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

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Abstract

Background—Despite concerns raised in the literature on the adverse pregnancy outcomes of women with physical disabilities, there is little information about unmet needs of women with physical disabilities during pregnancy and childbirth.

Objective—This article provides an in-depth examination of unmet healthcare needs during and around the time of pregnancy among a sample of women with physical disabilities. It also offers recommendations to other women with physical disabilities who are considering pregnancy.

Methods—Twenty-five phone interviews were conducted with women with physical disabilities from across the United States who had a baby in the past ten years. Individual semi-structured qualitative interviews lasting about two hours were conducted. Interviews were audio-recorded, transcribed, and analyzed using an iterative, interpretive process.

Results—Women reported a wide range of disabling conditions. Analysis revealed three broad themes related to unmet needs during pregnancy among women with physical disabilities. They included (1) clinician knowledge and attitudes, (2) physical accessibility of health care facilities and equipment, (3) need for information related to pregnancy and postpartum supports. The women also provided recommendations to other women with disabilities who are currently

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pregnant or thinking of becoming pregnant. Recommendations related to finding a clinician one trusts, seeking peer support, self-advocating, and preparing oneself for the baby.

Conclusions—This study sheds light on the unmet needs and barriers to care of women with mobility disabilities during pregnancy and childbirth. The study findings highlight the need for policy and practice recommendations for perinatal care of women with mobility disabilities.

Keywords

disability; pregnancy; perinatal health; women with physical disabilities; qualitative

Introduction

The literature on pregnancy among women with physical disabilities suggests that, after adjusting for age, women with chronic physical disabilities are as equally likely as their nondisabled peers to be currently pregnant. (1) However, women with physical disabilities may have a somewhat elevated risk for poor birth outcomes such as low birth weight and preterm birth compared to women without disabilities. (2-4) In addition, women with physical disabilities report that their clinicians are often ill-equipped to manage their pregnancies effectively and that health care professionals often lack knowledge about their disabilities and may possess negative stereotypes about the sexuality of women with disabilities. (5-20) Lack of accessible medical offices, examination tables and scales creates additional barriers to the proper monitoring of pregnancy. (6, 7, 21) However, scant information is available to guide women with physical disabilities who are considering pregnancy and motherhood.

Using descriptive qualitative data gathered from individual interviews with twenty-five women with mobility disabilities, we seek to build on prior research by systematically examining the unmet needs and barriers to perinatal care experienced by women with physical disabilities. In addition we outline recommendations made by women in the study to other women with physical disabilities considering pregnancy and childbirth. Our findings increase understanding of the specific dimensions of unmet needs for women with disabilities during pregnancy and could shed light on potential strategies to enhance the pregnancy experience and maternal and birth outcomes of women with physical disabilities.

Methods

The study was approved by the University of Massachusetts Medical School, Review Board.

Participants

As part of a larger mixed method study on the health needs and barriers to care around the time of pregnancy, interviews were conducted with women with physical disabilities from across the United States. To be eligible, a woman must have had a physical disability or health condition that affected her ability to walk or to use her arms or hands at the time of her pregnancy, have delivered a child within the last 10 years, and be age 55 or younger at the time of the interview.

Information about the study was disseminated through a variety of methods including email lists, websites, and social media of disability-related organizations, local community-based organizations, blogs and social media of individuals active in the disability community.

Out of the 31 women the study coordinator screened or attempted to screen, 2 were screened as ineligible, 2 were not able to be reached for screening, and 2 were interviewed but later determined by the investigators to be inappropriate for the study due to absence of mobility impairment and were excluded from analysis. The final sample analyzed contains 25 women. Once the study coordinator determined a woman to be eligible, the coordinator scheduled the interview and provided confirmation of the details of the interview and the informed consent document. This study was granted a waiver of documentation of consent by the IRB, so the women were not required to sign and return it. At the beginning of each interview, the interviewer confirmed receipt of the informed consent and asked the women if they had any questions or concerns they wanted to discuss.

Data collection

Interviews were conducted in English by one of two interviewers over the phone and lasted a maximum of two hours. The interviews followed a semi-structured moderator's guide developed by the study's co-investigators informed by the literature and a preliminary focus group. Interviews were audio-recorded and transcribed. Data collection continued until saturation was reached at 25 interviews and until no new themes emerged from the data.

Data Analysis

Interview transcripts were content analyzed in an iterative, interpretive process. This content analysis was intended to be descriptive not to generate theory. The investigators reviewed transcripts and identified an initial set of themes, which evolved into a codebook as additional transcripts were reviewed. Codes were continuously revised as themes and patterns emerged. One primary coder coded all the interviews and met repeatedly with the Principal Investigator throughout the coding process to discuss and clarify codes. A process for assessing reliability and consistency of coding across data was established based on Kurasaki's method. (22) The data were analyzed using *Atlas.ti*.

Results

Participant Characteristics

The average age of the women at the time of the youngest child's birth was 32. Nearly half of the women had children between the ages of 5-10, and two were pregnant with their second child at the time of the interview. Fifteen women had a pregnancy which was planned and ten unplanned. Twenty had fathers present in the lives of their child and five fathers were not present (see table 1).

Women in the study reported a range of disabling conditions including dwarfism, muscular dystrophy, osteogensis imperfecta (OI), spinal muscular atrophy (SMA), cerebral palsy, amputation, spinal cord injury, spina bifida, and multiple sclerosis. Eighteen of the women use some form of assistive technology.

Unmet needs

Data analysis revealed three broad themes related to unmet needs during pregnancy among women with physical disabilities. They included (1) Clinician knowledge and attitudes, (2) Physical accessibility of health care facilities and equipment, and (3) Need for information related to pregnancy and postpartum supports. These findings are described below using case examples and participant quotes.

1. Clinician Knowledge and Attitudes

Clinician Knowledge: Many of the women in the study described *“a real lack of information within the [obstetrician/gynecologist] community”* about the effect of their disability on pregnancy. Women often relied on their own research and information from other women with disabilities. Her only source of knowledge was through other women. *“So, you know, based on [another woman's] experiences, I knew kind of what to ask, but from a medical professional perspective --there was no one I could ask.”* Another respondent with spina bifida commented “*(I)t just kind of felt like they didn't know -- I was teaching them a lot of things, which is not totally uncommon.”* Several women said that their clinicians had never had a patient with any visible physical disability.

Clinician Attitudes: Women in the study reported a range of attitudes about their pregnancies from clinicians. For example, one woman said that her obstetrician/gynecologist was very supportive of her decision to have a child. Although the clinician was not experienced in providing care to women with her condition, she felt that the doctor *“understood that I was making this decision, I was making an educated decision.”* Another woman felt that was she being cared for like any other patient *“…I mean, she knew how badly we wanted to have a baby and was supportive … I feel like she treats me like a regular patient and like I don't have a disability.”*

Other women described being viewed by their clinicians as asexual, incapable of bearing children and being a mother. During a preconception appointment with an obstetrician, a woman who uses a wheelchair, was told that she “*would automatically deliver at 26 weeks and my child, if it lives, would be mentally and physically disabled…Strictly because I was in a wheelchair and I needed care myself.”* Another woman recalled a comment her clinician made to her upon finding out she was pregnant: *“I think probably the weirdest [comment] was … from my doctor…. He asked us how we got pregnant, and if we had used a turkey baster.”*

Women reported that nursing staff displayed a similar range of attitudes as the obstetricians involved in their care. More than one woman used the adjectives “great” and “wonderful” when describing the nursing staff. In contrast, however, some of the nurses expressed an unwillingness to help when needed. During childbirth, when one respondent was getting ready to push, the nurse *“refused to take the one [leg] and my husband had to actually come over and hold it because she didn't want to touch my stump.”* A few other women reported that the nurses were unwilling to assist with disability-related functional limitations. For example, one respondent recounted that, “*I was using a bedpan because I wasn't able to get* *up. And they were, like, complaining about having to help me with it … and they said that my husband needed to do it."*

As one woman described, *"the nurse that was prepping me was like, 'That's a good helper you have there.' And I looked at her and I'm like, 'You mean my husband, the father of this?' And I pointed to my stomach… It's like it didn't connect in her head that … I have a disability and oh, I'm married."* Another woman with an amputation below the left knee was told by a nurse that "it was wonderful that somebody like me would still want to have a kid."

2: Physical accessibility of health care facilities and equipment—The women frequently reported physically inaccessible medical offices and equipment, such as inaccessible examination tables and weight scales. Most women reported that they had never encountered an accessible exam table even before becoming pregnant. When describing getting up on an examination table, one woman noted, *"It's a pain… pregnant or not. And it was hard and towards the end [of the pregnancy]… I'd get a stool and put a stool next to a chair, put a chair next to the table, and just kind of stair step my way up there."* In this instance, some women reported they preferred and in many cases were expected to be transferred by their partner/spouse. Similarly, a woman reported having difficulty being in her wheelchair due to her increased weight and never being weighed during her entire pregnancy. *"I'm not sure how much I gained actually, because there isn't really -- my doctors don't have a way of weighing me."*

Women in the study often described clinicians' attempts to determine their weight through indirect methods. One woman described the clinician weighing her spouse and then having her spouse hold her and weighing both together. Another woman described what happened when her clinician weighed her in her wheelchair, tracking the combined weight of the woman and her wheelchair together, saying *"(a)nd after he realized that I only put on like not even six pounds through about half of the pregnancy, [he said],'I'm not worried … I can tell by looking at you that you're at a healthy weight, you're OK.*" Another woman noted that "*(t)hey sort of looked at me and said … you're holding your weight fine.*"

During postpartum, women were often placed in inaccessible hospital rooms. For example, a woman who had a cesarean section reported having to carry a stool around in order to access the toilet, sink, and hospital bed. Women also had difficulty with bassinets and changing tables that were too high and too deep as well as restrooms that were inaccessible to wheelchair users. In some cases, women had to be taken to an accessible shower on a separate floor of the hospital.

3: Need for information—The women clearly identified a need for information about the potential impact of their disability on pregnancy and appropriate perinatal care. Many of the women in the study reported receiving and finding very little information on (1) the interaction of their disability and pregnancy, (2) appropriate prenatal care clinicians, and (3) postpartum supports including baby equipment. Information was most often retrieved through informal means, such as other women with similar experiences who had been pregnant, with one explaining that she had learned *"(the) most from other moms with disabilities."*

Unfortunately, some women did not have any success finding information or connecting with mothers with similar disabilities. For example, one respondent noted, *“I really didn't have anybody to turn to, so there -was - not much information that I knew about pregnancy and having a disability … There's nobody I knew -- who was disabled and having kids.”* In more recent years, women described finding social media to be a helpful source of information, but still found information lacking.

Women also articulated a need for information on postpartum supports including breastfeeding and accessible baby equipment such as bassinets, cribs, changing tables, baby bath equipment, and carriers. Women in this study had great difficulty finding accessible baby equipment and in many cases, used innovative methods to adjust baby equipment to their needs.

One participant, described the difficulty in changing diapers in community settings, *“Changing tables … [are] often hung way too high for me so …we often go back to the van or we've found ¨ another spot to do changes.”* Another respondent talked about doing extensive research to find an accessible baby carrier that would fit her specific needs.

Recommendations to Other Women with Physical Disabilities: At the end of the interview, the women in the study were asked to provide specific recommendations to other women with physical disabilities who are considering pregnancy and motherhood (see Table 2). Qualitative analysis of the recommendations revealed four major types of recommendations, including:

1. Select an appropriate clinician
2. Seek peer support from other mothers with disabilities
3. Be assertive and self-advocate
4. Prepare for pregnancy, childbirth, and postpartum

(1) Select an appropriate clinician: The mothers recommended carefully selecting a health care clinician who is “*open minded and supportive,”* as well as a clinician who has *“experience with people who have similar disabilities.”* It was vital, according to many of the women in the study, to “*find a good doctor that's willing to work with you. If he's not, you find another.”*

(2) Seek peer support from other mothers with disabilities: Another recommendation to other women with physical disabilities considering pregnancy and childbirth was to seek out support from women with similar disabilities who have given birth. One of the women suggested going *“online and talk[ing] to other disabled mothers first just to kind of get the tips and tricks of what's easier so you don't have to figure it out yourself.”* Women also advised accessing peer support early on the in the process, preferably during preconception and that they had learned *“most from have been from other moms with disabilities”.*

(3) Be assertive and self-advocate: Most women interviewed identified self-advocacy as essential. Self-advocacy encompassed believing in oneself, including one's own right to bear children. As one of the participants stated *"I don't think anyone has the right to tell anyone else that they should or shouldn't have a child."* Another woman advised *"You don't know what you are capable of yourself*" and "*don't be afraid to do it."* The importance of being assertive, asking questions and asking for help when needed was repeatedly emphasized by many of the women that were interviewed. One woman advised, *"Don't be afraid to talk to the doctor, nurses and everybody that's on your team so that they know exactly what you need and what you want."*

(4) Prepare for pregnancy, childbirth, and postpartum: Women in the study strongly recommended that women with physical disabilities should conduct their own research about the impact of their disability on the pregnancy and how their body would react to pregnancy. They suggested that the research should be conducted, whenever possible, before their pregnancy and before meeting with their prenatal care clinician. One participant suggested that women with physical disabilities should do their own research so that they *"Don't rely on the doctor to tell you whether or not you can do it. I mean, I didn't -- my doctor didn't tell me or advise me not to get pregnant."* One mother explained "*You have to advocate, you have to do your homework, you have to know, you know, what you need so that you can explain it to them [clinicians] and know when they're off base.*"

Talking to women with similar disabilities who have been through pregnancy and childbirth was important not only as a form of support but also as a means of research *"because you'll be able to do your research best by talking to other people that are near the same disability as you … they're the best teachers.*" Talking to peers was a way to gather information that was not available through their health care clinicians and other sources.

Participants also stressed the importance of looking into adaptive equipment such as *"accessible crib, the reclining wheelchair, making the home a little bit more accessible for bath time"* or, as one woman suggested, meeting with an occupational therapist in order to make the home environmentally accessible.

Discussion

This study used qualitative methodology to examine the perinatal care experiences of US women with physical disabilities. The results of the study highlight their unmet needs for care, information, and support during their pregnancy and at postpartum. Consistent with findings from earlier studies, these women reported several barriers to a positive, healthy pregnancy experience. The barriers included clinicians' lack of knowledge and their attitudes, inaccessible offices and equipment, inaccessible baby care equipment, and a lack of information on the effect of their disability on pregnancy. In addition, this study identified specific recommendations to other women with physical disabilities considering pregnancy and motherhood.

The findings of this study suggest that even now, twenty-five years after passage of the Americans with Disabilities Act and despite an emerging body of literature, little has changed with regard to the perinatal care experiences of women with physical disabilities. As in previous studies, this study shows that the lack of clinician knowledge and training continues to put women with physical disabilities at risk of receiving inaccurate or inappropriate advice about the risks and potential complications of pregnancy. This risk can result in difficulty making informed decisions and presents challenges to appropriate perinatal care for women with physical disabilities. The lack of clinician knowledge and training also creates challenges during the actual process of childbirth such as the choice of the method of delivery and with regard to risks that may arise during the childbirth process. Similarly, inaccessible examination tables and weight scales put women at risk of inadequate monitoring during pregnancy. Follow-up care in the hospital is compromised both by clinicians' lack of disability-specific training and by broader systemic issues such as low nurse/patient staffing ratios. These difficulties are exacerbated in those situations where clinicians have biased perceptions of women's sexuality. Lack of clinician training and knowledge can result in even the most well-intentioned clinicians providing inadequate, inappropriate, or even damaging advice to women with disabilities.

Disability and motherhood have historically been addressed as separate issues in health care and in public policy, including maternal and child health policy. There has not been a systematic effort to address the perinatal care needs of women with physical disabilities or a unified set of policies designed to ensure that their needs are met. The experiences and recommendations of the women with disabilities in this study and in previous work demonstrate that women are frequently left to research the potential impact of their pregnancy on their own and to turn to each other for information and support. While this self-advocacy and peer support have value in and of themselves, women should also feel that they are able to receive adequate information and support from their clinicians.

There are emerging efforts to address this issue, such as the web-based resource list and training modules created by the American College of Obstetricians and Gynecologists. (23) Developments such as this one represent meaningful progress on this issue, but there remains much work to be done. Despite the mounting evidence of the need for better preparedness among clinicians as demonstrated in this and previous studies, there are no specific training requirements regarding perinatal care for women with disabilities for obstetricians or for any of the nursing specialties. Section 4302 of the Affordable Care Act (24) requires provider organizations to report on their efforts to train providers about working with people with disabilities and Section 5307 (25) requires that providers actually receive disability cultural competence training, but neither provision has been enforced, nor is there an explicit mention of the needs of mothers with disabilities as a specific area of focus in either provision. (26)

Maternal and child health programs could also do more to provide clinician training, for example, by integrating requirements for perinatal care training for mothers with physical disabilities into their broader clinician education efforts. They could also make an affirmative effort to include women with physical disabilities in their maternal and child health programs whereas these mothers are currently included in such programs largely by happenstance. Additionally, maternal and child health programs could offer programs to facilitate peer support either independently or in collaboration with diagnosis-specific groups, such as the Muscular Dystrophy Association or with organizations such as independent living centers, which offer peer counseling as a core service. (27)

Although assistive technology is covered under Medicare, Medicaid, and some private policies, this coverage does not always include child care equipment because it may not be deemed “medically necessary” or may not conform to other program rules. (27-29) Some Medicaid programs permit the purchase of services, such as personal assistance services, to permit individuals to work. Similar changes to include items and services that facilitate parenting would represent significant progress. One example would be the “Nurturing Assistance” program that operates in Ontario, Canada that allows the time required for assistance with child care tasks to be included in the evaluation of need for personal assistance services for parents with physical disabilities. (27) Maternal and Child health programs could also play a role in disseminating information and training about assistive technology for parenting in cooperation with the National Center for Parents with Disabilities, along with other community organizations and health care providers.

Limitations

A major limitation of this study is that the women were all volunteers, which introduces the possibility of selection bias. It may be that women who participated were those who felt good about their experiences with childbirth, despite the challenges they may have encountered. Women who felt less positive about their experiences or had worse outcomes may have chosen not to participate. Since women were recruited using social media, disability-related organizations, and community-based organizations, the women who heard about the study are likely to be those that are well-connected in the disability community. The data in this study may not reflect the views of women who are less connected. The study sample was mostly White, interviews were only conducted in English, and recruitment materials were all in English. Therefore the unmet needs and barriers unique to women with physical disabilities of different racial/ethnic backgrounds may not be reflected in this study. Specific information about socio-economic status was not collected so the impact of socio-economic status on pregnancy experiences cannot be ascertained from this study. The data presented represent women's own perceptions of care they received. We could not validate the women's reports. White it is possible that memories were skewed or distorted over time, the detailed accounts provided by the women suggest that their recollections are accurate.

Conclusion

Just as public policy has evolved in the direction of encouraging individuals with disabilities to work, so it should support the aspiration of many women with disabilities to become parents. Clinicians should be provided the education necessary to prepare them to care for these women and both formal and informal supports should be made more widely available. The study also highlights a critical need for information on the potential impact of disability on pregnancy. In order to address the gaps in available information, developing strategies to disseminate information on pregnancy and disability, including prenatal care, to women with physical disabilities who are currently pregnant or are considering pregnancy should be an immediate priority.

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Table 1

Mothers with Physical Disabilities Sample Characteristics (at time of interview)

	n=25
Age	
21-25	4
26-30	8
31-35	9
36+	4
Race	
Non-Hispanic White	19
Other	6
Parity	
1	14
1+	11
Youngest child's age	
Under 1	6
1-3	4
3-5	4
5-10	11
Child has disability	7
Assistive technology use	18

Table 2
Recommendations to Other Women with Physical Disabilities

Recommendation	**Quotes**
1. Select an appropriate clinician	• Find a good doctor that's willing to work with you. If he's not, you find another • Definitely find an OB that is open-minded and supportive.
2. Seek peer support from other mothers with disabilities	• The things that I've learned the most from have been from other moms with disabilities. • I'd say go online and talk to other disabled mothers first just to kind of get the tips and tricks of what's easier so you don't have to figure it out yourself, but then just go do it.
3. Be assertive and self-advocate	• Don't be afraid to talk to the doctor, nurses and everybody that's on your team so that they know exactly what you need and what you want. • You have to advocate, you have to do your homework, you have to know, you know, what you need so that you can explain it to them and know when they're off base.
4. Prepare for pregnancy, childbirth, and postpartum as much as possible	• Start carrying -- carry that gallon of milk around the house. • Doing a little more legwork than I did in determining what you need beforehand, just to make the process a little bit easier, like the accessible crib, the reclining wheelchair…