Published in final edited form as:

J Obstet Gynecol Neonatal Nurs. 2016 ; 45(6): 781–789. doi:10.1016/j.jogn.2016.07.007.

Perinatal Experiences of Women With Physical Disabilities and Their Recommendations for Clinicians

Suzanne C. Smeltzer, RN, EdD, ANEF, FAAN,

Professor and Director of the Center for Nursing Research, Villanova University College of Nursing, Villanova, PA

Monika Mitra, PhD,

Associate professor in the Lurie Institute for Disability Policy, Heller School for Social Policy and Management, Brandeis University, Waltham, MA

Lisa I. Iezzoni, MD, MSc,

Professor in the Harvard Medical School, Mongan Institute for Health Policy, Massachusetts General Hospital, Boston, MA

Linda Long-Bellil, PhD, JD, and

Assistant professor in the Center for Health Policy and Research, University of Massachusetts Medical School, Shrewsbury MA

Lauren D. Smith, MPH

Research associate in the Lurie Institute for Disability Policy, Heller School for Social Policy and Management, Brandeis University, Waltham, MA

Abstract

Objective—To explore the perinatal experiences of women with physical disabilities (WWPD) and their associated recommendations for maternity care clinicians to improve care.

Design—A mixed-method study was conducted using a semi-structured interview guide to identify the experiences of WWPD. This qualitative descriptive study is part of a larger study and was conducted to examine the perceptions of WWPD about their interactions with maternity care clinicians and their recommendations for maternity care clinicians to improve care.

Participants—Twenty-five women with physical disabilities who gave birth within the last 10 years and were 21–55 years of age were recruited and agreed to participate in the study.

Methods—Participants were asked about their interactions with clinicians during pregnancy and their recommendations for clinicians to improve perinatal care for women with physical

Corresponding Information: Suzanne C. Smeltzer, RN, EdD, ANEF, FAAN, Center for Nursing Research, Villanova University College of Nursing, 800 Lancaster Avenue, Villanova, PA 19085, suzanne.smeltzer@villanova.edu.

Disclosure

The authors report no conflict of interest or relevant financial relationships.

Publisher's Disclaimer: This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final citable form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

disabilities. Transcribed interviews were analyzed using content analysis. Themes that emerged from analysis of the interviews were identified and coded. Kurasaski's coding was used to establish the reliability of the coding.

Results—Three themes emerged from analysis of the interview data: clinicians' lack of knowledge about pregnancy-related needs of WWPDP; clinicians' failure to consider knowledge, experience, and expertise of women about their own disabilities; and clinicians' lack of awareness of reproductive concerns of WWPDP. Women provided recommendations that warrant attention by clinicians who provide perinatal care for women who live with physical disabilities.

Conclusion—Participants experienced problematic interactions with clinicians related to pregnancy and identified recommendations for maternity care clinicians to address those problems with the goal of improving perinatal health care for WWPDP.

Keywords

pregnant women; women with disabilities; unmet perinatal health care needs; physical disabilities

Women with disabilities that affect mobility, including those with significant physical limitations, are becoming pregnant each year, and the number of pregnancies in this population is expected to continue to increase (National Institute of Child Health and Human Development, 2010). It is estimated that almost 165,000 women with disabilities that affect their upper or lower extremities become pregnant each year. This includes more than 44,000 women who report severe physical disabilities (Iezzoni, Yu, Wint, Smeltzer, & Ecker, 2013). Despite the passage of the Americans with Disabilities Act 25 years ago, individuals with disabilities, including those with physical disabilities, continue to experience barriers to health care (Peacock, Iezzoni & Harkin, 2015); the negative effects of these barriers extend to pregnant women with physical disabilities. A growing body of research has demonstrated that women with disabilities have unmet needs and experience complications related to pregnancy and childbearing that are uncommon in women without disabilities (Iezzoni, Yu, Wint, Smeltzer, & Ecker, 2014, 2015; Mitra, Clements, Zhang, & Smith, 2016a; Mitra, Long-Bellil, Iezzoni, Smeltzer, & Smith, 2015). Women with physical disabilities (WWPD) reported negative attitudes toward them from acquaintances as well as strangers (Iezzoni, Wint, Smeltzer, & Ecker, 2015a; Nosek, Rintala, Howland, Foley, & Bennett, 1995). They have also reported negative attitudes to their pregnancy on the part of health care clinicians and lack of knowledge about their needs related to pregnancy (Begley et al., 2009; Mitra et al., 2016b; Nosek et al., 1995). Women with disabilities have described inaccessible health care settings, including hospital rooms and clinical offices, and absence of adjustable tables and scales needed to obtain weights if they have limited mobility or are wheelchair users (Iezzoni, Wint, Smeltzer & Ecker, 2015b). Additional issues identified by WWPDP include their need for information about the interaction of their disability and pregnancy, and for knowledgeable health care clinicians who are sensitive to their needs and respectful of their desire to become parents (Mitra et al., 2016b; Smeltzer, 2007a).

Lack of transportation and the presence of inaccessible facilities have been identified as major barriers to the reproductive health care of WWPDP (Iezzoni, Wint et al., 2015b; Nosek et al., 1995). Negative attitudes, behaviors, and lack of awareness and insensitivity to the

needs of women with disabilities during pregnancy (Mitra et al., 2016b; Nosek et al., 1995; Smeltzer, 2007a) have been identified as barriers that are often even more difficult to overcome than the physical barriers (Schopp, Sanford, Hagglund, Gay, & Coatney, 2002).

CALLOUT 1

This study was part of a larger mixed-method study of the unmet needs and barriers to perinatal care experienced by WWPD (Mitra et al., 2015a; 2016b). Other parts of the study included quantitative analysis of data from large national data sets and data obtained through surveys. The results of analysis addressed in this article are limited to the interactions of WWPD with maternity care clinicians and women's recommendations to improve perinatal care for WWD.

Methods

A qualitative descriptive research study (Sandelowski, 2000; 2010) with telephone interviews was conducted to examine the descriptions and perceptions of WWPD about their perinatal experiences and their recommendations for strategies to improve perinatal health care. Women were recruited for the study using several strategies that included use of e-mail lists, websites, social media of disability-focused agencies and local community-based organizations, blogs, and social media pages of individuals active in the disability community. Eligibility included reporting a current physical disability or condition that limited the participants' abilities to walk without assistance or use their arms or hands. The disability had to be present during a pregnancy within the last 10 years. The participants needed to be between 21 and 55 years of age at the time of their study participation. Women who learned about the study through the recruitment strategies and were interested in participating in the study were asked to contact the project coordinator and interviews were scheduled. Participants were sent an informed consent document prior to the interview. Individual interviews were conducted by two co-investigators using a semi-structured interview guide based on literature, a preliminary focus group, and the results of the researchers' previous research and experience working with WWPD.

The interview guide included 56 questions with additional probes that addressed a wide range of topics related to perinatal experiences of women in general with specific questions related to their perceptions of the interaction of their disability and pregnancy. These included discussion of the women's specific disability, their own and others' views about pregnancy in women with disability, prenatal care issues, labor and delivery issues, physical accessibility, and postpartum care issues. The analysis reported in this paper focused on the women's descriptions and perceptions of their interactions with their maternity care clinicians and women's recommendations to clinicians address problematic interactions. The institutional review boards of University of Massachusetts, Brandeis University, Villanova University and the Massachusetts General Hospital approved the study. Documentation of written consent was waived by the IRB. Informed consent was reviewed with the women and they provided verbal consent to participate.

Sample

Thirty-one women responded to the invitation to participate. Two of the women could not be reached for screening, two were deemed ineligible when screened, and two were interviewed but later identified as ineligible because of lack of mobility impairment. Twenty-five WWPD participated in the telephone interviews. Table 1 presents demographic characteristics of the participants. Their mean age of women at the time their youngest child was born was 37.4 ± 7.0 . Fifteen women reported that their pregnancies were planned and ten reported unplanned pregnancies. Women reported diverse disabling conditions: 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 used some form of ambulation or wheeled mobility aide.

Procedures

Telephone interviews were scheduled at times convenient for the women and two members of the research team who conducted all interviews. The interviews, up to 2 hours in length, were conducted in English, audio-recorded, and transcribed by a professional transcription service. The accuracy of the transcriptions was verified by a member of the research team. Traditional content analysis was used to analyze the transcriptions (Hsieh & Shannon, 2005; Sandelowski, 2000; 2010). The transcriptions of the interviews were independently read by members of the research team to identify salient points. The research team then used those salient points to identify categories of concerns related to interaction with clinicians and recommendations related to those concerns made by women for the health care providers. The transcriptions were again reviewed to identify specific examples of their interactions with clinicians and the recommendations provided by the women. Codes were continuously revised and final themes with supporting examples of women's quotes were identified (Lincoln & Guba, 1985). Reliability of coding was established using Kurasaki's (2000) method of coding, which is useful with coding data from a variety of qualitative approaches. This content analysis was intended to be descriptive and not to generate theory. Atlas.ti was used to assist with data analysis.

CALLOUT 2

Results

Women with physical disabilities described their interactions with health care providers and provided a number of recommendations for clinicians about how they could improve perinatal care for women with physical disabilities. Three major categories of themes related to women's interactions with health care providers emerged from the analysis: *clinicians' lack of knowledge about pregnancy-related needs of WWPD*; clinicians' failure to consider knowledge, experience, and expertise of WWPD about their own disabilities; and *clinicians' lack of awareness of reproductive concerns of WWPD*. Women also provided recommendations to health care providers associated with each of these three themes. Examples of selected responses for each theme are provided in Table 2.

Clinicians' lack knowledge about perinatal needs of women with physical disabilities—Most women believed that their clinicians had little knowledge about the

effect of disability on pregnancy in general or of the potential effect of their specific disability during pregnancy, labor and delivery. Women indicated that in some cases clinicians viewed them as “problems”: “They just somehow think that we’re going to be more of a problem for them. I think they’re afraid, and I don’t know if it’s about liability or possibly their fallibility.” Several women attributed clinicians’ bias and negative reactions to lack of clinicians’ knowledge about perinatal needs of WWPDP.

Women perceived that they were being treated as less than normal: “there was just a lack of understanding, and I think there was also a lack of understanding that just because I happen to have a disability, did not mean that I was not perfectly normal, for lack of a better word.”

The women reported being most comfortable with clinicians who did their research, reviewed the health history of their patients, consulted with the patients’ doctors and other doctors who had treated women with similar conditions.

Related Recommendations

Several participants recommended that clinicians who are not knowledgeable about a woman’s disability and its effect on her pregnancy acknowledge their lack of disability-specific training and experience, but indicate their willingness to learn about it. They urged clinicians to indicate that they are willing to learn by finding relevant information on the topic. They urged clinicians to say to women “I need to research this.” They recommended that if clinicians have little knowledge about the pregnancy-related issues of WWPDP, they seek this information and become better informed to improve their care. They identified a variety of sources of information that clinicians could use to educate themselves about their patients’ disability, including conducting their own literature and Internet searches to obtain information about specific disabling conditions. In addition, they recommended that clinicians obtain information about their patients’ disability from their health histories or medical records and by consulting with other clinicians who have worked with the patient, including their primary health care clinician, rehabilitation specialists, and other specialists (e.g., pulmonologists, neurologists) who participate in their health care: “I would say get the research and find out from other doctors (clinicians), like my doctor did. Get my past health records, and things like that to see how everything was for me.” One woman stated, “...they should not be afraid to talk to the neurologist or physiatrist and work with them.”

The participants suggested that clinicians obtain information through organizations that support individuals with specific disabilities (e.g., Osteogenesis Imperfecta Foundation, United Cerebral Palsy Association, Little People of America). They further indicated that providers could learn from other women with similar disabilities who have gone through childbirth. Other women with the same disability could be an important source of information because many WWD know others with the same disability through links to organizations and agencies that provide support and services to women. Respondents also suggested that clinicians locate and review case studies of pregnant women who have specific types of disabilities.

An additional recommendation was for clinicians to use the information they obtained to think through what information mothers with disabilities might need related to caring for

their newborn once they are discharged home, for example, how they are going to be able to carry, care for, and feed the newborn once discharged home.

Clinicians' failure to consider women's own knowledge, experience, and expertise about their own disabilities—The second theme was women's experiences of having their clinicians ignore or discount their sometimes life-long knowledge, experience, and expertise about their own disabilities. Although WWPD can be a valuable source of information for their clinicians about their disability, many reported that clinicians often failed to ask women about their own experiences and disability or ignored their attempts to share information with clinicians. All study participants articulated that having lived with a long-term physical disability, they knew their bodies well: "...we know what's going on with our bodies. We know our bodies best, unless, you know, unless there's a medical emergency." Women stated that clinicians often underestimated what they knew about their own disabilities. One woman stated,

Every time I talked, everything I said to him, he blew me off. And I said, "You know, I'm an expert on my body. I know what's normal and what's not normal." And the fact that he would refuse to take cues from me, he refused to take any suggestions I had. You know, and... I even said to him..."I was a patient here before. Why don't you pull up the info...from last time...just pull up the notes, the chart from last time." And he was like, "No, no. I'm fine. I've got this." You know, and it was...I mean, I hear horror stories from women with disabilities all the time in terms of dealing with the medical profession, especially around maternity issues, and it was the first time that I was just sort of like, "wow."

Another participant stated:

One of the real challenges is finding doctors who are respectful and who treat you like you have intelligence...And you need to make sure, especially when you have some experience with a condition, they take what you say seriously, and that they don't assume you have no cognitive ability because you have a disability....I have had (that experience) often enough that I'm really cautious.

One participant indicated that clinicians often make unfounded assumptions about pregnancy-related needs of WWPD without confirming facts with them. Having confidence that the clinician understood their specific needs was important to the women in the study.

Not all of women's experiences were negative. Those participants who reported positive experiences explained that their clinicians' abilities to listen to them and to communicate with them as well as to be respectful of their views were key to their experiences being positive. One woman described her positive experience with her clinician: "[He] respected me, he valued my opinion and my choices and he respected my experience...he was the one experienced at delivering high-risk babies, but I was the one, you know, that knew my own body."

Related Recommendations

Based on interactions in which clinicians discounted women's knowledge and experience, the participants recommended that clinicians take the time to ask, listen, and respect the knowledge and experience of WWPD. They recommended that clinicians "trust...listen to the patients. Don't just necessarily shrug us off." Participants suggested that clinicians learn from the woman herself. As one woman's recommendation to clinicians was "Definitely do your research, ask those questions, ask questions of the patient. If you really want to know about how things affect me or certain things, ask me as well." Participants also stated that clinicians should ask what they can do to be of help because the patient is the one who is going to know, unless the disability is newly acquired. They recommended that clinicians listen to their patients to better understand their disability and its effects on their pregnancies.

Study participants stated that good communication goes beyond listening to the woman and addressing the needs of her disability and her abilities. They recommended that clinicians treat WWPD with the same respect and care as other women. They indicated that respect and dignity should be the cornerstone of the care provided to WWD just as they are for all other women. Respect and listening were identified as paramount in the care of WWD: "Listen to her fears, concerns, but also listen to her abilities and not just her disabilities, know her. To me, the biggest thing is them respecting you."

Clinicians' lack of awareness of reproductive concerns of women with physical disability—Women indicated that clinicians often treated them as if they were asexual and unable to become pregnant (prior to seeking pregnancy care), to maintain a pregnancy, or to parent a child. The study participants reported that as WWPD, they continue to receive the message from clinicians that they cannot or perhaps should not become pregnant and have children because they have a disability. In some cases, women's clinicians chastised them for becoming pregnant, which generated distress, uncertainty, and anger on the part of the women, who often had pursued pregnancy only after carefully weighing the pros and cons of pregnancy and childbearing.

Several participants indicated that because of lack of knowledge and personal bias about pregnancy and childbearing in WWPD, some clinicians imposed their own views on women: "He literally told me that I needed to remain abstinent." Another woman reported that her clinician said to her, "If I were your parents, I would do anything I could to convince you to adopt." Another woman indicated that a clinician said to her before she became pregnant, "Look how disabled you are and you really shouldn't be...you should not get pregnant." Women indicated that some clinicians seemed to be unaware that WWPD have "the ability and the right to have a child, just like anyone else, and as a medical care provider, they need to not have their own personal views affect what advice they might give to a patient." Another woman noted,

I just think that medical professionals need to remind themselves to remove your bias and your judgment from work with all of your other patients and women with disabilities deserve the same respect and integrity. You know, if I go to you for your

medical opinion about my pregnancy I want just that, I don't want your personal opinion.

The women felt that clinicians should realize that having a disability is not a contraindication to pregnancy and motherhood. One woman noted that clinicians are likely to see increasing numbers of people with disabilities as children and as parents because of less stigma associated with disability and growing awareness that individuals with disabilities "can be sexual and they don't have to feel like they can't reproduce just because they're different." Clinicians made assumptions about the woman's sexuality and their ability to parent:

I think that they just need to not be so quick to make assumptions. You know, I mean there are plenty of able-bodied women that have children just on a whim, or they get pregnant constantly. I went into this fully educated and knowing my body could handle it. I just needed the support from a doctor that could help with the pregnancy part.

Several women reported that their health care providers were solely focused on their physical disabilities as in the case of a woman with spinal muscular atrophy (SMA) who is a wheelchair user:

The first couple of preconception appointments I had, the OBs were very negative. They of course did not really understand SMA, so they were coming in just seeing the disability, with some preconceived notions. I had one tell me that I 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.

Related Recommendations

Women recommended that health care professionals look beyond a woman's disability and not forget that the person who's in front of them is a new mother who has the same emotions, desires, and needs as other women. They urged clinicians to treat WWPD in the same way they regard and treat other women. Another participant said clinicians "...just kind of need to get their eyes open to the fact that disabled people are sexual, too, and they're going to reproduce." They recommended that clinicians "Treat them as women. They're women who get pregnant just like everybody else and we're able to be parents...just because you're disabled, but you're not – you haven't stopped being a woman, or you still want to be a mom."

The participants indicated that health care clinicians need to set aside their personal bias, prejudices and personal views when providing reproductive and prenatal care to women with physical disabilities. They urged clinicians to avoid personal judgments, stereotypes and biases against pregnancy and motherhood among women with disability. They further recommended that women with disabilities be a voice at the table when guidelines and policies related to topics ranging from infertility to birthing options for WWPD are discussed.

Discussion

In this qualitative descriptive study, we addressed experiences and perceptions of WWPD related to pregnancy and women's recommendations for health care clinicians based on those experiences. The women's experiences and their recommendations reflected the gaps in perinatal health care for women with diverse disabilities that have been identified in other studies and emphasized the importance of interactions of clinicians with women with disabilities (Begley et al., 2009; Iezzoni, Yu et al., 2013; 2014; Mitra et al., 2016b; Nosek et al., 1995; Schopp et al., 2002; Smeltzer, 2007b). Although a number of women in the study identified positive aspects of the care they received, they nevertheless perceived issues and gaps in care that warrant attention by clinicians who provide perinatal care to WWPD.

This lack of knowledge about disability in general and about pregnancy in WWPD specifically is likely related in part to lack of attention to disability in the education and training programs of clinicians. The resulting lack of clinicians' knowledge puts WWPD at higher risk during pregnancy than women without disabilities. Many of these women are at higher risk for complications of pregnancy than other women because of complex health issues related to their disability (Iezzoni, Yu et al., 2014, 2015; Mitra et al., 2016a; Signore, Spong, Krotoski, Shinowara, & Blackwell, 2011). Although some of the issues identified by the women in this study may also occur in women without disabilities, the WWPD who participated specifically addressed the issues within the context of having a physical disability.

Women provided a number of recommendations in response to their perceptions that their clinicians lacked adequate knowledge about disability and its effect on pregnancy and childbearing. They indicated that clinicians need to be aware of the complexity of women's disabilities and of the interaction between their disability and pregnancy. Although a number of authors have addressed the inadequacy of educational preparation of health professionals to provide quality care to individuals with disabilities (Kirschner & Curry, 2009; Smeltzer, 2007b; U.S. Department of Health and Human Services; 2005), progress to address this issue has been slow. Concerted efforts to address the gap in health professionals' education about disability and the interaction of disability and pregnancy are needed to ensure that WWPD receive care that is safe and likely to result in good outcomes for the women and their children (Signore et al., 2011; Tarasoff, 2015). The participants also indicated that health care professionals should include WWPD in the dialogue around reproductive health and that they should "be a voice at the table" when such issues are addressed.

Mitra, Long-Bellil, Smeltzer and Iezzoni (2015) developed a perinatal care framework to better understand the health of WWPD during the perinatal period. An important mediating factor identified in this framework is clinicians' knowledge and attitudes towards pregnancy among WWD that potentially influence birth outcomes and quality of life for women. Use of this framework can aid clinicians and educators in providing appropriate care and support. Further research is also needed to examine the effect of strategies to increase clinicians' knowledge and improve their attitudes towards pregnancy among WWPD on the care they deliver.

The experiences of women in our study and their recommendations also reflected lack of awareness or sensitivity on the part of women's health care clinicians. Participants described lack of knowledge, awareness, sensitivity, and respect, as well as stereotyping as factors that contributed to their receiving compromised perinatal care. Although pregnancy and childbirth in women with disabilities have become more common and are viewed with less stigma than previously (Iezzoni, Wu et al., 2013), the responses and recommendations of the women in this study suggested that stereotyping and stigma still exist. Several women stated emphatically that they were seeing health care professionals for medical and maternity care and did not want or welcome clinicians' personal opinions and judgments that reflected bias and negative reactions to pregnancy in WWPD. There is an important role for health professional organizations, such as the Association of Obstetricians and Gynecologists (ACOG), American College of Nurse-Midwives (ACNM), and Association of Women's Health, Obstetric and Neonatal Nurses (AWHONN), to address these issues and to develop and disseminate practice guidelines, and provide educational opportunities to their members so that they are prepared to provide high quality, sensitive care to WWPD related to pregnancy and childbearing.

The participants in this study indicated that discussion of reproductive health care of WWPD and development of practice guidelines should include WWD to ensure that the issues and the guidelines address issues that are of concern to them. Again, they want their views, opinions, and experiences to be recognized, heard, and valued.

Despite the concerns identified in the literature about the adverse pregnancy outcomes of WWPD, few policy and practice recommendations exist for perinatal care for this population. When developing such policies and practice guidelines, professional organizations and agencies should involve WWPD because only women who have directly experienced unmet needs during pregnancy can accurately and comprehensively define and describe their experience. Even well-meaning clinicians often fail to recognize barriers and poor care experiences among persons with disabilities (Iezzoni & O'Day, 2005). Furthermore, because persons with mobility disability continually navigate challenging physical and social environments, they often have developed highly-honed practical solutions to improving care they receive during pregnancy.

Limitations

Similar to many qualitative studies, selection bias was a possible limitation of this study because women responded to invitations to participate posted on social media and conveyed through disability-related and community-based organizations. Additionally, elite bias is possible because the participants in the sample generally had access to computers and the Internet to receive social media messages; women without these resources were likely beyond the reach of the recruitment strategies. Further, interviewees may be well connected to others with disabilities and their recommendations may not reflect those of women who are not as well connected to such organizations. Women in the study had diverse types of physical disabilities; however, women with other types of disabilities are not represented in the sample. The sample was homogenous in ethnicity; all spoke English and most were White. Women's experiences were conveyed by self-report in response to interview

questions and were not verified with their clinicians. The inclusion criterion of having given birth within the last 10 years could have led to selective recall, another possible study limitation.

Conclusion

Recommendations for maternity care clinicians caring for WWPD were based on the perinatal experiences of women with physical disabilities. Women's recommendations were based on their perceptions that health care clinicians lack knowledge about pregnancy within the context of disability and clinicians' failure to increase their knowledge to a level that inspires confidence in the women. The need on the part of clinicians to listen to WWPD and to respect them and their expertise and knowledge based on years of living with their disability was identified by almost all participants in the study. Further, women recommended that clinicians avoid stereotyping and bias and to view WWPD as sexual persons capable of becoming pregnant, having children, and becoming mothers. They expressed the need for clinicians to learn and understand women's disabilities, and to see women beyond their disabilities. Education of health care professionals about disability is essential to remove stigma and bias toward WWPD. Education of clinicians about the interaction of disability with pregnancy was identified as essential if WWD are to receive the high quality health care during pregnancy that they and their offspring deserve.

References

- Begley, C.; Higgins, A.; Lalor, J.; Sheerin, F.; Alexander, J.; Nicholl, H.; ... Kavanagh, R. Women with Disabilities: Barriers and Facilitators to Accessing Services During Pregnancy, Childbirth and Early Motherhood. Dublin, Ireland: National Disability Authority; 2009.
- Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qualitative Health Research*. 2005; 15(9):1227–1288. DOI: 10.1177/1049732305276687
- Iezzoni LI, Yu J, Wint AJ, Smeltzer SC, Ecker JL. Prevalence of current pregnancy among US women with and without chronic physical disabilities. *Medical Care*. 2013; 51(6):555–562. DOI: 10.1097/MLR.0b013e318290218d [PubMed: 23604018]
- Iezzoni LI, Yu J, Wint AJ, Smeltzer SC, Ecker JL. General health, health conditions, and current pregnancy among U.S. women with and without chronic physical disabilities. *Disability & Health Journal*. 2014; 7(2):181–188. DOI: 10.1016/j.dhjo.2013.12.002 [PubMed: 24680047]
- Iezzoni LI, Yu J, Wint AJ, Smeltzer SC, Ecker JL. Effects of disability on pregnancy experiences among women with impaired mobility. *Acta Obstetrica et Gynecologica Scandinavica*. 2015a; 94(2):133–140. DOI: 10.1111/aogs.12544 [PubMed: 25417861]
- Iezzoni LI, Yu J, Wint AJ, Smeltzer SC, Ecker JL. Physical accessibility of routine prenatal care for women with mobility disability. *Journal of Women's Health*. 2015b; 24(12):1006–12. DOI: 10.1089/jwh.2015.5385
- Iezzoni LI, Wint AJ, Smeltzer SC, Ecker JL. "How did that happen?" Public responses to women with mobility disability during pregnancy. *Disability and Health Journal*. 2015; 8(3):380–387. DOI: 10.1016/j.dhjo.2015.02.002 [PubMed: 25944504]
- Iezzoni, LI.; O'Day, BL. More than ramps: A guide to improving health care quality and access for people with disabilities. Oxford, England: Oxford University Press; 2005.
- Kirschner KL, Curry RH. Educating health care professionals to care for patients with disabilities. *JAMA*. 2009; 302(12):1334–1335. DOI: 10.1001/jama.2009.1398 [PubMed: 19773571]
- Kurasaki KS. Intercode reliability for validating conclusions drawn from open-ended interview data. *Field Methods*. 2000; 12:179–194. DOI: 10.1177/1525822X0001200301
- Lincoln, YS.; Guba, EG. Naturalistic Inquiry. Newbury Park, CA: Sage Publications; 1985.

- Mitra M, Clements KM, Zhang J, Iezzoni LI, Smeltzer SC, Long-Bellil L. Maternal characteristics, pregnancy complications and adverse birth outcomes among women with disabilities. *Medical Care*. 2015a; 53(12):1027–1032. [org/10.1097/MLR.0000000000000427](https://doi.org/10.1097/MLR.0000000000000427). [PubMed: 26492209]
- Mitra M, Clements KM, Zhang Y, Smith LD. Disparities in adverse preconception risk factors between women with and without disabilities. *Maternal and Child Health Journal*. 2016a; 20(3):507–515. [org/10.1007/s10995-015-1848-1](https://doi.org/10.1007/s10995-015-1848-1). [PubMed: 26518009]
- Mitra M, Long-Bellil LM, Smeltzer SC, Iezzoni LI. A perinatal health framework for women with physical disabilities. *Disability and Health Journal*. 2015b; 8(4):499–506. DOI: 10.1016/j.dhjo.2015.05.007 [PubMed: 26189010]
- Mitra M, Long-Bellil L, Iezzoni LI, Smeltzer SC, Smith LD. Pregnancy among women with physical disabilities: Unmet needs and recommendations on navigating pregnancy. *Disability and Health Journal*. 2016b; 9(3):457–463. [org/10.1016/j.dhjo.2015.12.007](https://doi.org/10.1016/j.dhjo.2015.12.007). [PubMed: 26847669]
- National Institute of Child Health and Human Development, Office of the Director. Pregnancy in women with physical disabilities. 2010. <http://www.nichd.nih.gov/news/profiles/KnowNICHD/signore/Pages/default.aspx>
- Nosek MA, Young ME, Rintala DH, Howland CA, Foley CC, Bennett JL. Barriers to reproductive health maintenance among women with physical disabilities. *Journal of Women's Health*. 1995; 4(5):505–518. [org/10.1089/jwh.1995.4.505](https://doi.org/10.1089/jwh.1995.4.505).
- Sandelowski M. Whatever happened to qualitative description? *Research in Nursing & Health*. 2000; 23(4):334–340. DOI: 10.1002/1098-240X(200008)23:4<334::AID-NUR9>3.0.CO;2-G [PubMed: 10940958]
- Sandelowski M. What's in a name? Qualitative description revisited. *Research in Nursing and Health*. 2010; 33(1):77–84. DOI: 10.1002/nur.20362 [PubMed: 20014004]
- Schopp LH, Sanford TC, Hagglund KJ, Gay JW, Coatney MA. Removing service barriers for women with physical disabilities: Promoting accessibility in the gynecologic care setting. *Journal of Midwifery & Womens Health*. 2002; 47(2):74–79. [org/10.1016/S1526-9523\(02\)00216-7](https://doi.org/10.1016/S1526-9523(02)00216-7).
- Signore C, Spong CY, Krotoski D, Shinowara NL, Blackwell SC. Pregnancy in women with physical disabilities. *Obstetrics & Gynecology*. 2011; 117(4):935–947. DOI: 10.1097/AOG.0b013e3182118d59 [PubMed: 21422868]
- Smeltzer SC. Improving the health and wellness of persons with disabilities: A call to action too important for nursing to ignore. *Nursing Outlook*. 2007a; 55(4):189–193. [org/10.1016/j.outlook.2007.04.001](https://doi.org/10.1016/j.outlook.2007.04.001). [PubMed: 17678684]
- Smeltzer SC. Pregnancy in women with disabilities. *Journal of Obstetric, Gynecologic, & Neonatal Nursing*. 2007b; 36(1):88–96. DOI: 10.1111/j.1552-6909.2006.00121.x
- Tarasoff LA. Experiences of women with physical disabilities during the perinatal period: A review of the literature and recommendations to improve care. *Health Care for Women International*. 2015; 36(1):88–107. DOI: 10.1080/07399332.2013.815756 [PubMed: 23998776]
- US Department of Health and Human Services. The Surgeon General's call to action to improve the health and wellness of persons with disabilities. US Department of Health and Human Services, Office of the Surgeon General; 2005.

Table 1Demographic Characteristics of Sample of Women with Physical Disabilities (at time of interview), *N*=25

Age	
21–25	4
26–30	8
31–35	9
36	4
Mean age: 37.4 ± 7.0	
Race	
Non-Hispanic White	19
Other	6
Highest Education Level	
High school	2
Some college	7
4-year college degree	11
Graduate degree	5
Marital Status	
Married	19
Not married	6
Parity	
1	14
>1	11
Youngest child's age	
<1 year	6
1–3 years	4
3–5 years	4
5–10 years	11
Assistive technology use	
Used mobility aid	18
Did not use mobility aid	7

Table 2

Categories of Women's Interactions with Clinicians Providing Perinatal Care to Women with Physical Disabilities and Women's Recommendations

Interaction	Sample Quotations
<p><i>Clinicians lack knowledge about pregnancy-related needs of women with physical disabilities.</i> Conduct your own research and seek information about the disability or disabling condition from multiple sources, including women themselves. Acknowledge that you don't know about a woman's disability and its effects during pregnancy but be willing to learn.</p>	<p>"If they want to provide good care, they have to do a lot of research and not always if they have the time, but if they really want to provide the best care, they have to research it." "And if you don't understand, don't be ashamed to say, 'I need to research this' or ask the mother, 'Do you know somebody with your disability that has had a baby?'"</p>
<p><i>Clinicians fail to consider women's knowledge, experience, and expertise about their own disabilities.</i> Listen to women with physical disabilities and respect their knowledge and experience.</p>	<p>"We know what's going on with our bodies. We know our bodies best, unless, you know, unless there's a medical emergency." "Ask questions such as 'What works for you or has worked for them in the past?'" "Trust your patients. We've been through a lot, and we know what we're talking about, you know." "Respect the woman that is having the baby...really listen to her."</p>
<p><i>Clinicians lack awareness of reproductive concerns of women with physical disabilities.</i> Regard women with physical disabilities as sexual beings who are capable of becoming pregnant, bearing children, and being parents; view women beyond their disabilities and without personal biases and stereotypes.</p>	<p>"Because you're disabled...you haven't stopped being a woman, or you still want to be a mom." "Treat them as women. They're women who get pregnant just like everybody else and we're able to be parents." "Women with disabilities have the ability and the right to have a child, just like anyone else, and...care providers need to not let their own personal views affect what advice they give to a patient." "Medical (health) professionals need to remind themselves...to remove their bias and judgment from work with all of their patients. Women with disabilities deserve the same respect and integrity."</p>