

# Perinatal care experiences of women with physical disabilities in Ontario

Lesley A. Tarasoff, MA, PhD Candidate  
Dalla Lana School of Public Health  
University of Toronto

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# Background

- American research indicates that women with physical disabilities give birth at similar rates to non-disabled women (1,2), yet they encounter numerous barriers to perinatal care (3-5) including:
  - Physical barriers
  - Attitudinal barriers
  - Informational barriers
- We know very little about the perinatal care experiences and outcomes of women with physical disabilities in Canada and Ontario because physical disability is often not included as a demographic item on population-based surveys (e.g., the Canadian Maternity Experiences Survey), among other reasons.

1) Iezzoni et al., 2013; 2) Horner-Johnson et al., 2016; 3) Signore et al., 2011; 4) Tarasoff, 2015; 5) Mitra et al., 2016

# Methods

Identify as a woman with a physical or mobility-limiting disability
Reside in the province of Ontario, Canada
Given birth within the last 5 years
Fluent in English and age 18+

- Convenience sample
- Demographic questionnaire
- Semi-structured interviews: baseline with 13 participants; follow-up with 10 participants
- Analysis informed by constructivist grounded theory (1)

# Participants

Variable	N = 13
<b>Disability*</b>	
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

\*Some participants reported having more than one disability or health condition

Variable	N = 13
<b>Use of Assistive Device</b>	
Yes	11
<b>Pain</b>	
Always present	7
Comes and goes	3
No pain	3
<b>Marital Status</b>	
Married	9
Common law	3
Single/Never married	1

- Mean age = 36.5 years (range 26-44)
- Most were well-educated
- All resided in cities with populations of over 130,000, mainly in the GTA

# Outcomes

Variable	N = 13
Prenatal Course Attendance	
Yes	7
“Crash course”/In hospital	2
No	4
Main Perinatal Care Provider*	
Obstetrician	11
Family doctor	2
General practitioner	1
Midwife	2
Other	3

\*Some participants reported having more than one main provider (e.g., a team of rotating obstetricians and nurses) or changing their perinatal provider part way through pregnancy

Variable	N = 13
Type of Birth	
Vaginal	5
Cesarean	8
Planned	5
Unplanned/Emergency	3
Total Number of Children	
One	7
Two	4
Three	1
Four**	1

\*\*Includes twins and 2 step-children

# Care Experiences

- 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
  5. Misunderstandings of disability and disability-related needs

# Inaccessible care settings

- *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 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*
- *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]*

# Negative attitudes

- *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?*
- *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].*

# Lack of knowledge and experience

- *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.*
- *They had experiences with persons with disabilities but not specifically with persons with cerebral palsy.*
- *They didn't know how my meds would interact with [my son] ...there were a lot of unknowns definitely.*

# Lack of communication and collaboration among providers

- *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.*
- *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

- *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.*
- *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.*

# Conclusions

- The perinatal care system is not set up with women with physical disabilities in mind.
- Barriers to perinatal care may contribute to poor outcomes.
- More research and training is needed to address barriers to perinatal care for women with physical disabilities.
  - Inclusion in population-based and prospective studies
  - More disability-related training
  - Collaboration among perinatal and disability-related providers
  - Inclusion of women with physical disabilities in educational initiatives and care plans

# Thank you! Questions?

## Thank you

- Supervisory committee
- Study participants

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## Questions?

- [lesley.tarasoff@utoronto.ca](mailto:lesley.tarasoff@utoronto.ca)
- [www.latarasoff.com](http://www.latarasoff.com)

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