits and specialized supports. Such improvements could reduce the risks for postpartum hospital admissions and emergency department visits among women with intellectual and developmental disabilities.

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Author Disclosure Statement

No competing financial interests exist.

References


Address correspondence to:
Hilary K. Brown, PhD
Women’s College Research Institute
Women’s College Hospital
76 Grenville Street
Toronto, ON M5S 1B2
Canada

E-mail: hilary.brown@wchospital.ca