

Research Paper

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 health care 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 2 h 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 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. © 2016 Elsevier Inc. All rights reserved.

Keywords: Disability; Pregnancy; Perinatal health; Women with physical disabilities; Qualitative

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

Financial disclosure: Authors have no financial interests to disclose.

This research is funded by a grant from the National Institutes of Health, Eunice Kennedy Shriver National Institute of Child Health & Human Development. Award Number: R01HD074581.

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experience and maternal and birth outcomes of women with physical disabilities.

Methods

The study was approved by the University of Massachusetts Medical School Institutional 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 2 h. 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, osteogenesis 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

Table 1
Mothers with physical disabilities sample characteristics (at time of interview)

| | <i>n</i> = 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 |

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