



Maternal Health

Recommendations about Pregnancy from Women with Mobility Disability to Their Peers



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A B S T R A C T

Background: Although growing numbers of women with mobility disability are becoming pregnant and desiring motherhood, relatively little is known about their pregnancy experiences or what they might recommend to other women with mobility disability contemplating pregnancy.

Methods: Using a semistructured, open-ended interview protocol, we conducted 2-hour telephone interviews with 22 women who had a significant mobility disability before becoming pregnant and had delivered babies within the prior 10 years. We recruited most interviewees through online social networks. We used NVivo software to sort interview transcript texts and performed conventional content analyses to identify major themes.

Results: Participants' mean \pm standard deviation age was 34.8 ± 5.3 years; most were White, well-educated, and middle income and 18 used wheeled mobility aids. Recommendations for other women with mobility disability coalesced around five themes: recognizing the possibility of giving birth, advocacy and support, being informed, approaches toward obstetrical practitioners, and managing fears about losing custody of their child. Lacking information about what to expect during their pregnancy was a significant problem. Women got information about pregnancy from diverse sources, but questions arose about accuracy and relevance of this information to individual circumstances. Women urged their peers to advocate for their preferences and needs with obstetrical practitioners.

Conclusions: Women with mobility disability who had delivered babies offered constructive advice for their peers who desire pregnancy. Increasing availability of accurate and relevant information about pregnancy among women with mobility disability is critically important, as is training obstetrical practitioners to provide patient-centered care to these women during pregnancy.

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Every year, an estimated 145,000 civilian, noninstitutionalized American women with severe mobility disability report being currently pregnant (Iezzoni, Yu, Wint, Smeltzer & Ecker, 2013). Pregnancy among women with significant mobility disability confounds long-held stereotypes and assumptions

about their social roles and life goals (Becker, Stuifbergen, & Tinkle, 1997; National Council on Disability, 2012). Little systematic information had been available about pregnancy experiences among these women (Filax & Taylor, 2014; Nosek, Howland, Rintala, Young, & Chanpong, 2001; Signore, Spang, Krotoski, Shinowara, & Blackwell, 2011).

Recently, an expanding literature documents various aspects of preconception, pregnancy, and immediate postdelivery experiences among women with mobility disability. Compared with other women, women with mobility disability have higher rates of comorbid and behavior-related health conditions that are pregnancy risk factors (Iezzoni, Yu, Wint, Smeltzer, & Ecker, 2014, 2015; Kim, Kim, Hong, & Fredriksen-Goldsen, 2013; Mitra

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et al., 2015; Mitra, Clements, Zhang, & Smith, 2016). They may also have higher rates of pregnancy complications, including preterm birth (Mitra et al., 2015) and postpartum depression. Women with mobility disability can experience specific prenatal and delivery complications relating to their underlying disabling conditions (Baschat & Weiner, 2004; Gajjar, Ansar, & Singhal, 2014; Iezzoni, Wint, Smeltzer, & Ecker, 2015a; Kirschner, Gill, Panko Reis, & Hammond, 2005; Morton et al., 2013), although these complications may have few long-term adverse consequences (Iezzoni et al., 2015a; Morton et al., 2013).

In addition, women with mobility disability may not receive routine prenatal care because of inaccessible examination tables and weight scales (Iezzoni, Wint, Smeltzer & Ecker, 2015c; Mitra, Long-Bellil, Iezzoni, Smeltzer, & Smith, 2016). They may feel their obstetrical clinicians have inadequate knowledge or discriminatory attitudes about pregnancy among women with mobility disability (Mitra, Clements, et al., 2016; Smeltzer, 2007). Finally, when in public while visibly pregnant, these women may confront perplexed comments, intrusive questions, or hostile responses from strangers (Iezzoni, Wint, Smeltzer, & Ecker, 2015b).

Anecdotal evidence suggests that, when thinking about becoming pregnant or when actually pregnant, most women—regardless of disability status—want information about what happens during pregnancy and how to achieve the best outcomes for themselves and their child. An entire industry addresses this desire: a March 1, 2016, search of the online bookseller Amazon.com found 9,371 books categorized as addressing “pregnancy and childbirth.” However, women with mobility disability may not have the “typical” pregnancy experience. Few books seem to address their specific concerns.

The purpose of this paper is to suggest what new mothers with mobility disability would recommend to their peers about various aspects of the pregnancy experience. We use responses from 22 mothers with mobility disability who have already described pregnancy complications (Iezzoni et al., 2015a), prenatal care experiences (Iezzoni et al., 2015c), and public reactions to their pregnancies (Iezzoni et al., 2015b). Toward the end of 2-hour research interviews, we asked participants what they would recommend to other women with mobility disability who desire pregnancy.

Methods

The Massachusetts General Hospital/Partners HealthCare Institutional Review Board (IRB) approved this study. If women agreed to participate after interview procedures and protections were described, this acquiescence constituted implied informed consent.

Recruiting Participants

To be eligible for our study, when they became pregnant, women must have used one or more ambulation aid (cane, crutches, walker) or wheeled mobility device (manual or power wheelchair or scooter) or have had significant difficulties with arm or hand movement. Potential participants must also have delivered their youngest child within the previous decade. We aimed to interview 20 participants, the number generally viewed as sufficient to reach thematic saturation.

Efforts to identify participants through the Massachusetts General Hospital obstetrical practice and local disability community groups yielded only 2 interviewees. The IRB approved

our soliciting participants outside metropolitan Boston using online social networks. Within several days of posting an IRB-approved announcement on social media (Facebook groups), 45 women from around the country contacted us seeking participation. We screened 27 women by telephone, first come, first served. Twenty-four women met study inclusion criteria, and we scheduled 21 for interviews. One woman subsequently dropped out, saying childcare made her too busy. In our final sample, 2 women came from local sources and 20 from the nationwide social network (Iezzoni et al., 2015a).

Interview Protocol and Procedures

We developed a semistructured, open-ended interview protocol that covers eight broad topics about pregnancy and immediate postpartum experiences (protocol available upon request). Before concluding with demographic characteristic questions, the protocol asked for their recommendations to other women with similar disability who want to become pregnant.

After obtaining verbal informed consent, L.I.I. performed the 22 telephone interviews, which averaged approximately 2 hours and occurred from October 2013 to December 2013. We mailed participants a \$50 gift card after the interview. A professional transcription service typed transcripts verbatim from digital audio recordings. All names are pseudonyms; we have changed identifying details to protect confidentiality.

Data Analysis

We used conventional content analysis (Hsieh & Shannon, 2005) to identify major themes across participants' responses to the recommendations question. Some major themes—such as approaches to obstetricians and the value of different information sources (e.g., Internet, prenatal classes)—were also mentioned in responses to other questions. After specifying key themes from the recommendation question, we used NVivo 10 (QSR International, Melbourne, Australia) qualitative analysis software to again sort all 22 texts using topic codes for these themes.

We sometimes indicate the numbers of interviewees reporting specific themes. The 22 interviewees do not represent the general population of women with mobility disability who have given birth; these numbers do not aim to suggest the population prevalence of women's recommendations. We give these numbers to show clearly how many participants mentioned specific themes instead of relying on vague words such as “a few,” “several,” or “many.”

Results

Table 1 shows participants' characteristics. Mean \pm standard deviation age was 34. \pm 5.3 years; most were White, non-Hispanic, and well-educated; and they came from 17 states across the United States. Eighteen used manual or power wheelchairs. Sixteen women had at least one child 3 years old or younger. Five broad themes emerged from the data analysis: recognizing the possibility of giving birth, advocacy and support, being informed and information sources, approaches toward obstetricians, and managing fears about losing custody of their child.

Table 1
Interviewee Characteristics (n = 22)

Interviewee Characteristics	n
Age category (y) at time of interview	
25–29	1
30–34	13
35–39	4
40–49	4
White race*	20
Hispanic ethnicity	2
Geographic region at time of birth [†]	
Northeast	7
Midwest	7
South	5
West	3
Education	
High school	2
Some college	5
College degree	7
Graduate degree	8
Condition causing disability	
Cerebral palsy	4
Spinal cord injury	8
Other condition [‡]	10
Mobility aid(s) or other assistive technology used at time of most recent pregnancy [§]	
Cane or crutches	4
Walker	2
Manual wheelchair	12
Scooter	1
Power wheelchair	5
Leg braces or ankle-foot orthotic	2

* Black = 1; Native American = 1.

[†] States include: Arizona, Georgia, Illinois, Maine, Massachusetts, Minnesota, Missouri, New Hampshire, New Jersey, New Mexico, North Carolina, Ohio, Oklahoma, Rhode Island, South Carolina, Texas, and Utah.

[‡] Arthrogyriposis (n = 2), Charcot-Marie-Tooth (n = 1), congenital myasthenia (n = 1), missing three limbs, congenital (n = 1), multiple long-term injuries from car crash (n = 1), NARP (neuropathy, ataxia, and retinitis pigmentosa) (n = 1), osteogenesis imperfecta (n = 1), spina bifida (n = 1), and incomplete spinal cord injury and mitochondrial disease (n = 1).

[§] All women used at least one mobility aid, and some used different aids in different settings.

Recognizing the Possibility

Nine women repeated variants of Rachel's (mid-40s, spinal cord injury [SCI]) statement: "If you want children, you can. You can do it." As Maureen (early 30s, missing 3 limbs) said, "Just go for it!" Kayla (mid-30s, SCI) went further: "We make great mothers!" Most of these nine women acknowledged their peers—or more likely others—could have doubts. "Don't worry about what other people are going to think. You're stronger than you think you are," said Annemarie (early 40s, arthrogyriposis), "It's possible. Do it." Sara (early 30s, spina bifida) urged women "not to worry as much or let other people discourage them. Because there are resources, and... with the right support system too, there's always a way to do it." Becky (mid-40s, SCI) recognized both the complexity and possibilities:

It's important for women with disabilities to be given the opportunity to consider having children. ... It's not talked about. ... It's challenging to be a parent... for everyone, and I think having a disability doesn't have anything to do with having good parenting skills frankly. ... There are women who don't have a lot of mobility who are... wonderful mothers and have wonderful children. ... I don't think you have to have a perfect body to have a child... I think it's more about do you

have all the other things that you need to have to raise a child, which are far more important than walking around. ...

I don't think girls with disabilities are getting any kind of sexual health education, pregnancy, any of that in high school. So if you grow up with a disability, you're also not growing up with the idea that, 'Someday I'm going to be a mom.' And why not?

Advocacy and Support

Nearly all interviewees noted needing to advocate for themselves and building strong support systems. Table 2 presents typical quotations on this theme, which pairs self-advocacy with others' support: some women linked advocating for themselves with forming their support system—and accepting help. "Be open to support," said Rachel. "One of the hardest lessons for me is it's okay to ask for help sometimes." Samantha (mid-40s, congenital myasthenia) concurred: "It's kind of a philosophical thing, but be realistic about the help that you need, and be willing to accept it." For several women online social networks, such as Facebook groups, provided critical and sometimes immediate support. For example, after new mother Nicole (early 30s, SCI) described sensing disapproval from other diners when she took her baby to a restaurant, her Facebook friends responded within 10 minutes, giving her encouragement: "It was exactly what I needed, like okay, I'm cool, you know? ... My people are out there, ... and they know that I'm capable of this."

Many women who mentioned self-advocacy combined that with recommending women be as healthy as possible when contemplating pregnancy, stipulating that women know their bodies better than anyone else. "Approach it from the mindset that you are getting your body ready to go through this experience," urged Nicole. "Love your body and... enjoy the process of getting healthier and getting prepared." Francie (early 30s, multiple conditions) "asked for physical therapy while pregnant, so that way I could be at my best baseline when giving birth." Even though pregnancy brings new physical sensations, Annemarie reminded her peers, "You know yourself better than anybody else does, and don't forget it." Samantha was one of few interviewees to explicitly raise caution:

I would suggest being as prepared as possible, like being really honest with yourself about what your limitations are specifically. Like for me, my upper arm strength is very weak. ... What areas of child care or pregnancy... is that going to affect? And then find solutions for it. I really think people should be responsible about knowing whether you should get pregnant in the first place or not.

Being Informed and Information Sources

All interviewees emphasized the need for information to guide them during pregnancy and to assist in making critical decisions, such as about delivery. Most interviewees recognized that, although other pregnant women likely feel the same way, aspects of mobility disability raise particular concerns during pregnancy. For most interviewees, not having adequate information about how disability would affect their pregnancy ranged from worrisome to "scary" to "terrifying." In addition to their obstetrical providers (see below), women mentioned four major sources of information: formal prenatal classes, "self-help" books, information on the Internet (e.g., websites, blogs, social

Table 2
Self-Advocacy and Support from Others Theme: Examples of Quotations

Pseudonym	Age	Condition	Quotation
Self-advocacy			
Gabriela	Early 30s	SCI	"Advocate hard for yourself because nobody is going to do it for you. ... You have to know what you want."
Jennifer	Early 30s	Charcot-Marie-Tooth disease	"Make sure that you're prepared and ask the questions. ... It's almost like, you know, people don't expect women with disabilities to be having babies or have sex or do anything. But... hello, people! We live natural lives."
Bethany	Late 30s	SCI	"Yeah, be an advocate for yourself. Don't be afraid to speak up, and just learn as much as you can about everything. I think that was part of my problem [in my first pregnancy] was that I was so blithe about everything. I thought everything would just fall in place for me, and when it didn't, it was really hard to deal with. So advocate for yourself. Educate yourself."
Francie	Early 30s	Multiple conditions	"You need to be your own advocate, and you need to know your stuff. ... What I had going for me was that when they started questioning me about my competency and sending me an occupational therapist, I could rattle off a bunch of products [different strollers] that I had tried. ... They had no clue what I was talking about... You need to know what you're doing. Don't expect them to help you. You need to tell them that you have a plan. That's one big thing: do your research."
Rachel	Mid-40s	SCI	"I always tell people that they need to be prepared to advocate for themselves, certainly that they deserve the experience they expect—and hopefully they expect a good experience. I would hope they don't expect a bad experience because they don't deserve that."
Support from others			
Cecilia	Early 30s	Cerebral palsy	"Try to get other support systems in place so that you have people that have gone through it or are going through it and have a network. I think having a network of peers is the most valuable asset that any person could have at any point in their life. That's the way for us with disabilities. ... For a long time, ... I was scared to even be involved with people with my disability... because I didn't want to be compared to them, and – I wanted to be seen as a capable woman... But now I see the value of it."
Rachel	Mid-40s	SCI	"I felt like I had a lot of peer support around me, a lot of women who'd been there, done that... so I did not feel like I was alone in this process." Her peer counselor from the time of her injury 10 years previously "was one of the first people I thought of."

Abbreviation: SCI, spinal cord injury.

networks), and other women, notably their peers with mobility disability. Interviewees' views of these sources varied, although almost all women valued insights from peers (Table 3).

Five women did not attend prenatal classes (e.g., because of planned cesarean sections, premature births, concerns about relevance to them). Among the other women, 10 felt that much of the material did not apply to them, although 8 (including several of the 10) felt they nonetheless learned some useful information; and 3 found prenatal classes provoked anxiety or fear unrelated to their disability (Table 3). Several women mentioned pregnancy self-help books but opinions about their value differed. Nicole observed that "*What to Expect When You're Expecting*... was my bible. ... We went to that all the time about foods and... whatever it may be." She acknowledged that the book failed to cover disability-related issues and suggested "*What to Expect When You're Expecting on Wheels* or something... would be really cool." In contrast, Cecilia (early 30s, cerebral palsy) argued, "Stay away from reading *What to Expect When I'm Expecting* [sic] because you're setting yourself up [for] heartache... My pregnancies didn't mirror what was in the book."

Internet resources also prompted mixed reactions, with 11 participants reporting positive perceptions, whereas 7 viewed the Internet negatively (Table 3). Internet sources include organizational websites, social networks, blogs, and YouTube videos involving women with mobility disability who had given birth. Five women mentioned "Through the Looking Glass" (www.lookingglass.org), a website addressing infants, children, or parents with disabilities and their families; four women reported this site was helpful. However, even women who spent considerable time searching the Internet cautioned that information found there must be carefully vetted and may not apply to individual circumstances.

Eight women urged their peers to seek information from other women with mobility disability who had had babies. As

Becky said, "My pregnancy was a pregnancy just like anybody else's, but it was just enough different that... talking to an able-bodied woman who was pregnant was like we were on two different planets." Lauren (early 30s, osteogenesis imperfecta) suggested talking "to other moms who have disabilities." She argued that websites fail to present "the whole story" and that, even though family and friends might be supportive, "We're, in some ways, afraid to talk openly about our vulnerabilities because we're so judged by other people." Talking with other women with disabilities reduces that fear:

So talk to people. Establish those relationships. Ask the questions you want to ask. I've never felt like somebody who is considering parenthood with a disability can ask me anything that's out of bounds just because they're coming at it from such a different spot than some stranger that's going to ask me something rude. There's never a rude question if you're actually considering [becoming pregnant] because it's a big, huge step. Parenthood is big for anybody, but for people with disabilities, women with disabilities especially, I think having no models makes it even more... uncertain.

Approaches toward Obstetricians

All interviewees had obstetricians deliver their babies except Jennifer (early 30s, Charcot-Marie-Tooth disease), who got all her pregnancy care at a community-based birthing center staffed and run by certified nurse midwives. "My doctors had told me I should be able to give birth fine," Jennifer observed. She had no medical problems or anticipated complications from her disability. "My whole life has been so medicalized. This was a natural part of life, and I'm supposed to be able to do it just like other women. So why would I go to the hospital?" Jennifer had

Table 3
Views of Sources of Information about Pregnancy and Childbirth: Examples of Quotations

Pseudonym	Age	Condition	Quotation
Birthing classes			
Gabriela	Early 30s	SCI	Did not attend. "I felt like they would scare me more than anything, and I felt like also the information might not apply to me. I had looked up online the things they cover in the classes..." She practiced changing diapers on her niece. "I'm like a very natural person, and I just figured, you know what? I'm going to figure it all out."
Hannah	Mid-30s	Multiple bone injuries	The birthing classes "were great. It scared the crap out of us [because] ...they show picture of women in labor, and they're crying and screaming, and I was like 'No, I can't do it!' But it was at the hospital where we delivered, so we got to go and see a birthing room, and it made it real, which was scary. It also answered questions that we had. Unfortunately, we were, of course – I was the only disabled woman there... I'm so used to being the only disabled woman in a group. I just don't expect anything different because that's how it always is... It totally served the purpose, and I think it did what we needed to teach us."
Nicole	Early 30s	SCI	"There wasn't too much [that applied to my labor.] But we learned so much, you know, about preparing for the baby and washing the baby. ... There were more like I would say baby-related stuff that we learned that was helpful."
Becky	Mid-40s	SCI	"We went to birth class, but we're not going to be getting down on the mat like all the other couples. We just would kind of sit there through the whole thing, and it was fine. I'm not saying I wished I'd had some sort of special birth class. But it would have been nice to have been considered in it... Everybody wrote me off, so I wrote myself off." Getting information about labor with SCI would have been helpful, maybe from "the birth class lady, [but] that's not what she knows."
Maureen	Early 30s	Missing 3 limbs	"I did not feel that they understood how to do my disability, especially because I have no legs. It seems like legs are really important when you think about pushing. When I finally had [my baby], I was in labor for 20 hours – and it was difficult to figure out how to push without legs. For some reason it just seems like legs are necessary for that."
Annemarie	Early 40s	Arthrogyposis	The person teaching the birthing class did not understand disability – "not even close. But... the whole process itself gave me the thoughts in my head to be able to then try to figure out how that would work for me. Like, okay, you sit like this, and this is supposed to help calm you. Well, I can't sit like this, so what can I do? So it gave me the ideas in my head that I needed. But [the classes] were no help, no."
Internet-based information resources			
Nicole	Early 30s	SCI	"Since I got pregnant, I have discovered a few... Facebook groups for Parents on Wheels and Mommies on Wheels... The Internet is our best resource."
Bethany	Late 30s	SCI	"I found Through the Looking Glass [on the Internet]. I was looking online... trying to find information, and it's actually... not really funny – sad maybe is more the term – about how much [websites] like WebMD... were supposed to be this wealth of medical knowledge, and they had almost nothing about disability and pregnancy..." She turned to other women for information. "Most of the disabled women friends that... I know have had babies, I met either on these message boards for just disabled people in general – because the topic comes up chatting – or through other women with disabilities who are on Facebook. ... It's networking."
Samantha	Mid-40s	Congenital myasthenia	"Get informed. I go on the Internet all the time. You have to be really careful about what sources you're reading, too. Especially if it's individual experiences, because... we're all so different."
Kayla	Mid-30s	SCI	"I was on the Internet all the time trying to connect with other women with disabilities who had had children, and I couldn't find a single solitary one."
Cecilia	Early 30s	Cerebral palsy	"Stay away from Googling."
Information from other women about pregnancy			
Kachina	Early 30s	SCI	Women should "have someone else to go to that they can talk [to]... a network of other disabled women that have gone through it, so that way if they're first-timers, they know what to look out for, what to expect with their bladder, ... if they need to see a specialist ... different things like that."
Rachel	Mid-40s	SCI	"The wonderful news is there's so many more of us out there having children. ... There is a peer network of people who have paved the way and, you know, it's a wonderful resource. And if you happen onto it for nothing other than a single question, it's there to be tapped into."
Cecilia	Early 30s	Cerebral palsy	Women should "have people that have gone through it or are going through it and have a network. I think having a network of peers is most valuable asset that any person could have at any point in their life. That's the way for us with disabilities."

Abbreviation: SCI, spinal cord injury.

an "easy" delivery: after her daughter's head emerged, her husband completed the delivery.

About one-half of the other interviewees—including many who were happy with their care—recommended to their peers ways to approach obstetricians. In particular, women urged their peers to know what they wanted from their obstetrical provider, investigate local practitioners, find a clinician suited to their needs and goals, and then advocate for themselves (Table 4). Some women felt that obstetricians needed more "open minds" and positive attitudes about pregnancy among women with mobility disability and they should learn more about providing obstetrical care to these women. Gabriela's

(early 30s, SCI) comments exemplify recommendations for approaching obstetrical practitioners:

Find a doctor that you're comfortable with and advocate hard for yourself. You have to know what you want. A lot of doctors nowadays are real heavy into C-sections... I wanted to avoid a C-section [so I could] care for my child after delivery. I didn't want to be laid up in bed... [for] weeks and weeks to heal. ...

I met with anesthesiologists as well, so that we had a plan for what exactly was going to happen because I didn't want to go into labor and have strange people there who don't know what's going on and... because I'm in labor, I'm not able to

Table 4
Recommendations Relating to Physicians: Examples of Quotations

Pseudonym	Age	Condition	Quotation
Samantha	Mid-40s	Congenital myasthenia	"Make sure you're at a good doctor. I would interview the OBs and see what their attitudes are toward women that are pregnant. I was very fortunate that these doctors were very experienced. They were specialized, but your doctor may not be. So you may need to get specialized care so you're not some guinea pig where they're afraid you're going to die."
Margie	Late 20s	Arthrogyriposis	"I looked up all the OB/GYNs ... If you don't like your doctor, if you don't trust your doctor, if your doctor is not listening to you and the things that you want to do, things that you feel are best for you, then find a different doctor."
Bethany	Late 30s	SCI	"As far as receiving the care that you need, be specific. I mean, reach out. ... Find other women that have been through that experience and find out what they knew and what they experienced so that you can go to your doctor and say, 'I think I'm going to need x, y, and z.' Because if you don't – and this isn't just for pregnancy, this is for all of our care as disabled individuals – we need to tell them or they're not going to give it to us."
Gabriela	Early 30s	SCI	"Try to get a team, have conversations with your OB about what your strategy is. Meet with the anesthesiologist. Don't deal with anybody you're not comfortable with. I was fortunate that I found an OB that I was comfortable with, and I was fortunate that I found an anesthesiologist that was on the ball. ... In a different hospital, I don't know, but maybe they're going to have people that aren't as aware. But at least if you are educating yourself and you're self-advocating, you are conveying that information that the doctors need."

Abbreviations: GYN, gynecologist; OB, obstetrician; SCI, spinal cord injury.

advocate for myself... So we set that all up. ... That worked out well.

The doctor comes in and checks me and snaps his fingers... "Okay, we're ready to go. The baby is coming out. We're going right now." The baby's head was down, everything was coming out, so he just snapped everybody together in a minute. He was fabulous because he had already discussed this with me ahead of time.

Gabriela had a vaginal delivery, encouraged by her obstetrician: "8 or 10 pushes and the baby was out. ... It was amazing."

Managing Fears of Losing Custody of Their Child

As a counterpoint to enthusiastic positive comments, throughout their interviews many participants expressed fears about losing custody of their child—being judged by some legal authority as an unfit parent because of their mobility disability. Interviewees who articulated such fears recommended various strategies for handling these emotions and asserting their legitimacy as mothers, including knowing their legal rights, maintaining a good relationship with their child's pediatrician, keeping detailed records of all aspects of the child's health and care, being cautious in public settings, not posting comments that could be misinterpreted on Facebook, and having friends and others observe the woman performing child care tasks so they could testify, if required, about her competence. Fears become especially pointed when relationships with the child's father falter: losing custody in divorces or breakups is a real possibility.

Interviewees generally seemed alone and isolated in these fears. One interviewee who had faced child abuse charges spent considerable time and resources refuting the accusations: "Once they had the facts, they reversed the findings. But in the meantime it went on my record as though I had abused my own child." Another woman said this worry follows her "every day, every day. If I was carrying [my child] and I lost my balance, oh my gosh, someone's going to take him from me. Every day." An interviewee who is a doctorally trained health care professional acknowledged, "I've always been concerned that other people will think that I can't care for my child, and... that [they] would want to take my baby away from me." According to Lauren:

It would just take one ignorant person... to call [child protective services] or to think the wrong thing. ... People just have ridiculous assumptions. I've heard people say, "Oh, does Lilly [Lauren's daughter] ever get to go play on the playground?" She goes to the playground more than my brothers' kids go! ... The point is that somebody doesn't know something about our family, and they assume that Lilly is in some way harmed. They think of themselves as this good citizen, like, "I didn't want to do [report them], but I did." [That's] how the ball can get rolling. ... That is a huge fear of our family and other families. ... It's scary the way the law reads: that... they don't really need due cause [if the parent has] physical disability or substance abuse. ... You can get stuck in [the child protective services] system forever. I've heard horror stories. I just think about all the milestones that I've enjoyed with Lilly, and to miss out on even a small one would be just horrible.

Lauren is working to change her state's laws, but she acknowledges change will come slowly.

Discussion

All women in our study had successfully given birth and were happy with motherhood. Therefore, it is not surprising that most enthusiastically recommended to other women with mobility disability that, if they want to become pregnant, they should do so. Nonetheless, the women indicated challenges that their peers should anticipate, including finding accurate information about pregnancy among women with their specific type of mobility disability, having adequate support, identifying clinicians with whom they feel comfortable, and managing their fears about losing custody of their child because of mobility disability. Self-advocacy—supported by researching options and clarifying goals and expectations—must occur at all times.

Lack of trustworthy information is a major concern. Although some women reported learning useful information in formal prenatal classes, others did not, even though these classes purport to offer general resources about parenting. Although some interviewees frequently searched the Internet for both information and support, vetting information to ensure its accuracy was recognized as critical. However, the relative paucity of

research about pregnancy among women with mobility disability complicates efforts to evaluate information's accuracy, although women clearly recognized that certain sources (e.g., blogs) are more problematic than others. According to interviewees, standard medical information Web sites, which might be trusted for accuracy, contain no information on pregnancy and mobility disability. Another complexity is that the limited research on disability and pregnancy focuses primarily on specific conditions, such as SCI. Therefore, even if women find information online about pregnancy and mobility disability, that information may not apply to their circumstances.

Women must therefore turn to their obstetrical practitioners for information about their pregnancies. However, interviewees suggested that finding the right clinician might require interviewing candidate practitioners to ensure they feel comfortable and supported by that clinician. This clearly is possible in locales with multiple obstetrical practices, but will be more difficult in areas with few practitioners (e.g., rural regions). Again, it requires women with mobility disability to research their options, articulate their preferences for care, advocate for themselves, and locate willing practitioners.

Fears about losing custody of their child because of mobility disability were common. According to a 2012 report from the National Council on Disability, persons with disability are more likely to lose custody of their child than are nondisabled parents (National Council on Disability, 2012). Parents with psychiatric or intellectual disabilities have much higher rates of losing custody than do parents with mobility disability. Nonetheless, 13% of parents with physical disability report discriminatory treatment in custody cases (National Council on Disability, 2012). Two-thirds of dependency statutes allow courts to determine that someone is an unfit parent based on disability, and every state allows family or dependency courts to consider disability in custody decisions (National Council on Disability, 2012). Typically, evidence is gathered about parental fitness using unadapted assessments of parenting. Thus, fears expressed by interviewees are well-founded.

Our study has important limitations, particularly relating to our small, nongeneralizable sample of interviewees. We recruited participants through social networks, which yielded little racial and ethnic diversity. Although researchers increasingly recruit study subjects through social networks, especially when studying relatively rare conditions (Johnson, Mueller, Williams, & Gutmann, 2014; Schumacher et al., 2014), racial and ethnic homogeneity limits the generalizability of our findings. We did not validate women's assertions about their disability. However, women's reports were consistent throughout 2-hour interviews, suggesting their statements about disability accurately represented participants' experiences. For clarity, we present numbers of women reporting specific situations, recognizing that these figures do not represent generalizable numbers.

Implications for Practice and/or Policy

All five major themes—recognizing the possibility of giving birth, advocacy and support, being informed, approaches toward their obstetrical practitioner, and managing fears about retaining child custody—have important implications for clinical practice and policy. First, with women mobility disability becoming increasingly confident about giving birth, obstetrical practitioners should expect to see these women in their practices. Second, practitioners should anticipate that many of

these women will have done extensive research, have clear preferences for their care, and perhaps know more than their clinicians about their disability. Thus, women with mobility disability could be effective partners in their pregnancy care, particularly contributing expertise about their disabling condition. Given potential histories of being frequently marginalized or dismissed, these women may also advocate strongly for their views, perhaps at times differing with clinicians (e.g., about choice of delivery mode). Understanding these histories and what motivates preferences of women with mobility disability could allow clinicians to strengthen their relationships with patients, especially around the critical dimensions of trust and respect.

Third, most women will likely want more information about how their disability will affect their pregnancy. Practitioners should be aware of trustworthy resources that can educate and inform pregnant women with mobility disability so that these women and their practitioners can plan and act from scientific evidence, to the extent possible. However, at the policy level, more research is needed to expand that scientific evidence base about how pregnancy affects women with mobility disability. Obstetrical practitioners need more training about providing patient-centered care to women with mobility disability. In addition, prenatal class instructors should consider how to make sessions meaningful and productive for women with mobility disability. Professional associations representing prenatal class educators, such as the International Childbirth Education Association, the Childbirth Education Organization, and the Academy of Childbirth Educators, might want to consider developing specific curricula for women with mobility disability and their partners.

Fourth, obstetrical practitioners should expect that women with mobility disability might carefully consider their choice of provider, when they have that option. In particular, these women might investigate local practitioners, searching for clinicians who would best meet their needs and goals and/or are willing to be partners in shared decision-making around pregnancy management. The interviewees urged obstetricians to have more "open minds" and positive attitudes about pregnancy among women with mobility disability and learn more about providing obstetrical care to these women. We are unaware of studies of obstetrical practitioners about their attitudes toward women with disability and pregnancy. But from the women's perspective—as reflected in our interviews—it seems that some potentially discriminatory attitudes may persist. Again, given their prior life experiences, women with mobility disability will likely have heightened sensitivity to these attitudes, even if practitioners are unconscious of such biases.

Finally, fears of women with mobility disability about losing child custody are well-justified by the documented history of prior discrimination. Clinicians with longitudinal relationships with these women, such as primary care physicians, should be aware that these fears might arise and proactively provide reassurance. Having trusting relationships with their clinicians will be crucial for women to feel they can share these fears. For example, women might be afraid that asking too many questions about childcare—or admitting the stresses that many young mothers feel—might raise doubts about their parenting ability. Practitioners could anticipate these concerns by proactively providing childcare recommendations or addressing routine questions of early motherhood with these patients. This could reassure women that they are simply experiencing the common fears of most new mothers.

Conclusions

Women with mobility disability who have given birth have important recommendations for their peers who desire pregnancy and for obstetrical, primary care, and other practitioners who provide longitudinal care to these women. Believing that it is possible to successfully deliver a child is the first step, followed by self-advocacy, research, articulating preferences for care, and finding obstetrical practitioners with whom they feel comfortable. Lack of comprehensive, accurate, and relevant information and challenges finding willing practitioners remain significant impediments. Nonetheless, the growing number of women with mobility disability want their peers who desire pregnancy to know that other women have successfully done so before them. Finding supportive peers and obstetrical, primary care, and other practitioners are key strategies for improving the experiences during pregnancy and early motherhood of women with mobility disability.

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