

Editor's key points

- ▶ Literature on the health and health care needs of pregnant women with intellectual and developmental disabilities (IDD) is limited. This study aimed to characterize the risks and challenges faced by pregnant women with IDD.
- ▶ Pregnant women with IDD face unique social and environmental obstacles. Antenatal records for about two-thirds of the pregnancies in this study identified poor social support and parenting concerns, and about half identified family violence as a concern. For half of the pregnancies, the women did not have reliable partners, and 7 of the 10 women had at least one form of abuse documented.
- ▶ Many pregnant women with IDD faced stressful encounters with Child and Family Services, and clinical encounter notes demonstrated discord between their own perceptions of their parenting ability and the perceptions of their health care providers.
- ▶ Pregnant women with IDD are a vulnerable population and would likely benefit from increased supports from primary care providers.

Exploring the prenatal experience of women with intellectual and developmental disabilities

In a southeastern Ontario family health team

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Abstract

Objective To identify psychosocial challenges facing pregnant women with intellectual and developmental disabilities (IDD) using retrospective, routinely collected electronic medical record data.

Design A retrospective qualitative study using narratives and supporting documents found in the electronic medical record of an academic family health team (FHT).

Setting Academic FHT in southeastern Ontario.

Participants A sample of 10 women with a diagnosis of IDD, rostered to physicians at the academic FHT, who delivered a child between January 2010 and June 2015 (14 pregnancies). Exclusion criteria included women who received prenatal care from a midwife and women for whom no delivery or antenatal records were available.

Methods Thematic analysis of data collected from a retrospective chart review.

Main findings Many women with IDD had yes marked on their antenatal records for poor social supports, family violence, and parenting concerns. Women with IDD had pregnancies that were characterized by complex social environments, financial instability, discord between their perceptions and their physicians' perceptions, and stressful encounters with Child and Family Services.

Conclusion Findings in this study support previous research that pregnant women with IDD are a vulnerable population, at higher risk of adverse health outcomes. There is a need for specific care guidelines for health care providers, as well as additional resources and social supports.

Déterminer les expériences prénatales des femmes qui ont des déficiences intellectuelles ou développementales

Dans une équipe de santé familiale du sud-est de l'Ontario

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Résumé

Objectif Déterminer les défis psychosociaux auxquels font face les femmes enceintes qui ont des déficiences intellectuelles et développementales (DID), et ce, à l'aide de données rétrospectives de dossiers médicaux électroniques régulièrement consultés.

Type d'étude Une étude rétrospective qualitative à l'aide de documents narratifs et de pièces justificatives tirés des dossiers médicaux électroniques d'une équipe universitaire de santé familiale (EUSF).

Contexte Une EUSF du sud-ouest de l'Ontario.

Participants Un échantillon de 10 femmes ayant des DID qui étaient inscrites auprès de médecins de l'EUSF et qui avaient accouché d'un enfant entre janvier 2010 et juin 2015 (14 grossesses). Parmi les critères d'exclusion, mentionnez les femmes qui avaient reçu des soins prénataux d'une sage-femme et celles pour lesquelles aucun dossier d'accouchement ou de soins prénataux n'était disponible.

Méthodes Une analyse thématique de données provenant d'une revue rétrospective de dossiers.

Principales observations Pour plusieurs des femmes qui avaient des DID, le dossier prénatal confirmait un manque de support social, de la violence familiale et des préoccupations concernant leur capacité d'élever des enfants. Les grossesses de ces femmes se caractérisaient par un environnement social complexe, une instabilité financière, un désaccord entre leur opinion et celle de leur médecin, et des contacts éprouvants avec le Service de l'Enfance et de la Famille.

Conclusion Les observations de cette étude confirment les études antérieures qui indiquent que les femmes qui ont des DID constituent un groupe vulnérable qui est plus à risque d'être en mauvaise santé. Les soignants devraient disposer de directives spécifiques à ce genre de cas; il faudrait aussi plus de ressources et de support social.

Points de repère du rédacteur

► Il n'existe pas beaucoup de publications qui traitent de la santé et des soins dont ont besoin les femmes enceintes qui ont des déficiences intellectuelles et développementales (DID). Cette étude voulait déterminer les risques et les défis auxquelles ces femmes doivent faire face.

► Les femmes qui ont des DID font face à des obstacles sociaux et environnementaux uniques. Dans cette étude, les dossiers prénataux d'environ les deux-tiers des grossesses ont révélé un support social insuffisant pour ces patientes et des préoccupations concernant leur rôle comme parents; de plus, environ la moitié se sont montrées inquiètes à propos de la violence familiale. Dans la moitié des grossesses, les femmes n'avaient pas de partenaire fiable, et 7 des 10 femmes avaient subi une forme quelconque d'abus sexuel documentée.

► Plusieurs femmes enceintes qui ont des DID ont eu des contacts éprouvants avec les Services à l'Enfance et à la Famille, et les comptes rendus de ces rencontres montrent qu'il y a discordance entre ce qu'elles pensaient de leur capacité d'élever des enfants et ce qu'en pensaient leurs soignants.

► Les femmes enceintes qui ont des DID forment un groupe vulnérable; elles bénéficieraient vraisemblablement d'un meilleur support de la part des soignants du milieu des soins primaires.

In the early and mid-20th century, the institutionalization and involuntary sterilization of women with intellectual and developmental disabilities (IDD) was legal and common practice in Canada, the United States, and many European countries.¹ Repeal of these laws and deinstitutionalization of individuals with IDD has led to increasing numbers of women with IDD living in community settings.² It has also become more common for these women to give birth. Literature on the health and health care needs of pregnant women with IDD is limited.

Population-based studies in the United States, the United Kingdom, Australia, Sweden, and Canada on maternal characteristics and birth outcomes of women with IDD have identified that this population is at higher risk of adverse birth outcomes, including preeclampsia, cesarean section, and preterm birth.³⁻⁹ Additionally, phenomenologic studies investigating the subjective experience of pregnancy in women with IDD have described the social challenges they face, including negative experiences with health care providers,¹⁰ anxiety and distress over custody of their expected or newborn child,¹¹ and lack of accessible informational support, emotional support, and social companionship.¹² Collectively, these studies illustrate a need for health care that addresses the unique challenges facing this population.

The Canadian consensus guidelines for the primary care of adults with IDD emphasize the complexity of the health care needs of adults with IDD.^{13,14} This study coincides with the addition of pregnancy care considerations to the updated 2018 guidelines.¹⁵ The aim of this study is to further characterize the risks and challenges facing pregnant women with IDD from a primary care perspective.

— Methods —

Study population

Study participants were identified through searching the electronic medical record (EMR) system of a family health team (FHT) in southeastern Ontario. A search template was created to isolate records that had been assigned an IDD ICD-9 code (**Table 1**), and that also had an attached antenatal record or completed “Related Child” field. The ICD-9 codes in **Table 1** are specific to the EMR at the FHT and do not correspond exactly with the International Classification of Diseases. From this, 10 women with IDD who had a total of 14 deliveries between 2010 and 2015 were identified. Exclusion criteria included women who received prenatal care by a midwife and women for whom no delivery or antenatal records were available.

Data source

The EMR system of the FHT was examined. Information in the EMR included written notes from every clinical encounter at the FHT since 2010 (and earlier for some patients), as

well as associated documents and records (eg, antenatal records, bloodwork reports, government assistance forms, delivery records, referral and consultation letters).

Data collection

Participant EMR records and associated information were reviewed. Notes and text excerpts were transcribed to Microsoft Word for analysis.

Data analysis

Thematic analysis of the EMR notes was performed. An initial review of antenatal reports for the participants revealed that many had yes selected for the psychosocial discussion topics of poor social support (9 of 14), family violence (6 of 12), and parenting concerns (9 of 14) on their antenatal records (**Table 2**). The EMR notes and text were coded under these 3 main themes.

Ethics

Ethics approval to access patient records at the FHT and the region’s associated tertiary care centre was granted by the Queen’s Health Science Research Ethics Board.

— Findings —

Poor social support

Many of the women lived or grew up in complex social environments, characterized by unstable relationships and financial instability.

Unstable relationships. Instability permeated many of the women’s relationships. In 7 of the 14 pregnancies, the women did not have reliable partners, as evidenced

Table 1. The ICD-9 classification of IDD

CLASSIFICATION	ICD-9 CODE
Mild mental retardation	317
Moderate mental retardation	3180
Severe mental retardation	3181
Profound mental retardation	3182
Down syndrome	7580
Fragile X syndrome	75983
Prader-Willi syndrome	75981
Autosomal deletion syndrome	7583
Infantile autism	2990
Cerebral degeneration in child	330
Chromosomal anomalies	758
Infantile cerebral palsy	343
Maternal alcohol affecting newborn	76071
Developmental delay not otherwise specified	3157
IDD—intellectual and developmental disabilities.	

Table 2. Psychosocial status in pregnancy of women with IDD, based on responses recorded on the Ontario antenatal records of 14 deliveries to 10 women with IDD

PSYCHOSOCIAL DISCUSSION TOPICS	N (%)
Poor social support	
• Yes	9 (64.3)
• No	4 (28.6)
• Undocumented	1 (7.1)
Family violence	
• Yes	6 (42.9)
• No	6 (42.9)
• Undocumented	2 (14.3)
Parenting concerns	
• Yes	9 (64.3)
• No	3 (21.4)
• Undocumented	2 (14.3)

IDD—intellectual and developmental disabilities.

by notes stating that their partners were not supportive of the pregnancies, that their partners were not involved, or that the father was unknown. Some of the women also had complicated relationships with their relatives—being estranged from their immediate family, being threatened and physically hurt by relatives, or growing up in foster care where they might have experienced few stable long-term relationships. On the other hand, some women did have supportive relationships. Their relatives were often the caregivers of any previous children apprehended by Child and Family Services (CFS). If they were struggling with their partners, many would cite extended family or parents as primary supports.

Financial instability. All of the women were unemployed, and some received support from the Ontario Disability Support Program. As a result, financial instability created uncertainty with regard to nutrition, housing, and transportation. Many women had difficulty fulfilling basic nutritional needs. They depended on relatives, food banks, and government assistance. One woman reported not having enough money at the beginning of her pregnancy for multivitamins and folic acid. A clinical encounter note from another woman read, “Has not been eating well due to vomiting and financial status, unable to buy groceries this week.” Almost half of the women had documentation in their charts that they were experiencing difficulty obtaining adequate nutrition.

Eight of the 10 women had documented evidence of an unstable housing situation. These women had documented need for low-income housing or moved between locations during their pregnancies, including group homes; the homes of family members, friends, or partners; and motels and shelters.

Family violence

History of sexual, physical, or verbal abuse. Many of the women had complex psychosocial backgrounds involving abuse by partners, former partners, or family members. Some had long histories of abuse starting from childhood and adolescence, often by older male family members. Seven of the 10 women had at least one form of abuse—sexual, physical, or verbal—documented in their medical records (not necessarily during pregnancy). Of the 7 women who experienced documented abuse, 4 were documented as having received referrals for social work services, although only 2 had consistent meetings with a social worker.

Parenting concerns

Many participants’ charts cited issues related to parenting. These included discussions about pregnancy planning, a misalignment between patient and physician perspectives of parenting abilities, and involvement of CFS.

Pregnancy planning. Of the 14 deliveries, 6 were specified as “unplanned.” For the women who received primary care at the FHT before pregnancy (8 of 10), sexuality and birth control was discussed at least once before pregnancy. The 4 women who received primary care at the FHT as adolescents all had documented discussions about sexually transmitted infections, birth control, and sexual activity. Of interest, only 1 woman had a documented discussion about parenting and parenting capacity during pregnancy.

Misalignment between patient and physician perspectives of parenting abilities. Clinical encounter notes demonstrated misalignment between the women’s perspectives on their parenting potential and their physicians’ assessment of their abilities.

For example, in one antenatal visit, the patient reported “no concerns about ability to care for new baby,” yet the physician wrote, “After discussion with [another doctor] this afternoon re: pt’s ability to care for a newborn infant, I called CAS [Children’s Aid Society] and outlined our concerns.” Another woman reported at a regular antenatal visit that she was “getting ready with baby stuff—new crib, change-table, etc. She is convinced things are different this time and CAS doesn’t need to be involved.” The plan written by the physician was, “strongly encouraged patient to meet with CAS prior to delivery.”

Involvement of CFS. While apprehension was not always the result, CFS was involved in 13 of the 14 pregnancies. Some of the women expressed anxiety and frustration about CFS. Documented examples of their reactions include the following:

[Patient] is very scared that CAS will come to take the baby away, as she states has happened before.
[Patient] wants to know if CAS needs to be informed.

[Patient] indicated that she is “going crazy” not knowing what will happen with CAS. She stated that she has asked many times about her file, what the plan is, and if there is anything else she should be doing.

[Patient] expressed anger at the situation (children being placed in CAS), insisting that she was prepared to parent her 2nd child, and had supportive people to assist her here.

In some cases, the women did not know what the plan was regarding custody of their unborn child until close to or at the time of the delivery.

— Discussion —

This study sought to explore the challenges facing pregnant women with IDD from a primary care perspective. This study was designed to be exploratory and to serve as a first step for more extensive characterization of the findings.

A review of the women’s EMRs identified a number of shared experiences. The women’s unstable relationships and experience of abuse by close relatives and partners were consistent with experiences described by other women with IDD.^{16,17} Although 4 of the 7 women who suffered abuse received referrals for social work services, only 2 attended meetings consistently. This might be owing to stigma associated with social work services or might be a result of financial instability and a lack of reliable transportation to attend appointments. Alternatively, it might be the result of poor executive function leading to difficulty remembering appointments or comprehending their usefulness. This reflects a clear need for an alternative approach to providing social support outside of traditional clinic encounters. Consideration could be given to home visits, telephone encounters, and joint “opportunistic” encounters with the primary care physician when the patient presents for antenatal appointments.

The high proportion of yes answers to the topic of parenting concerns might demonstrate that women with IDD are aware of the parenting challenges facing them and feel that they lack appropriate resources and support. This corroborates the findings of Potvin et al that women with IDD lack informational support, emotional support, and social companionship during pregnancy.¹² On the other hand, while the antenatal record is meant to reflect the women’s own answers, it is plausible that some of the recorded answers might in fact reflect their physicians’ views. Particularly if communication was a considerable challenge, the physician might have inferred the response.

Most of the women had previously documented discussions with their physicians about contraception. Yet, almost half of the deliveries were specified as unplanned. Only one woman had a documented discussion about parenting during the pregnancy. Lennox et al identified communication difficulties to be one of the primary

barriers for general practitioners providing health care to patients with IDD. The communication difficulties include not only the physician’s ability to obtain information from the patient, but also the patient’s ability to understand the physician’s recommendations.¹⁸

Further, there was evidence of discord between the women’s confidence in their abilities to parent and their physicians’ assessment of their abilities. This misalignment could be a result of a few factors. Given the complicated family environments in which many of these women grew up, their challenges in adaptive functioning, and the paucity of documented discussion about parenting in their health care encounters, they might not have adequate insight into the responsibilities associated with parenting. On the other hand, some physicians might hold negative biases about the women’s capabilities because of misconceptions about patients with IDD, knowledge of the woman’s complex social background, or lack of experience with the care of this population.

The involvement of CFS in the pregnancies of women with IDD is an issue that warrants further investigation. While some of the women accepted their involvement, others were anxious and stressed about their encounters. In some cases, this was rooted in previous experiences in which apprehension had occurred. In others, it was owing to perceived communication deficits between the woman and CFS. This is a challenging situation for primary care providers to navigate. A proactive referral to CFS can be a source of extra support for pregnant women in complex social situations. However, it is difficult to mitigate distress over CFS involvement, as the woman’s distress might be caused by limited insight into her own parenting capacity or by previous CFS apprehension.

This study corroborates the idea that pregnant women with IDD face unique social and environmental obstacles. Because these situations are often beyond their control, there is a pressing need for additional supportive resources. Examples include better training for physicians caring for individuals with IDD,¹⁹ greater income assistance, increased accessibility of affordable and safe housing and transportation, increased monitoring, and flexibility within health care appointments to facilitate communication and comprehension.

Limitations

The findings of this study should be interpreted with consideration of its limitations. First, the size of the study population was limited by the volume of pregnant women with IDD at the FHT. Second, while some of the subjects received all of their antenatal care from their primary care physicians at the FHT, others received partial care from obstetricians at the regional tertiary care centre. The specifics of those medical encounters might not have been transferred to the patients’ EMR files. Thus, the amount of information available in each subject’s file varied. Documentation of topics discussed during an

encounter might also have varied. Third, patients with IDD are a heterogeneous group with varying degrees of adaptive functioning and communication abilities. The method by which the case subjects were identified did not specify the degree of disability, nor was degree of disability considered in the interpretation of the data.

Conclusion

Observations in this study support previous research findings that pregnant women with IDD are at higher risk of adverse outcomes and are more likely to face social and environmental obstacles during pregnancy. There is a need for more resources to be made available to them, particularly from a primary care perspective. Further research is needed to develop effective clinical interventions to improve their outcomes. 🌿

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Contributors

Dr Xie developed the study design, conducted data collection and analysis, and wrote the manuscript. **Dr Gemmill** provided substantive input at all stages. Both authors approved the final version for submission.

Competing interests

None declared

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