



Pregnancy among women with physical disabilities: unmet needs and recommendations on navigating pregnancy

Introduction

Though research suggests that women with physical disabilities are just as likely to be pregnant as women without disabilities, there isn't as much information for women with physical disabilities about navigating pregnancy, childbirth, and motherhood. Women with physical disabilities may face unique challenges when it comes to pregnancy care; they have reported that their clinicians do not have all the information necessary to manage their pregnancies, may be misinformed about their disabilities, and express harmful stereotypes about disability and sexuality. Many clinicians do not have accessible offices and equipment such as scales. Additionally, research has shown that women with physical disabilities may be at higher risk for poor birth outcomes like low birthweight and premature birth. Our goal with this study was to identify the unmet needs and barriers that women with physical disabilities experience during pregnancy, childbirth and motherhood so that care can be improved at a systemic level.

We conducted a qualitative study that consisted of interviews with 25 women with physical disabilities. To participate, women must have given birth in the past ten years and been 55 or younger when they were interviewed. Recruitment methods included disability- and community-related email lists, websites, and social media. Participants were interviewed in English for up to two hours; after the interviews, the transcripts were reviewed for relevant themes related to disability, pregnancy, and childbirth.

Results

Participant characteristics

- Most participants were white and not Latina.
- The average age of the participants at the time of their youngest child's birth was 32.
- Fifteen women had planned pregnancies.
- Ten women had unplanned pregnancies.
- Eighteen women used some form of assistive technology.
- Nearly half the women had children between the ages of 5 and 10.
- Seven women had children who also had disabilities.

Unmet needs

The interviews revealed three general types of unmet need for pregnant women with disabilities.

1. Clinician knowledge and attitudes

Many women reported that their clinicians were less knowledgeable about their specific disability than they would have preferred, some offered inaccurate information, and some expressed negative stereotypes about people with disabilities. One obstetrician warned a woman who used a wheelchair that she would “automatically deliver at 26 weeks,” and if her child were to survive the pregnancy, it “would be mentally and physically disabled.” The women perceived these statements to be solely based on the fact that she uses a wheelchair. Another obstetrician asked a woman how she was able to be pregnant and jokingly asked whether she used a turkey baster. One nurse refused to touch a woman’s amputated leg to help push during labor. Another nurse told a participant that “it was wonderful that somebody like (her) would still want to have a kid.”

Despite some women’s negative experiences, some women described very positive experiences with their providers. One woman described her providers as “treat(ing) her like a regular patient” without a disability. Another said that her doctor “understood that... she was making an educated decision.”

2. Physical accessibility of health care facility and equipment

Participants often encountered inaccessible medical offices and equipment, including exam tables, weight scales, bathrooms, and hospital beds. Several women reported not ever being weighed throughout their pregnancy. Some clinicians tried to guess their weight by looking at them, while several were weighed while their partner held them.

3. Need for information about pregnancy and postpartum supports

Participants received very little information about the interactions between their disabilities and their pregnancies. Women often found themselves relying on informal support networks. Unfortunately, some women were isolated from other women who shared the same disabilities and could not receive advice derived from first-hand experiences. It was also difficult for them to identify knowledgeable clinicians. Once their children were born, participants also struggled to find information about accessible equipment they could use with their children, like cribs, bassinets and changing tables.

Recommendations for other women with physical disabilities

We asked the women in the study what advice they would give to other women with physical disabilities who are pregnant or considering becoming pregnant. Their advice included:

- **Find a supportive clinician.** Look for a clinician who is open-minded, supportive, respectful, and willing to learn about your specific disability as needed. If you feel a clinician is not right for you, find a different one.

- **Seek peer support from other mothers with disabilities.** Seek peer support early in pregnancy. Peer support could be in different formats such as online groups or local and national disability-related organizations.
- **Be assertive and advocate for yourself.** Do not be afraid to self-advocate and stand up for your needs and preferences.
- **Prepare as much as possible.** Do your own research about how your disability might affect pregnancy, preferably before the pregnancy and meeting with their prenatal care clinician. Researching adaptive equipment like accessible cribs and reclining wheelchairs.

Limitations

There were some limitations to this study that may affect the generalizability of the study to the broader population of women with physical disabilities.

- All the women participating were volunteers; women who felt more positive about their pregnancy experiences may have been more likely to choose to participate than those who had more negative experiences.
- Study information was distributed through social media, disability organizations and community organizations, meaning that the participants may be more connected to the disability community than non-participants.
- Participants were overwhelmingly White and were all English-speakers. Interviews and recruitment materials were only available in English, so may not reflect perspectives of women with different racial and ethnic backgrounds.
- The study did not collect information about social class, so this study cannot draw any conclusions about a relationship between class and pregnancy experiences for women with physical disabilities.
- The data are qualitative, based on women's own self-perceptions. There is a possibility that participants' memories may be skewed or inaccurate, though their detailed recollections suggest that they are accurate.

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