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Research paper

Barriers to providing maternity care to women with physical disabilities: Perspectives from health care practitioners

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ABSTRACT

Background: Women with physical disabilities are known to experience disparities in maternity care access and quality, and communication gaps with maternity care providers, however there is little research exploring the maternity care experiences of women with physical disabilities from the perspective of their health care practitioners.
Objective: This study explored health care practitioners' experiences and needs around providing perinatal care to women with physical disabilities in order to identify potential drivers of these disparities.
Methods: We conducted semi-structured telephone interviews with 14 health care practitioners in the United States who provide maternity care to women with physical disabilities, as identified by affiliation with disability-related organizations, publications and snowball sampling. Descriptive coding and content analysis techniques were used to develop an iterative code book related to barriers to caring for this population. Public health theory regarding levels of barriers was applied to generate broad barrier categories, which were then analyzed using content analysis.
Results: Participant-reported barriers to providing optimal maternity care to women with physical disabilities were grouped into four levels: practitioner level (e.g., unwillingness to provide care), clinical practice level (e.g., accessible office equipment like adjustable exam tables), system level (e.g., time limits, reimbursement policies), and barriers relating to lack of scientific evidence (e.g., lack of disability-specific clinical data).
Conclusion: Participants endorsed barriers to providing optimal maternity care to women with physical disabilities. Our findings highlight the needs for maternity care practice guidelines for women with physical disabilities, and for training and education regarding the maternity care needs of this population.

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Recent studies of unmet needs and barriers to maternity care for women with physical disabilities demonstrated that women experienced complex interactions with their maternity care providers.[1,2] While many women experienced their provider as supportive, compassionate and helpful, women also perceived negative attitudes and stereotypes about the sexuality and motherhood of women with physical disabilities from providers. Women reported a lack of knowledge on the part of the practitioner about their specific needs related to pregnancy, inaccessible health care settings including health care offices, equipment and birth facilities, and perceived failure of practitioners to consider the woman's knowledge and expertise related to her own disability.[1,2] Similar findings have been noted in other studies of maternity care experiences and outcomes of women with various disabilities, including physical disabilities.[3–6]

Though these communication gaps and attitudinal barriers reflect the interactions and experiences of men and women with disabilities with the larger health care system,[7–9] there is a paucity of research exploring the maternity care experiences of U.S. women with physical disabilities from the perspective of their health care

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practitioners. This study explored maternity care providers' experiences and challenges in caring for women with physical disabilities in the United States. This is part of a larger mixed-method study to understand the unmet needs and barriers to perinatal care among women with physical disabilities.

Methods

The researchers recruited 14 obstetrician-gynecologists and certified nurse midwives with experience providing maternity care to women with physical disabilities. Practitioners were identified and recruited through the American Congress of Obstetrics and Gynecology, the American College of Nurse Midwives, affiliations with disability-related organizations, publications in the area of pregnancy and disability, indications of work with women with physical disabilities in online professional profiles, and snowball sampling. The study team reached out to the identified health care practitioners to confirm experience caring for pregnant women with physical disabilities and invited them to participate in individual semi-structured telephone interviews. Informed consent was obtained during the scheduling process.

The researchers identified and contacted 33 health care practitioners in February through April of 2015. Sixteen practitioners were unable to be reached and/or scheduled, and an additional three stated that they did not have sufficient experience caring for women with physical disabilities. The researchers conducted and analyzed 14 semi-structured interviews, which lasted an average of 45 min each.

All interviews were conducted over the phone by a study co-investigator who is also a health care practitioner. Interviews were audio-recorded with the participant's consent and then professionally transcribed. After collecting details about the practice and experience caring for women with physical disabilities, our interview guide focused on participant perceptions of unmet needs/barriers for women with physical disabilities related to maternity care and birth and barriers for health care practitioners in caring for women with physical disabilities. Participants were also asked about their perceptions regarding the utility of developing guidelines or practice recommendations and their recommendations for other health care practitioners related to caring for this population.

For this preliminary review of a novel topic, the researchers chose to use a process that was intended to be descriptive and not to generate theory. As an initial step, four investigators independently generated descriptive codes through reviewing two transcripts each. The codes were then discussed and refined in a series of team meetings and a descriptive codebook was developed based on the descriptors present in the data, as well as thorough review of the literature and application of public health theory. Next, one primary coder then applied the codebook to all 14 transcripts using descriptive analysis, and codes were further modified and revised throughout this process. The primary coder met with the principal investigator frequently to further refine the codebook in response to issues that arose within the data and inter-coder conflict. Inter-coder conflicts were settled by consensus. After codes were generated and all transcripts coded, we applied a theory driven conceptual framework developed from our knowledge of public health theory, a deductive qualitative technique that has been used by other health services researchers in tight, results-oriented qualitative designs.[10] Our application of social science/public health theory focused on organizing the codes into four levels of barriers, which were identified using theming. Atlas.ti version 7 was used to manage the codes.

This study was reviewed and approved by the Brandeis University, University of Massachusetts Medical School and Villanova University School of Nursing Institutional Review Boards.

Results

The sample included health care practitioners with expertise in obstetrics/gynecology, maternal-fetal medicine, certified nurse midwifery, and medical genetics. The participants had an average of 22 years of experience caring for pregnant women with physical disabilities, with a range of 6–40 years of experience. They cared for a varying volume of women with physical disabilities, with a range of a few per year to five or more per month. The participants practiced in a variety of settings, including hospitals, university practices, solo practices, and specialty clinics specifically for women with disabilities. They reported providing care to women with a range of physical disabilities including multiple sclerosis, muscular dystrophy, cerebral palsy, spinal cord injury, amputation, and dwarfism, among others. Most of the participants are currently seeing women with physical disabilities in their practices. Several previously worked in practices where they saw women with disabilities but they have since moved to different practices.

Numerous barriers were identified through our descriptive analysis and were grouped into four levels of barriers: Practitioner level; Clinical practice level; System level; and Barriers relating to lack of scientific evidence. Fig. 1 depicts the levels of barriers and Table 1 summarizes the identified barriers, with representative quotes.

Practitioner level barriers

Participants described several practitioner level barriers to optimal maternity care for women with physical disabilities, including (1) practitioner lack of training and education related to maternity care and specific clinical needs of women with physical disabilities (in general), (2) unwillingness and, in some cases a lack of confidence, among practitioners in general in providing maternity care to women with physical disabilities, and (3) inadequate coordination of care between practitioners.

Almost all participants described a lack of education and training related to the maternity care needs of women with physical disabilities. As noted by one practitioner, “It would be really great if during fellowship there was something, or even during residency there was some sort of … educational tool to … help us out.” participants felt that this lack of training can lead to extremely

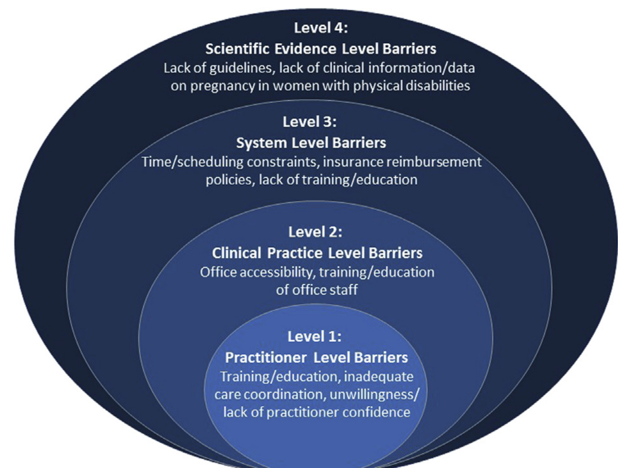

Fig. 1. Four levels of practitioner-identified barriers to providing maternity care to women with physical disabilities.

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