



Experiences of Women with Physical Disabilities Related to Pregnancy



College of Nursing

VILLANOVA
UNIVERSITY



College of Nursing

VILLANOVA
UNIVERSITY

Suzanne C. Smeltzer, EdD RN, ANEF, FAAN¹

Monika Mitra, MA, BSC, PhD²

Lisa I. Iezzoni, MD, MSC³

Linda Long-Bellil, PhD, JD⁴

Lauren D. Smith, BS, MPH²

¹Villanova University College of Nursing

²Lurie Institute for Disability Policy, Brandeis University

³Harvard Medical School/Mass General Hospital

**⁴Center for Health Policy & Research University of Mass
USA**

**The presenter and authors report no
conflicts of interest**

**Funded by a grant from
National Institutes of Health
Eunice Kennedy Shriver
National Institute of Child Health &
Human Development**

Grant Number: 1R01HD074581

Objectives

- 1) Describe pregnancy-related experiences of women with physical disabilities (WPPD), a growing health disparity globally.**
- 2) Identify recommendations of participants to clinicians to improve the pregnancy-related experiences of women with physical disabilities.**

Background

165,000 WPPD become pregnant each year in USA; more than 44,000 have severe disabilities.

The number of WPPD becoming pregnant each year is increasing.

Historically, women with disabilities were discouraged from considering pregnancy and met with very negative reactions if they did so.

Negative reactions, barriers, and experiences continue to occur despite progress and passage of the Americans with Disabilities Act (ADA).

Background...

Negative experiences/barriers include:

- Inaccessible health care settings, hospital rooms and clinical offices
- No adjustable exam tables and weight scales
- Lack of information among women and their health care clinicians about the interaction of disability and pregnancy
- Insensitive health care clinicians who lack knowledge about perinatal needs of women with disabilities

Background...

Consequences of poor health care and negative experiences of WPPD related to pregnancy and childbearing include:

- **Delay in seeking health care to avoid receiving unwanted advice or negative reactions from HCPs**
- **May not seek preconception counseling and/or “tune up” prior to pregnancy (e.g., medication assessments, treatment of secondary conditions that increase risks during pregnancy)**
- **May not receive high-risk pregnancy care (e.g., SCI) or prenatal care at all**
- **May not receive information/supports to help during pregnancy and with child care**

Purpose of Study

To explore:

- **Perinatal experiences of women with physical disabilities (WPPD)**
- **Recommendations of WPPD for obstetric care clinicians to improve care**

Research Design

A mixed-methods study addressed unmet healthcare-related needs of WWPD and barriers to care.

A qualitative descriptive component of study addressed perinatal experiences of WWPD and their recommendations for obstetric clinicians.

Inclusion Criteria

- **Women with disabilities that limited their ability to walk without assistance or to use their arms or hands.**
- **Disability present during pregnancy and at time of study.**
- **Delivered a live infant within the last 10 years.**
- **Be between 21-55 years old at time of the study.**
- **Willing and able to participate in the study and in telephone interviews.**

Procedures

- **IRB approval was obtained from 4 universities of the investigators.**
- **WWPD ere recruited through flyers posted to social media sites and disability organizations' websites.**
- **Those interested in participating were asked to contact the research coordinator.**
- **Consent forms were sent to those interested who met inclusion criteria.**

Procedures...

Informed consent reviewed verbally and verbal consent obtained at start of interview.

Two investigators, with physical disabilities, conducted all telephone interviews.

Interview guide was based on research team's experience and results of previous research studies.

Focus: interactions of WPPD with clinicians during pregnancy recommendations for clinicians to improve perinatal care for WPPD.

Data Analysis Procedures

2-hour interviews were conducted in English, audio-recorded, and transcribed by professional transcription service.

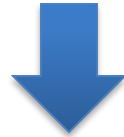
After verification of accuracy of transcriptions, traditional content analysis was used in analysis.

Iterative process: read, salient points identified, categories identified and text of all transcripts read again and coded.

Atlas.ti software version 7 was used to assist with data analysis.

Sample

31 women responded to the invitation to participate



6 were excluded (not reachable or deemed ineligible by inclusion criteria)



25 women participated in 2-hour telephone interviews

Sample (n = 25)

Mean age at birth of youngest child
31.9 \pm 5.3 years

Planned vs. unplanned pregnancy
15 planned; 10 unplanned

Parity

First pregnancy for 14 women

Diverse disabilities (18 used assistive devices)

Amputation

Cerebral palsy

Dwarfism

Multiple sclerosis

Muscular dystrophy

Osteogenesis imperfecta

Spina bifida

Spinal muscular atrophy

Spinal cord injury

Resulting Themes

3 themes related to women's interactions with obstetric clinicians were identified:

- **Clinicians' lack of knowledge about pregnancy-related needs of women with physical disabilities**
- **Clinicians' failure to consider knowledge, experience, and expertise of women with physical disabilities about their own disabilities**
- **Clinicians' lack of awareness of reproductive concerns of women with physical disabilities.**

Theme 1: Clinicians' Lack of Knowledge About Pregnancy-Related Needs of Women with Physical Disabilities (WWPD)

- **Lack of knowledge about interaction of disability and pregnancy, including effect of disability during pregnancy, labor, and birth.**
- **WWPD seen as “problems”.**
- **WWPD viewed clinicians' bias and negative reactions as due to their lack of knowledge about perinatal needs of WWPD.**

Voices of Women with Physical Disabilities

“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.”

“They somehow think we’re going to be more of a problem for them...”

Recommendations of WPPD related to Lack of Knowledge

- ◆ **Acknowledge own lack of knowledge about issues but be willing to learn.**
- ◆ **Research the topic if knowledge is lacking.**
- ◆ **Consult with other clinicians involved in the woman's care.**
- ◆ **Consult websites of disability organizations (eg, United CP Association, Little People of America, Osteogenesis Imperfecta, others).**

Theme 2: Clinicians' Failure to Consider Knowledge, Experience, and Expertise of WWPD about their own Disabilities

- **Women's experiences with their own disability were often ignored or discounted.**
- **Clinicians often failed to ask WWPD about their disability and ignored their attempts to share information about it.**

Voices of Women with Physical Disabilities

“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.’”

“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.”

Recommendations Related to Failure of Clinicians to Recognize Knowledge, Experience, and Expertise of WWPD about their own Disabilities

- ◆ **“Treat WWPD with the same respect and care as other women.”**
- ◆ **“If you really want to know about how things affect me or certain things, ask me.”**
- ◆ **“Don’t assume that women with a disability have no cognitive ability just because we have a disability.”**

Theme 3: Clinicians' Lack of Awareness of Reproductive Concerns of WWPD.

- **WWPD receive the message from clinicians that they cannot (or should not) become pregnant and have children because they have a disability.**
- **Lack of awareness that WWPD have the same right and desire as other women to have children**

Voices of Women with Physical Disabilities

“He literally told me that I needed to remain abstinent.”

“Look how disabled you are and you really shouldn’t be...you should not get pregnant.”

“If I were your parents, I would do everything I could to convince you to adopt.”

Recommendations of WWPD related to Clinicians' Lack of Awareness of Reproductive Concerns of WWPD

- ◆ **Set aside personal biases, prejudices, and personal views.**
- ◆ **If asked for recommendations about pregnancy, then share them; otherwise, keep them to yourself.**
- ◆ **Treat WWPD the same as any other woman seeking pregnancy–related care.**

Discussion

27 years after the passage of the Americans with Disabilities Act of 1990...

WWPD still experience multiple barriers, biases, prejudices, and stereotyping by obstetric clinicians.

Experiences of WWPD and recommendations reflect the continuing gaps in perinatal health care for women with diverse disabilities.

Discussion...

Findings, including recommendations of study participants, reflect the importance of interactions between WWPD and clinicians.

Clinicians' lack of knowledge reflects continued failure of health care professions' education to address disability in curricula.

WWPD are at increased risk for poor maternal and infant outcomes because of inadequate perinatal care.

Limitations of Study

Inability to generalize findings because of design of study (but the qualitative findings mirror those of the quantitative data of this mixed method study).

Responses may not reflect those of women who did not respond to invitation to participate and who may not have access to Internet.

Although diverse, the sample did not include women with all possible types of physical disabilities.

Summary & Conclusions

Need for research to address perinatal needs of women with other types of disabilities

Need to address failure of health professions to incorporate disability in educational curricula.

Although the Americans with Disabilities Act (ADA) is 27 years old, issues remain and need to be addressed as more women with disabilities choose to become pregnant.



**Pregnant woman
With physical disability**



**Young mother with
Physical Disability**



College of Nursing

VILLANOVA
UNIVERSITY

Contact information

Suzanne.smeltzer@villanova.edu 610-519-6828