



SPECIAL ISSUE: Sexual and Reproductive Health of Women with Disability  
Research paper

## “We don't know. We've never had anybody like you before”: Barriers to perinatal care for women with physical disabilities



Lesley A. Tarasoff

Dalla Lana School of Public Health, University of Toronto, 6th Floor – 155 College Street, Toronto, Ontario M5T 3M7, Canada

### ARTICLE INFO

#### Article history:

Received 5 December 2016

Received in revised form

6 March 2017

Accepted 9 March 2017

#### Keywords:

Physical disability

Pregnancy

Perinatal health

Qualitative

### ABSTRACT

**Background:** While more women with physical disabilities are becoming mothers, many encounter barriers to perinatal care and experience poor outcomes. Little is known about the perinatal care experiences and outcomes of women with physical disabilities in Canada.

**Objective:** This qualitative study sought to understand the perinatal care experiences and outcomes of women with physical disabilities in one Canadian province, with an emphasis on identifying barriers to care.

**Methods:** In-depth interviews were conducted with 13 women with physical disabilities who had given birth in the last 5 years. Follow-up interviews were conducted with 10 of the 13 participants. All interviews were audio-recorded and transcribed verbatim. Data analysis was informed by a constructivist grounded theory approach.

**Results:** Based on analysis of participants' interviews, five themes regarding barriers to care were identified: (1) Inaccessible care settings, (2) Negative attitudes, (3) Lack of knowledge and experience, (4) Lack of communication and collaboration among providers, and (5) Misunderstandings of disability and disability-related needs.

**Conclusions:** Study findings reveal that the perinatal care system is not set up with women with physical disabilities in mind and that barriers to perinatal care may contribute to poor outcomes. More research and training are needed to address barriers to perinatal care for women with physical disabilities. Collaboration among perinatal and disability-related providers and meaningful inclusion of women with physical disabilities in educational initiatives and care plans are vital to improve care experiences and outcomes.

© 2017 Elsevier Inc. All rights reserved.

With medical advances, growing community participation, and recognition of the reproductive rights of persons with disabilities,<sup>1,2</sup> women with physical disabilities increasingly have opportunities for childbearing. Researchers in the United States have in fact found that women with physical disabilities are giving birth at similar rates to non-disabled women.<sup>3,4</sup>

Women with physical disabilities, however, experience significant perinatal health disparities when compared to non-disabled women. Notably, they experience increased rates of cesarean delivery and preterm birth.<sup>5–9</sup> Women with physical disabilities are also more vulnerable to risk factors associated with adverse pregnancy outcomes, such as poverty, poor mental health, obesity, abuse, and lack of emotional or social support.<sup>10–18</sup> Moreover, women with physical disabilities report encountering barriers to perinatal care,<sup>5,19–23</sup> including attitudinal barriers, informational

barriers, and inaccessible care settings. These barriers may contribute to poor maternal and infant outcomes.

The objective of this study was to better understand the perinatal care experiences and outcomes of women with physical disabilities in Ontario, Canada, and to identify barriers to perinatal care.

### Methods

In-depth, qualitative interviews were conducted to capture the perinatal care experiences and outcomes of women with physical disabilities who had recently given birth in the province of Ontario.

#### Recruitment and screening

To be included in the study, individuals had to: identify as a woman with a physical or mobility-limiting disability; reside in Ontario; be aged 18 years or older; have given birth within the last 5

E-mail address: [lesley.tarasoff@utoronto.ca](mailto:lesley.tarasoff@utoronto.ca).

years; and, be able to converse in English.

Interview participants were recruited through personal networks and the distribution of flyers via the electronic listservs and websites of over 60 organizations and groups that serve pregnant women, new parents, and/or people living with disabilities across Ontario. Flyers were also posted at a number of high risk birth units and rehabilitation centers in major urban centers and shared on social media.

Interested individuals contacted the author and were screened by telephone to determine eligibility. A total of 20 women contacted the study office. Of these, 13 were eligible to participate. The primary reasons for ineligibility were location (lived outside of Ontario) and age of children (over 5 years old).

#### *Data collection and ethics*

Using a semi-structured guide, qualitative interviews were conducted with 13 mothers with physical disabilities between November 2014 and November 2015. Baseline interviews lasted between 54 and 135 min (mean = 86 min). Ten of the 13 participants were interviewed in person, in locations of the participant's preference, and three were interviewed over the phone. Shorter, follow-up interviews were conducted with 10 of the 13 participants between June and September 2015, primarily over the phone.

Those participants who were recruited later in the study were not asked to complete a follow-up interview. These three participants' interviews tended to be longer however, as they were asked some of the questions created for the follow-up interview, which were based on preliminary analysis of earlier participants' baseline interview data. Further, saturation was achieved on a number of themes (including all themes presented in this manuscript, with at least 3 participants with different disability types reporting similar experiences). All interviews were audio-recorded, with the participants' consent.

After each interview, field notes were written to summarize key points and capture interactions and observations about the participant within the context of the interview (e.g., participants' emotional reactions). Field notes were used to highlight similarities and differences in participants' experiences and informed the direction of follow-up interviews. Follow-up interviews served as a method of confirmability, whereby participants' accounts were made richer and experiences discussed in baseline interviews were built upon or confirmed. Follow-up interviews in turn helped to establish credibility (other techniques used to meet standards of qualitative rigor and trustworthiness included memoing and peer debriefing).

This study received ethics approval from the Research Ethics Board at the Centre for Addiction and Mental Health and the Health Sciences Research Ethics Board at the University of Toronto. Participants received a honorarium of \$30 for each interview and public transit fare if they travelled to the author's office. Names used in this paper are pseudonyms.

Prior to each interview, participants provided written informed consent and completed a demographic questionnaire (before the baseline interview only), including items querying disability type, age, marital status, and education level, as well as items related to disability (e.g., pain and activity limitations) and their most recent perinatal experience (e.g., prenatal class attendance, main provider, type of birth).

#### *Data analysis*

All interviews were transcribed verbatim by the author or an undergraduate research assistant, and reviewed and verified by the author.

Data analysis was informed by a constructivist grounded theory approach,<sup>24</sup> whereby themes were actively co-constructed through the author's interaction with the data. The data presented here are part of a larger (dissertation) project exploring the transition to motherhood among women with physical disabilities, wherein the initial line-by-line coding process yielded 157 codes. This list of codes was then narrowed down to 59 codes which were shared and discussed with the author's supervisory committee (i.e., peer review and debriefing). Transcripts were then uploaded to NVivo<sup>25</sup> to assist with data management. Data from about half of those 59 codes were used for this present analysis. Coded segments within and between interviews were continuously compared and categorized into 5 themes concerning barriers to perinatal care presented below.

## **Results**

### *Participant characteristics and outcomes*

Participants reported having a range of disabling conditions, including cerebral palsy (CP) and spinal cord injury (SCI; see Table 1). Many participants reported experiencing chronic pain, and shared that their experiences of pain were at times more limiting than their physical condition. Most participants use an assistive device daily, including a cane, power wheelchair, scooter, crutches, and other devices and tools to assist with daily activities (e.g., tasks that require hand dexterity).

The average age of participants was 36.5 years (range 26–44). All but one were married or in a common-law relationship, and only one identified as non-white (Asian background). Most were well-educated and resided in large urban centers. Three had a child under the age of three months at the time of the first interview. Nine participants (including one of those with a child younger than three months old) had a child or children ranging in age from 10 months to 3 years at the time of first interview.

Most had an obstetrician as their primary perinatal care provider. Three participants also reported that they had a doula during pregnancy and/or present with them during labor and delivery, and four indicated that they had a postpartum doula and/or lactation consultant.

Though not formally assessed in the questionnaire, participants reported a range of postpartum outcomes, including what they considered to be postpartum depression and/or anxiety ( $n = 5$ ), and preterm birth ( $n = 3$ ). Five participants reported that their newborns spent time in the neonatal intensive care unit (NICU), including two due to medication withdrawal (2–4 week stays), and one due to maternal complications. Some reported that motherhood has resulted in increased pain and decreased mobility.

### *Qualitative themes*

Five interrelated themes regarding barriers to perinatal care were identified: (1) Inaccessible care settings, (2) Negative attitudes, (3) Lack of knowledge and experience, (4) Lack of communication and collaboration among providers, and (5) Misunderstandings of disability and disability-related needs. The latter theme was arguably the most prominent, linking and underlying all others.

#### *Inaccessible care settings*

Several participants encountered inaccessible perinatal care settings, including inaccessible washrooms and inaccessible equipment such as examination tables.

**Table 1**  
Select characteristics of study participants.

	n = 13
Age	
25–29 years	1
30–34 years	4
35–39 years	3
40–44 years	5
Disability <sup>a</sup>	
Arthritic condition	3
Cerebral palsy	4
Congenital amputation	1
Congenital blindness	1
Congenital bone growth disorder	1
Degenerative disc disease	1
Fibromyalgia	1
Muscular dystrophy	1
Osteoporosis	1
Scoliosis	2
Spinal cord injury	3
Assistive Device Use	11
Pain	
Always present	7
Comes and goes	3
No pain	3
Pain Limits Daily Activities	
Never	3
Rarely	0
Sometimes	5
Often	4
Always	0
Marital Status	
Married	9
Common-law	3
Single/Never married	1
Housing Situation	
Independent housing (house, condo, apartment)	11
Subsidized housing (apartment)	2
Highest Level of Education	
Some university	1
Diploma or certificate from community college	1
Bachelor's or undergraduate university degree	5
Graduate degree (e.g., MA, MSc, MSW, PhD)	6
Number of Children	
1	7
2	4
3	1
4 <sup>b</sup>	1
Prenatal Course Attendance	
Yes	7
"Crash course"/in hospital	2
No	4
Main Perinatal Care Provider <sup>c</sup>	
Obstetrician	11
Family doctor	2
General practitioner	1
Midwife	2
Other (e.g., family health team)	3
Type of Birth <sup>d</sup>	
Vaginal	5
Cesarean	8
Planned	5
Unplanned/Emergency	3

Notes.

<sup>a</sup> Some participants reported more than one disability or disabling condition.

<sup>b</sup> Includes twins and two step-children.

<sup>c</sup> Some participants reported having more than one perinatal care provider (e.g., a team of rotating obstetricians and nurses) or changing their main provider part way through pregnancy.

<sup>d</sup> Most recent birth.

There were no accessible beds and so my partner always had to lift me up onto the bed. And it just seemed really ridiculous to me because out of any place, this should be where there should be some specialized equipment. Every time you go in, you have to

provide a pee sample and the washroom wasn't accessible. It didn't make sense to me. I felt like disability wasn't an expected part of this high risk clinic, even though high risk was usually associated with medical conditions (Jennifer, who lives with muscular dystrophy and is a mother of one, accessed a "brand new maternity ward").

At one point [during the postpartum hospital stay] I'm saying to my husband I want to go take a shower. So I said to them [nurses], "do you guys have a walker I could borrow, or is there anywhere in this hospital, is there a bench?" "No." ... they had a floor for people that had suffered strokes, so they said, "the best we can do is you can go up there, they have a walker that's broken, and so it doesn't lock" (Whitney, who lives with CP and is a mother of three).

Beyond inaccessible perinatal care settings and challenging accessing assistive devices, one participant also reflected on how the NICU was inaccessible to her as a parent with a physical disability.

They didn't know how to deal with the disability [I have]. They really didn't .... The fact that I was bringing my [wheel]chair into the NICU freaked a lot of people out because I'm bringing in outside germs into a place where there's a lot of sick babies. But I was like, "I'm sorry. I cannot not [have my chair]. Provide me with a chair that's sterile then. What do you want me to do? You all walk in in your street shoes; it's the same kind of thing." ... There was no real [accommodation] (Hillary, who lives with a lumbar SCI and is a mother of one).

### Negative attitudes

Many participants reported encountering negative attitudes about disability and comments about their fitness for motherhood. In one instance, Whitney reported that her obstetrician's receptionist did not recognize her to be pregnant:

I went in for my appointment [to my OB and after] I went up to the secretary to book the next appointment. She actually whispered to the doctor, "She's not pregnant, is she?" And the doctor's said, "Well, yeah, that's why she's here."

While she was recovering from the birth of the first of her three children, Whitney also recalled that nurses made comments about her fitness for motherhood when she asked for assistance to get out of bed in order to go use the washroom: "I asked for help twice and got a lecture by the head nurse about how the heck are you going to take care of a baby?"

Julie, who lives with CP and is a mother of two, had a somewhat similar experience, reporting that some of the nurses "treated me like I shouldn't be having kids." Shortly after the birth of her first child, she recalled:

I said to the one nurse, I buzzed her—my husband's asleep on the chair, poor guy—it was like 4 in the morning ... "I really have to pee, can you help me up?" and she [nurse] said, "well what's your husband here for, isn't that what he's good at?! ... he knows how to lift you and everything." I go, "he doesn't lift me, I can move if you help me. I've just had surgery [cesarean]."

During her first pregnancy, Julie also recalled encountering an ultrasound technician who was "very rude": "She expected that I

*should be able to jump on this high bed by myself being 8 months pregnant, swollen feet, and disabled. And I couldn't get on the bed and she was screaming at me."*

Finally, Whitney shared two experiences of interactions with nurses who seemed to have negative attitudes about disability. These nurses seemed to be uncomfortable to support her disability-related needs.

The other thing that I could not wrap my head around is disability phobia. I told them specifically I need somebody to grab my legs on each end [during labor] .... But every time I have to push, the nurse drops my leg and the only thing I'm thinking of is, okay, I'm not an expert here, but like I've watched a birthing story or whatever on TVO. And able-bodied women get assistance with people holding their leg. They don't get their legs dropped every time they push. So that's why I said to her, "look, I realise that it might be heavy, it might not be the most comfortable – get another person to help you." They were just freaking [out].

I was walking to the elevator; one of the younger nurses says, "oh, have a nice time showering," but really mocking, to the other nurses, as if to say oh, you've got this chore to do. Not that she was showering me ... it was just a matter of I needed a shower with a bench or a chair put in that I can maneuver.

#### *Lack of knowledge and experience*

Most participants reported difficulties accessing information about pregnancy and disability, both from providers and community resources.

I had a hard time finding information.... Even online, I dug around the internet and there just wasn't a lot of information. What studies I did find were vague and said stuff what I already knew. I found the high risk [pregnancy] unit affiliated with hospital X when I started saying I would like to try having a kid. We had a consult with them and they basically said come back when you were pregnant so that was the extent of the information I was able to find. That was very frustrating. There were a lot of unknowns. I was told that the pain could be the same, could get worse, or could get better with pregnancy (Hillary).

Going through the medical establishment was complicated because they didn't have more information than I did .... if you ask them questions about resources that I could tap into to help me parent, they had no idea and no resources and they weren't hooked up to community groups ... I felt like when there were people who were encouraging, who were like, "Oh it's so encouraging to see disabled people having kids." When you are like, "Yeah! So how can you help me?" They're like, "Oh, I have no idea." (Jennifer).

While several participants reported that their perinatal care providers were eager and willing to learn, most reported that their providers' lacked knowledge regarding the interaction of pregnancy and disability and/or experience caring for women with physical disabilities.

They were pretty excited because they never had anyone with a disability at the hospital .... It was all like a big experiment (Kimberly, who lives with a cervical SCI and is a mother of one).

"We don't know. We've never had anybody like you before" ... I find it extremely hard to believe I'm the first person, the first mom with a disability, that you've ever come across .... But this is what they told me (Heather, who lives with a congenital amputation and is a mother of one).

I kept asking her, "so you've had experience with mothers with CP?" and she's like "oh yeah, yeah" ... No. [Another woman with CP] came into play and they were asking me questions to tell her because she had a different doctor but it was in the same group of doctors, [in] the same hospital. They had experiences with persons with disabilities but not specifically with persons with cerebral palsy (Angela, who lives with CP and is a mother of one).

The lack of knowledge and experience on the part of providers both surprised and frustrated participants, and in turn exacerbated their feelings of anxiety during pregnancy. Beyond worrying about how disability might impact pregnancy and vice versa, some participants were particularly concerned about how their medications might impact their infants and found that their perinatal care providers offered little clarity on this matter.

I had a fairly serious complication from my RA during pregnancy because I [had] come off my medications.... I don't think they were confident on the safety and the information (Sarah, who has lived with rheumatoid arthritis for much of her life and is a mother of two).

They didn't know how my meds would interact with [my son] ... there were a lot of unknowns definitely (Kimberly, whose son had a two-week NICU stay due to medication withdrawal).

Hillary's son, who was born "*vital signs absent*," also spent time in the NICU due to medication withdrawal:

I heard after the fact, the obstetrician saying, "Well, you know, they shouldn't have given her that medication when she was already on something else." .... Well, now you're saying that?! Why wasn't this talked about before? I kept asking before I went into active labour, "what kind of effect will this have on the baby?" And the anesthesiologist said, "Oh, it's fine, it's fine." Obviously they didn't take into account or underestimated the impact it would have in conjunction with the medication I was already on. That was really frustrating and frightening because it definitely had a detrimental effect on my son.

#### *Lack of communication and collaboration among providers*

Related to perinatal care providers' lack of knowledge and experience, several participants described a lack of communication and collaboration among perinatal and disability-related providers. For instance, commented Hillary:

There's a lot of siloing that goes on in the medical community, especially if you have a complex disability like mine when you have issues dealing with chronic pain and a physical disability that the two don't communicate. You get excellent care in those two separate areas but they don't communicate with each other.

Some participants, such as Sarah, tried to initiate inter-professional communication:

I was watched by internal medicine and I kept telling them to get in contact with my rheumatologist. I don't know how many times I asked and I don't think they ever did at all.

Together with a lack of knowledge and experience, some participants felt as though the lack of communication and collaboration among providers may have contributed to some of the poor outcomes that they and their infants had experienced. Sarah in particular felt this way, as she experienced major complications during labor and delivery and as a result spent 8 days in the ICU after her son was born:

I asked so many times for them to touch base because I know my rheumatologist has had many pregnant women [as patients]. ... He has a lot of experience but they never contacted him and I still remember, he was so angry after this whole [situation] because he came to visit me in ICU. So then they finally call me [he said]. But it was already too little, too late. I was in intensive care. I was critically ill. I think I came close to death, including my son. His Apgar score, when he was born, was 0. Luckily it went up. He wasn't breathing because I wasn't breathing.

Similarly, Hillary recalled that, moments after her son was born, *"nobody was really talking to each other; not a lot of collaboration and then just sort of a flurry of activity to do damage control after the fact."*

#### *Misunderstandings of disability and disability-related needs*

Many of the barriers encountered by participants might be best explained by a lack of understanding of disability and disability-related needs among perinatal care providers. Some participants shared that their providers seemed to fixate on one aspect of their disability over others (e.g., mobility over pain management or vice versa) and/or seemingly overlooked their disability or disability-related concerns to focus only on their pregnancy and delivery.

I don't really feel like I was cared for my arthritis very well by the obstetrical staff (Sarah).

There was a risk that I would lose mobility and he wasn't interested in helping me with any of that aspect. He was just focused on the delivery. ... I requested a prescription to go get afterwards and on the prescription pad for physio, they had put down the wrong diagnosis – MS [multiple sclerosis] – it's like oh, you really are clueless with what's going on (Jennifer, who has muscular dystrophy).

Relatedly, some felt as though their disability and disability-related concerns were dismissed as individual concerns and told that they would just "figure it out."

I kept trying to say to people I have a disability and I need some help and I need someone to pay attention to that. And I really wasn't getting a lot of uptake so in one way, it was kind of the opposite. People would say to me "oh well, you know, like look at you, you'll do fine. You get along fine. You're great. You'll just figure it out, I'm sure." Well, I don't think I can figure this out on my own; I would like some help (Heather).

Some participants reported feeling dehumanized, as though their providers equated them with disability, and similarly, some reported feeling like a spectacle. For example, Heather contended that, *"people talk about you and about your disability without actually talking to you about it."* In her follow-up interview, Heather shared a

particularly inappropriate encounter that she had with her obstetrician during pregnancy:

They don't see me as a person anymore. I'm a disability. ... We were talking about something to do with my concerns, and she reached over and pulled my sleeve up. I tend to keep my sleeve down because I find it cuts down on my daily awkward exchanges and interactions. But she pulled my sleeve up and held my arms out to this resident. Like, "well you can see, she's got this disability and this disability." And it made me feel like ok, so I'm not a person in this exchange. ... People didn't seem to pay much attention [to my disability]. When it did flip, it was the wrong kind of attention.

Finally, participants' reported instances of providers who seemed uninterested in consulting or acknowledging participants' embodied knowledge of disability.

I figured that it would be known, that you work with me, because I know my body, I'm very sensitive to my body. ... The second doctor that came along, "okay, I want you to scoot down and your butt's going to be in the air and you're going to like push," and I'm like, "no, that's not going to happen." I'm trying to explain to her I cannot be half hanging off a table, because of the surgeries that I've had, and trying to explain to her I have a disability, it's real, it's not just I have canes or I have a wheelchair or scooter because I've injured myself. ... I'm the doctor, I know what's best ..... She just ignored me (Whitney).

The doctor was really, really unhelpful .... they had me on my back and I needed to have my knees in the air but they had no equipment to help me keep my knees in the air ... I was like you're not listening to me at all, you have no interest in listening to me and you just want to get out of here (Jennifer).

I said "it will be difficult to get the baby out if you don't hold my hip outwards" So the first time the OB did not listen and I was in labour and I was hyper ... so that was sort of missed (Julie, who had a much better second birth experience when her OB "listened to what I told her").

## **Discussion**

Participants reported several issues that made their experiences accessing perinatal care challenging, including negative attitudes and a lack of knowledge among providers. Moreover, some participants felt as though the barriers that they encountered in perinatal care settings, including a lack of communication and collaboration among providers, may have contributed to poor outcomes for themselves and their infants.

Although it is not my intention to give the impression that the perinatal care experiences of all participants were entirely negative, borrowing words from Thomas,<sup>26</sup> this paper emphasized the "bad" or "poor" rather than "good" perinatal care experiences with the hope that, once understood, steps can be taken to address these barriers. The fact that many of the barriers to perinatal care reported by participants in this study echo those of the participants in Thomas' study<sup>26</sup> and more recent studies<sup>20–23,27</sup> further supports the contention that more needs to be done to address barriers to perinatal care for women with physical disabilities. It is appalling that little seems to have changed in nearly 20 years regarding the perinatal care experiences of women with physical disabilities. Indeed, many of the recommendations made below are consistent with those made 15–20 years ago.<sup>28–31</sup>

What this study and others like it illuminate is that the pregnant body is assumed to be a non-disabled body and the practices and physical space of perinatal care settings are set up according to this assumption. In other words, the narratives of participants in this study reveal that the perinatal care system is not set up with women with physical disabilities in mind, or that many of the barriers reported by participants are manifestations of informational and institutional erasure. These two mutually reinforcing types of erasure theorized by Bauer et al.<sup>32</sup> to describe the health care experiences of trans populations can be applied to women with physical disabilities in the context of perinatal care. Informational erasure includes both a lack of knowledge of marginalized groups and their needs and the assumption that such knowledge does not exist even when it may. Relatedly, institutional erasure occurs through a lack of policies that accommodate marginalized identities or “bodies, including the lack of knowledge that such policies are even necessary.”<sup>32(p. 354)</sup> Examples of institutional erasure include administrative forms that do not include marginalized identities and actual practices that exclude or ignore the possibility of providing service to marginalized populations, or in the context of this study, the possibility that women with physical disabilities can be pregnant in the first place, as evidenced by the interaction that Whitney had with her obstetrician's receptionist.

To address erasure, a greater understanding of why many women with physical disabilities continue to report poor care experiences and outcomes is needed. Notably, there is a need to examine what factors might exacerbate or explain risks for poor care experiences and outcomes for women with physical disabilities, such as social support, socio-economic status, pre-pregnancy mental illness, and provider-level barriers. With regard to the provider-level barriers, a number of researchers have recently asked obstetricians and related health professionals to identify what they consider to be challenges or barriers to providing care to women with physical disabilities. The results from these studies in many ways echo barriers to care identified by women with physical disabilities themselves.<sup>33–35</sup> For instance, Mitra and colleagues,<sup>34</sup> who interviewed 14 obstetrician-gynecologists and certified nurse midwives who had experience providing perinatal care to women with physical disabilities in the U.S., found that providers also identified lack of inaccessible care settings and equipment and disability-specific training as barriers. Similarly, providers in Ireland acknowledged that they lacked knowledge regarding disability and subsequently did not always feel competent caring for women with physical disabilities.<sup>33</sup>

Increasing disability content in medical school curriculum and continuing education is vital to improve care experiences and outcomes for women with physical disabilities.<sup>19,33–36</sup> To ensure that this content is relevant, actively involving women with physical disabilities in the planning (design) and evaluation of training programs is recommended.<sup>33</sup> While it may not be feasible for all general obstetricians to have or receive experiential training for women with physical disabilities, it seems reasonable that at least maternal-fetal medicine specialists receive this training—though this may not address issues of access, as some women with physical disabilities may not be able to afford specialist care or live in areas where they can easily access a specialist. Because women with physical disabilities may already have established relationships with their disability-related provider(s) (e.g., physiatrist, rheumatologist, pain management specialist, physical therapist), improving communication and collaboration among perinatal and disability-related providers may be a crucial strategy to address this gap. Finally, it should be noted that greater disability-related training is not only needed for obstetricians but for other health professionals, paraprofessionals, and staff in perinatal care settings (e.g., nurses, ultrasound technicians, receptionists),<sup>34</sup> as evidenced

by participants' negative interactions with these individuals.

To identify what factors might exacerbate or explain risks for poor care experiences and outcomes, Mitra and colleagues<sup>37</sup> have developed a perinatal health framework for women with physical disabilities that utilizes a life course approach. This framework is a valuable tool for researchers, providers, and decision-makers in that it outlines multiple factors, including individual factors (e.g., marital status, primary disabling conditions and secondary conditions, body structure and function, activity limitations), mediating factors (e.g., prenatal education, financial support, provider knowledge, maternal mental health, social support), maternal and infant outcomes, and environmental context (e.g. physical accessibility of home and care setting, legislation and policy), that may impact the perinatal health of women with physical disabilities throughout the life course. This framework then highlights the need for greater collaboration among perinatal and disability-related providers, as well as “the need to include the disabled women themselves in their ‘plan of care’ for pregnancy, childbirth and postnatal care.”<sup>33(p.297)</sup> In short, this framework goes beyond the medical model of care to consider the whole person, in context, throughout the life course.

This study contributes to the limited research<sup>38–40</sup> on the perinatal care experiences and outcomes of women with physical disabilities in Canada. This study is unique because draws on the recent perinatal experiences of women with physical disabilities. In fact, most of the study participants had given birth within the last 3 years (including three who had given birth within 3 months of their baseline interview). Yet, the findings of this study and other recent studies with women with physical disabilities with older children suggest that little has changed over time regarding the perinatal care experiences of women with physical disabilities.

This study adds to the knowledge on the relationship between medication use among women with physical disabilities and infant outcomes. Though this relationship was not assessed quantitatively in this study, participants' interview responses suggest that providers know little about this relationship or interaction. Because many women with physical disabilities use medication regularly, ideally before conception, it is advised that women with physical disabilities and their providers discuss the potential risks of medication on the fetus as well as on the woman's health and quality of life.<sup>5,36,41</sup>

One participant's comments regarding the inaccessibility of the NICU are also noteworthy, as no other study to my knowledge considers women with physical disabilities' experiences of the NICU. Hillary's experience suggests that the NICU is designed only as a place for “sick” babies, not “sick” or disabled parents. Thus, not only is there a need to re-think the physical set up of perinatal care settings (e.g., labor/delivery rooms) and equipment in those settings to accommodate women with physical disabilities, there is a need to make NICUs more accessible and accommodating of physical disability, particularly given that some women with physical disabilities are at increased risk of preterm birth and in turn low birthweight infants.<sup>5,6,9,41</sup> Using data from the 2002–2011 Rhode Island Pregnancy Risk Assessment Monitoring System, Mitra and colleagues,<sup>6</sup> for instance, found that 13.8% of women with disabilities had an infant in the ICU at birth compared to 9.6% of non-disabled women.

Finally, there is a need for broader understandings of disability and disability-related needs. Participants' narratives reveal that sometimes movement or mobility limitations related to disability are not always of primary concern. Instead, in some instances, participants' experiences of chronic pain warranted further attention than did their mobility limitations in the context of perinatal care. This finding further emphasizes the need for discussion on medication use at preconception and throughout the perinatal

period.

The findings of this study are somewhat limited as they may not reflect the experiences of all women with physical disabilities in Ontario or Canada. Like other qualitative studies,<sup>20,39</sup> the findings presented here are based on interviews with a convenience sample of women with physical disabilities, most of whom were married, white, heterosexual, well-educated, and reside in large urban centers. As such, their experiences may not be representative of all women with physical disabilities, particularly women with disabilities who reside in rural and remote areas and who are low-income and/or racialized. More research is needed on the perinatal care experiences of women with physical disabilities who may be marginalized in other ways beyond sex/gender and disability status (i.e., do all women with physical disabilities have the same opportunities for childbearing?).

## Conclusion

Carty's assertion that "physicians and other health care providers rarely have training in the accessibility and sociopolitical aspects of disability and chronic illness"<sup>29(p.369)</sup> seems to ring true nearly 20 years later. Women with physical disabilities continue to encounter barriers to perinatal care, including inaccessible care settings and providers who lack knowledge about disability. Moving forward, more research and training are needed to address these barriers. More urgently, perhaps, in order to improve care experiences and outcomes, providers need to do a better job of listening to and working with women with physical disabilities.<sup>29,42</sup>

If you want me to talk about my disability or to explain something, then you should ask me. Don't just decide for me (Heather).

## Disclosures

The author has no conflicts of interest to declare.

## Prior presentations

Some of the findings in this paper were presented at the Association of Ontario Midwives' 32nd AGM and Conference (May 2016), the Society of Obstetricians and Gynecologists of Canada 72th Annual Clinical and Scientific Conference (June 2016), and the American Public Health Association 144th Annual Meeting and Exposition (October 2016).

## Funding

This project was supported by the Social Sciences and Humanities Research Council of Canada (Grant no. 752-2014-2624) (Doctoral Award), the Canadian Institutes of Health Research (Fellowship in Health Care, Technology, and Place - TGF-53911), and the Dalla Lana School of Public Health, University of Toronto (Open Fellowship and Doctoral Completion Award).

## Acknowledgments

The author wishes to thank Lori Ross for her feedback on an early draft of this paper, Jing Bian for assistance with interview transcription, and the study participants for sharing their experiences.

## References

- Americans with Disabilities Act. *Americans with Disabilities Amended Act of 2008*; 2008. <https://www.ada.gov/pubs/adastatute08.pdf>.
- Nations United. *Convention on the Rights of Persons with Disabilities*. New York, NY: United Nations; 2006. Retrieved from: <http://www.un.org/disabilities/convention/conventionfull.shtml>.
- Iezzoni LI, Yu J, Wint AJ, Smeltzer SC, Ecker JL. Prevalence of current pregnancy among U.S. Women with and without chronic physical disabilities. *Med Care*. 2013;51(6):555–562.
- Horner-Johnson W, Darney BG, Kulkarni-Rajasekhara S, Quigley B, Caughey AB. Pregnancy among US women: differences by presence, type, and complexity of disability. *Am J Obstet Gynecol*. 2016;214(4):529.e1–529.e9.
- Signore C, Spong CY, Krotoski D, Shinowara NL, Blackwell SC. Pregnancy in women with physical disabilities. *Obstet Gynecol*. 2011;117(4):935–947.
- Mitra M, Clements KM, Zhang J, Iezzoni LI, Smeltzer SC, Long-Bellil LM. Maternal characteristics, pregnancy complications, and adverse birth outcomes among women with disabilities. *Med Care*. 2015;53(12):1027–1032.
- Kelly VM, Nelson LM, Chakravarty EF. Obstetric outcomes in women with multiple sclerosis and epilepsy. *Neurology*. 2009;73(22):1831–1836.
- Redshaw M, Malouf R, Gao H, Gray R. Women with disability: the experience of maternity care during pregnancy, labour and birth and the postnatal period. *BMC Pregnancy & Childbirth*. 2013;13:174.
- Morton C, Le JT, Shahbandar L, Hammond C, Murphy EA, Kirschner KL. Pregnancy outcomes of women with physical disabilities: a matched cohort study. *PM&R*. 2013;5(2):90–98.
- Mitra M, Clements KM, Zhang J, Smith LD. Disparities in adverse preconception risk factors between women with and without disabilities. *Matern Child Health J*. 2016;20(3):507–515.
- Steinmetz E. *Americans with Disabilities: 2002. Current Population Reports*. Washington, DC: US Department of Commerce, Economics and Statistics Administration; 2006. Retrieved from: <https://www.census.gov/prod/2006pubs/p70-107.pdf>.
- Pharr JR, Bungum TJ. Health disparities experienced by people with disabilities in the United States: a behavioral risk factor surveillance system study. *Glob J Health Sci*. 2012;4(6):99–108.
- Nosek MA, Foley CC, Hughes RB, Howland CA. Vulnerabilities for abuse among women with disabilities. *Sex Disabil*. 2001;19:177–189.
- DisAbleD Women's Network Canada. *Factsheet: Women with Disabilities and Violence*; 2014. Retrieved from: <http://www.dawnncanada.net/main/wp-content/uploads/2014/03/English-Violence-January-2014.pdf>.
- Nosek MA, Hughes RB. Psychosocial issues of women with physical disabilities: the continuing gender debate. *Rehabil Couns Bull*. 2003;46(4):224–233.
- Statistics Canada. *A Profile of Persons with Disabilities Among Canadians Aged 15 Years or Older, 2012*; 2015. Retrieved from: <http://www.statcan.gc.ca/pub/89-654-x/89-654-x2015001-eng.htm>.
- Mitra M, Manning SE, Lu E. Physical abuse around the time of pregnancy among women with disabilities. *Matern Child Health J*. 2012;16(4):802–806.
- Parish SL, Rose RA, Andrews ME. Income poverty and material hardship among US women with disabilities. *Soc Serv Rev*. 2009;83(1):33–52.
- Tarasoff LA. Experiences of women with physical disabilities during the perinatal period: a review of the literature and recommendations to improve care. *Health Care Women Int*. 2015;36(1):88–107.
- Mitra M, Long-Bellil LM, Iezzoni LI, Smeltzer SC, Smith LD. Pregnancy among women with physical disabilities: unmet needs and recommendations on navigating pregnancy. *Disabil Health J*. 2016;9(3):457–463.
- Smeltzer SC, Mitra M, Iezzoni LI, Long-Bellil L, Smith LD. Perinatal experiences of women with physical disabilities and their recommendations for clinicians. *J Obstet, Gynecol Neonatal Nurs*. 2016;45(6):781–789.
- Iezzoni LI, Wint AJ, Smeltzer SC, Ecker JL. Physical accessibility of routine prenatal care for women with mobility disability. *J Women's Health*. 2015;24(12):1006–1012.
- Walsh-Gallagher D, Sinclair M, McConkey R. The ambiguity of disabled women's experiences of pregnancy, childbirth and motherhood: a phenomenological understanding. *Midwifery*. 2012;28(2):156–162.
- Charmaz K. *Constructing Grounded Theory: A Practical Guide through Qualitative Analysis*. London, UK: SAGE Publications Ltd; 2006.
- QSR International Pty Ltd. *NVivo Qualitative Data Analysis Software (Version 11)*. 2014.
- Thomas C. Medicine, gender, and disability: disabled Women's health care encounters. *Health Care Women Int*. 2001;22(3):245–262.
- Bertschy S, Geyh S, Pannek J, Meyer T. Perceived needs and experiences with healthcare services of women with spinal cord injury during pregnancy and childbirth: a qualitative content analysis of focus groups and individual interviews. *BMC Health Serv Res*. 2015;15(1). <http://dx.doi.org/10.1186/s12913-015-0878-0>.
- Rogers J, Matsumura M. *Mother-to-be: A Guide to Pregnancy and Birth for Women with Disabilities*. first ed. New York, NY: Demos Medical Publishing; 1991.
- Carty EM. Disability and childbirth: meeting the challenges. *Can Med Assoc J*. 1998;159:363–369.
- Lipson JG, Rogers JG. Pregnancy, birth, and disability: women's health care experiences. *Health Care Women Int*. 2000;21(1):11–26.
- Thomas C, Curtis P. Having a baby: some disabled women's reproductive experiences. *Midwifery*. 1997;13(4):202–209.
- Bauer GR, Hammond R, Travers R, Kaay M, Hohenadel KM, Boyce M. "I Don't think this is theoretical; this is our lives": how erasure impacts health care for transgender people. *J Assoc Nurses AIDS Care*. 2009;20(5):348–361.
- Walsh-Gallagher D, Mc Conkey R, Sinclair M, Clarke R. Normalising birth for women with a disability: the challenges facing practitioners. *Midwifery*.

- 2013;29(4):294–299.
34. Mitra M, Smith LD, Smeltzer SC, Long-Bellil LM, Sammet Moring N, Iezzoni LI. Barriers to providing maternity care to women with physical disabilities: perspectives from health care practitioners. *Disabil Health J*. 2017. <http://dx.doi.org/10.1016/j.dhjo.2016.12.021> [Epub January 3, 2017].
  35. Joseph, M., Saravanabavan S., & Nisker J. (Submitted for publication). Physicians' Perceptions of Barriers to Equal Access Reproductive Health Promotion and Care for Women with Mobility Challenges.
  36. Byrnes L, Hickey M. Perinatal care for women with disabilities: clinical considerations. *J Nurse Pract*. 2016;12(8):503–509.
  37. Mitra M, Long-Bellil LM, Smeltzer SC, Iezzoni LI. A perinatal health framework for women with physical disabilities. *Disabil Health J*. 2015;8(4):499–506.
  38. Cooper N. *Pregnancy and Parenting Experiences of Canadian Women Living with Physical Disabilities* [Unpublished master's thesis]. Toronto, ON: University of Toronto; 2006.
  39. Prilleltensky O. A ramp to motherhood: the experiences of mothers with physical disabilities. *Sex Disabil*. 2013;21(1):21–47.
  40. Sterling L, Keunen J, Wigdor E, Sermer M, Maxwell C. Pregnancy outcomes in women with spinal cord lesions. *J Obstet Gynaecol Can*. 2013;35(1):39–43.
  41. Signore CC. Pregnancy in women with physical disabilities. In: Queenan JT, Spong CY, Lockwood CJ, eds. *Queenan's Management of High-risk Pregnancy: An Evidence-based Approach*. sixth ed. West Sussex, UK: John Wiley & Sons, Ltd; 2012:253–259.
  42. Kirshbaum M. Parents with physical disabilities and their babies. *Zero Three*. 1988;8:8–15.