

Pregnancy in Women With Intellectual and Developmental Disabilities

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Abstract

Objective: Our objectives were to describe the general fertility rate (GFR) and age-specific fertility rates (ASFRs) of women with intellectual and developmental disabilities (IDD) and the social and health characteristics of those with a singleton live birth, and to compare these to women without IDD.

Methods: In this population-based retrospective cohort study using linked Ontario health and social services administrative data, we identified 18- to 49-year-old women with IDD (N = 21 181) and without IDD (N = 990 776). The GFR and ASFRs (2009) were calculated for both groups and compared using rate ratios (RR) and 95% confidence intervals (CI). Among women with a singleton live birth (N = 423 with, N = 42 439 without IDD), social and health characteristics were compared using Pearson's Chi square tests.

Results: The GFR in women with IDD (20.3 per 1000) was lower than that in women without IDD (43.4 per 1000) (RR 0.47; 95% CI 0.43 to 0.51). ASFRs in 18- to 24-year-olds were similar in both groups. Among women with a singleton live birth, those with IDD were younger and had higher rates of poverty, epilepsy, obesity, and mental health issues. They also had high rates of medication use during pregnancy.

Conclusion: In the largest study of fertility in women with IDD to date, we found that ASFRs are similar in young women with and without IDD. Women with IDD with a singleton live birth experience significant social and health disparities during pregnancy. These findings suggest the need to develop services to support the reproductive health of this vulnerable group.

Résumé

Objectif : Nous avons pour objectif de décrire le taux de fécondité général (TFG) et les taux de fécondité propres à l'âge (TFPA) des femmes présentant des déficiences intellectuelles et développementales (DID), et de décrire les caractéristiques sociales et sanitaires de celles qui accouchaient d'un enfant vivant (à la suite d'une grossesse monofœtale). Nous avons par la suite comparé ces femmes à des femmes ne présentant de DID, en se fondant sur ces paramètres.

Méthodes : Dans le cadre de cette étude de cohorte rétrospective en population générale fondée sur des données administratives ontariennes liées et issues des services sociaux et de santé, nous avons identifié des femmes de 18 à 49 ans qui présentaient (n = 21 181) et qui ne présentaient pas (n = 990 776) des DID. Le TFG et les TFPA (2009) ont été calculés pour les deux groupes et ont été comparés au moyen de rapports de taux (RT) et d'intervalles de confiance à 95 % (IC). Chez les femmes ayant accouché d'un enfant vivant à la suite d'une grossesse monofœtale (n = 423 en présence de DID, n = 42 439 en l'absence de DID), les caractéristiques sociales et de santé ont été comparées au moyen de tests de chi carré de Pearson.

Résultats : Le TFG était plus faible chez les femmes qui présentaient des DID (20,3 sur 1 000) que chez les femmes qui n'en présentaient pas (43,4 sur 1 000) (RT, 0,47; IC à 95 %, 0,43 à 0,51). Les TFPA chez les 18 à 24 ans étaient semblables dans les deux groupes. Chez les femmes ayant accouché d'un enfant vivant à la suite d'une grossesse monofœtale, celles qui présentaient des DID étaient plus jeunes et connaissaient des taux accrus de pauvreté, d'épilepsie, d'obésité et de problèmes de santé mentale. Elles présentaient également des taux élevés de recours à la médication pendant la grossesse.

Conclusion : Dans le cadre de la plus importante étude à ce jour sur la fécondité des femmes qui présentent des DID, nous avons constaté que les TFPA des femmes présentant des DID étaient semblables à ceux des femmes ne connaissant pas de tels problèmes. Les femmes présentant des DID qui accouchent d'un enfant vivant à la suite d'une grossesse monofœtale connaissent des disparités sociales et sanitaires considérables pendant la grossesse. Ces constatations semblent indiquer que nous devons élaborer des services pour soutenir la santé génésique des femmes de ce groupe vulnérable.

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INTRODUCTION

Intellectual and developmental disabilities (IDD) are common, affecting one in every 100 individuals.¹ These neurodevelopmental disorders are marked by limitations in

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cognitive skills and communication, social skills, and executive functioning.² Historically, many women with IDD were institutionalized and/or sterilized.³ With establishment of community-based living and recognition of the rights of persons with disabilities,⁴ these practices are no longer common.⁵ Although studies of parenting skills in women with IDD date back to the 1940s,⁶ research on reproductive health is minimal.⁷ Accurate estimation of fertility rates in women with IDD and the social and health characteristics of those who give birth is critical for developing clinical programming and public health policy surrounding sexual health and contraception as well as care during pregnancy when support needs are likely intensive.

There is no current, valid estimate of the yearly fertility rate in women with IDD. Two clinical studies in the United States in the 1980s documented the occurrence of live births among women with IDD over an unknown number of years. A medical clinic survey of 11- to 23-year-olds with IDD (N = 87) reported three live births⁸; a gynaecological surgery clinic chart review noted six live births to 300 women with IDD (average age 38.4 years).⁹ To our knowledge, only the small population-based study reported by Weiber et al. determined a yearly fertility rate.¹⁰ These authors used a special education register to identify 98 women with IDD aged 15 to 33 years in a small Swedish county. They found an average yearly fertility rate of 20.4 live births per 1000 women with IDD (vs. 79.5 per 1000 for 15- to 33-year-olds in the county overall).

Likewise, there is limited understanding of the social and health characteristics of women with IDD who give birth. Women with IDD face multiple disparities: they are more likely than women without IDD to live in poverty,¹¹ to have chronic health conditions¹² and mental health issues,¹³ and to have poor access to primary care.¹⁴ They are also more likely to take multiple prescription medications, including psychotropics.¹⁵ Although these factors are predictors of maternal and neonatal morbidity,^{16,17} only one recent study examined the characteristics of pregnant women with IDD.¹⁸ This American retrospective cohort study found that women with IDD (N = 703, identified in 1998–2009) were more likely to be young, less educated, and unmarried. Important health characteristics (e.g., pre-existing health conditions, medication use) were unmeasured.¹⁸ Thus, it is unknown to what extent pregnant women with IDD in Canada face social and health disparities which could put their pregnancy at risk.

Our objectives were: to describe the general and age-specific fertility rates of Ontario women with IDD in the

2009 fiscal year as well as the social and health characteristics of those with a singleton live birth, and to compare these to women without IDD.

METHODS

We conducted a retrospective cohort study in Ontario, which is Canada's most populous province, with over 13 million residents and 140 000 births per year.¹⁹ We obtained data from the Institute for Clinical Evaluative Sciences (ICES). ICES is an independent, non-profit organization that houses databases containing administrative, socio-demographic, and clinical information gathered through health care utilization of Ontario residents, all of whom receive universal health care coverage. These databases capture psychiatric and non-psychiatric hospitalizations, emergency department visits, day surgeries, outpatient clinic visits, and primary care visits. Person-level data were linked across databases using a unique encoded identifier and were analyzed at ICES. Diagnostic information is recorded following Canadian Coding Standards for the International Statistical Classification of Diseases and Health Related Problems 10th Revision (hospital databases) or physician billing claim codes (primary care databases). ICES databases are valid for socio-demographic information, primary diagnosis, and physician billing claims.²⁰ We also used information from the Ontario Ministry of Community and Social Services, which was linked to ICES data to achieve complete ascertainment of IDD status based on the diagnostic codes listed as the reason for receipt of Ontario Disability Support Program benefits.²¹

All Ontario women aged 18 to 49 years in the 2009 fiscal year were eligible for the study. We classified women in the IDD group if they had IDD diagnostic codes recorded in health administrative data (≥ 2 physician visits or ≥ 1 hospitalization or emergency department visit since database inception) or in documentation for disability benefits.²¹ Based on a conceptual definition of IDD consistent with Ontario legislation, eligible diagnoses in health and social services administrative data included intellectual disability / "mental retardation," autism and other pervasive developmental disorders, fetal alcohol syndrome, and autosomal or chromosomal disorders; a complete list of diagnostic codes is available elsewhere.²¹ From the remaining women in Ontario, a random sample of 20% of 18- to 49-year-old women comprised the comparison group of women without IDD.

Social and health characteristics were examined in women with and without IDD who had a singleton live birth. We also described medication use in women with IDD who were currently eligible for Ontario Drug Benefits, as documented in ICES data²²; medication use in women

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