



Published in final edited form as:

Disabil Health J. 2015 July ; 8(3): 380–387. doi:10.1016/j.dhjo.2015.02.002.

“How did that happen?” Public responses to women with mobility disability during pregnancy

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Abstract

Background—Little is known about current societal attitudes toward women with significant mobility disability who are visibly pregnant.

Objective—To use qualitative descriptive analysis methods to examine perceptions of women with significant mobility disability about how strangers reacted to their visible pregnancies.

Methods—In late 2013, we conducted 2-h telephone interviews with 22 women with significant mobility difficulties who had delivered babies within the prior 10 years. The semi-structured, open-ended interview protocol addressed wide-ranging pregnancy-related topics, including statements from strangers. Most participants were recruited through social networks, coming from 17 states nationwide. We used NVivo to sort the texts for content analysis.

Results—The women’s mean (standard deviation) age was 34.8 (5.3) years; most were white, well-educated, and higher income, although half had Medicaid during their pregnancies; and 18 used wheeled mobility aids. Eighteen women described memorable interactions with strangers relating to their pregnancies or newborn babies. Strangers’ statements fell into six categories: (1) curious; (2) intrusively and persistently curious; (3) hostile, including concerns that taxpayers would end up supporting the mother and child; (4) questioning woman’s competence as a potential parent; (5) oblivious, not recognizing visible pregnancy or motherhood; and (6) positive. Many women reported strangers asking how their pregnancy had happened. The women doubted that visibly pregnant women without disabilities evoke the same reactions from strangers.

Conclusions—Women with mobility disability who are visibly pregnant may perceive reactions from strangers that appear intrusive. Planning ahead for handling such encounters could reduce the stresses of these interactions.

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Keywords

Disability; Pregnancy; Public; Societal attitudes; Qualitative research

The possibility that women with mobility disability might be sexually active and desire pregnancy challenges longstanding societal assumptions.^{1,2} Forced sterilizations of disabled women in prior centuries provide troubling historical precedents to these stigmatized attitudes.³ In the public's mind, women with significant mobility disability may not have the "physical grace or ease" central to "male notions of attractiveness."³ Even some clinicians have viewed women with disabilities as asexual or uninterested in physical intimacy.^{1,3-7}

These assumptions, however, are incorrect: women with mobility disability do become pregnant and have babies.^{1,2,8} Recent research using federal survey data estimates that, every year, nearly 44,200 American women with severe mobility disabilities report being currently pregnant.⁹ Other studies using population-based surveys document aspects of their pregnancy experiences, including comorbid health conditions, mental health, and behavioral health risk factors.¹⁰⁻¹⁴ However, relatively little recent information is available about the experiences of these women during their pregnancies. In particular, nearly a quarter century after signing of the Americans with Disabilities Act (ADA), what are public attitudes toward women with mobility disability who are visibly pregnant or have newborn infants?

The purpose of this qualitative descriptive analysis is to explore the types of responses women with significant mobility disability perceived from the public during their pregnancies or immediately after they gave birth. Anecdotally, many American women report that, when their pregnancies become visible, they often receive unsolicited comments and advice from passersby, curious but generally approving their impending motherhood. We sought to learn what comments strangers offer to women with mobility disability who are visibly pregnant. We expected that public attitudes may have improved from historically negative views,³ but that pregnant women with significant mobility disability – even today – would still receive some negative statements from strangers.

Methods

The Massachusetts General Hospital (MGH)/Partners HealthCare Institutional Review Board (IRB) approved this research. This study was part of a larger exploratory, mixed methods investigation of pregnancy among women with chronic mobility disability, which had 3 components: analyses of large survey data⁹⁻¹¹; reviews of MGH obstetrical electronic medical records; and qualitative descriptive analyses of in-depth individual interviews, considering a range of topics.¹⁵ The IRB-approved use of implied informed consent: women's agreeing to the interview after being informed of interview procedures and protections indicated consent to the study.

Study sample

Originally we planned to conduct in-person or telephone interviews with 20 women ages 21 years or older with mobility disability prior to pregnancy who had given birth at MGH within the last 5 years. We intended to randomly sample participants from women identified

through medical record reviews. For these reviews, we selected obstetrical cases with diagnosis codes that suggested the woman might have pre-existing mobility disability (e.g., spinal cord injury, cerebral palsy, multiple sclerosis, spina bifida). To qualify for our study, women at the time they became pregnant must have used an ambulation aid (cane, crutches, walker) or wheeled mobility aid (manual or power wheelchair or scooter) or have had significant difficulties using their arms or hands. However, our initial review of 100 records failed to find any women who convincingly met our criteria. Most commonly, despite their diagnoses, the women did not have significant mobility deficits documented in their obstetrical records.

We next sought IRB approval to identify women through disability advocacy, support, and sports organizations in greater Boston. We sent 11 such organizations an IRB-approved flyer describing this study, which many posted on their websites. This strategy yielded only 1 qualified participant. We then obtained IRB permission to solicit participants through networks of women with disabilities beyond Boston and to extend our timeframe (delivery within 10 rather than 5 years). Contacts by L.I.I. with advocates in other cities resulted in the project flyer being posted on social media (e.g., Facebook groups). Within several days, 45 women from around the country contacted the project office seeking participation in the study. A.J.W. screened 27 women total by telephone, on a first-come-first-serve basis; 24 met the criteria and 21 were scheduled for interviews. One subsequently declined participation, saying she was too busy with childcare. We later added 1 final participant recommended by an MGH obstetrician.

Interview protocol and procedures

Drawing upon literature reviews and our previous studies addressing health care experiences of persons with disabilities,^{5,16–21} we designed a semi-structured, open-ended interview protocol for this qualitative descriptive study. Qualitative descriptive studies provide comprehensive summaries of events or experiences without over interpretation of the meaning of the event or experience to study participants.^{22,23} This approach stays close to the data and provides information that is often of special interest to clinicians and policymakers. The interview protocol (available upon request) covers 8 broad topic areas: nature of disability and attitudes toward disability; attitudes toward pregnancy and disability; getting pregnant; reactions of family, friends, and strangers to the woman's pregnancy; pregnancy, labor, and delivery experiences, including complications¹⁵ and clinical care; physical accessibility of health care facilities; overview of post-partum experiences; and sociodemographic characteristics. A.J.W. gathered information the woman's age, years since most recent childbirth, and the nature of the women's disability during the screening telephone call; L.I.I. confirmed this information during the interview.

After obtaining verbal informed consent, L.I.I. conducted all 22 telephone interviews, which occurred from October 2, 2013 to December 16, 2013 and averaged roughly 2 h. Participants received a \$50 gift card. A professional transcription service produced verbatim transcripts from the digital interview recordings. All names are pseudonyms; small details about interviewees and their circumstances are changed to protect confidentiality. We stored the interview data in password-protected computer files.

Analysis

We used conventional content analysis²⁴ to identify major themes. The investigators read the interview transcripts several times to become familiar with the participants' responses. Based on reviews of the transcripts, L.I.I. generated an initial list of topics to use for coding the interview transcripts. Other members of the team agreed upon this list after reviewing several transcripts. L.I.I. and A.J.W. manually assigned topic codes to several texts in preparation for A.J.W. using NVivo 10 (QSR International) software to sort the transcript texts. The investigators independently reviewed texts within topic areas to identify major themes relating to the specific topic, reaching consensus on themes through discussion.

Interview questions included: "Strangers often say things to pregnant women about their pregnancies when they see them out on the street or in public places. Did this happen to you? If so, what kinds of things did people say to you?" The sorted texts reviewed here came from responses to these specific questions or from comments interviewees made spontaneously elsewhere during the interview that concerned public responses to either their pregnancy or being seen with their newborn baby.

We addressed trustworthiness of our results²⁴ by independent reviews of the transcripts by members of the study team and by the in-depth, extensive interviews, which reached thematic saturation by around the 17th interview (additional interviews had already been scheduled, and we felt obligated to complete them). Our results are also congruent with general findings and expectations about the roles, perceptions, and experiences of disabled women in U.S. society today^{1,2,8} and thus have good "face validity."

Results

Table 1 presents characteristics of the 22 interviewees. The vast majority were white, non-Hispanic, and well-educated; half had Medicaid insurance during their most recent pregnancy; and they came from 17 states nationwide. Eight had spinal cord injuries, 4 cerebral palsy, and the remainder had various other conditions. All women used assistive devices for mobility, 18 using wheeled mobility aids. Sixteen of the 22 women had at least one child three years of age or younger; all women had given birth within the prior 9 years.

Four women reported no memorable interactions with strangers about their pregnancies or newborns, either positive or negative. In some instances, women felt they got the same response – "weird looks on the street" – from strangers that they typically get because of their disability. However, as Cecilia (Latina, cerebral palsy) said, "Staring isn't always meaning they're judging me. It's just they're looking at me because I'm different from them." Kachina (spinal cord injury) lives with other Native Americans on a reservation, where she described everyone knowing each other and supporting women's pregnancies.

The other 18 interviewees recounted at least some statements from strangers relating directly to their pregnancies or being seen with their infants. Our analyses suggest that these statements fell into six themes: (1) curious; (2) intrusively and persistently curious; (3) hostile; (4) questioning competence of woman as a potential parent; (5) oblivious, not recognizing visible pregnancy or motherhood; and (6) positive. We found that women's

reactions also grouped into categories: surprised; annoyed; angry; amused; motivated to teach; and perceived public responses as “more of the same” general reaction to their disability. Below we present results grouped by category of strangers’ statements, offering quotations that exemplify each category.

Curious

Annemarie (early 40’s, white, college-educated, arthrogryposis, power wheelchair) has quick rejoinders when, as often happens, strangers approach her: “You have people that come up and say, ‘What’s wrong with you?’ ‘Nothing. What’s wrong with you?’” When she was pregnant with her son, this pattern morphed into strangers asking how she got pregnant, and Annemarie replied, “Same way you do ... Intercourse, just like you.” According to Annemarie, asking how she became pregnant is “a good curiosity question. But, as I’m sure you know, most people think that people with disabilities are asexual.” Given this, sometimes Annemarie would respond playfully when asked how she became pregnant, saying a single word – “misconception” – reflecting back the questioner’s ignorance about persons with disabilities.

Numerous women reported strangers asking this identical question: how had their pregnancies happened? For example, Adriana (early 30’s, Latina, cerebral palsy, power wheelchair) recounted, “Random people would just come up and say, ‘Oh, you can have sex?’ ‘How in the world did you get pregnant?’ ‘Was it artificial insemination?’” Several women said they replied simply, “I had sex.” Despite viewing this question as inappropriate, the women described responding calmly although perhaps with irony, implying that the questioner had little appreciation for basic facts of life.

Several women voiced doubt that nondisabled women are ever asked by strangers how they got pregnant. Nicole (early 30’s, white, graduate degree, spinal cord injury, manual wheelchair) sees herself as an educator: “Sometimes it’s like people’s boundaries go away with me. You know, it’s like you would never ask another walking person that.” Nicole asserts, “I don’t care. I’m comfortable with it. It’s very humorous, you know. It cracks me up. They always keep me guessing ... I’m like, *wow!* And I thought I’d heard it *all!*” Nicole is “pretty sure those people would not ask another person, you know, just a random person on the street ... But yes, it’s kind of off the wall, you know, and it’s probably even out of the ordinary for them.”

Intrusively curious

Levels of curiosity fall along a continuum. Sometimes women perceived strangers’ questioning as so persistent and insistent that it became intrusive. Becky (mid-40’s, white, graduate degree, spinal cord injury, manual wheelchair) described mounting aggravation as strangers persisted in questioning her both before and after she had her daughter:

All of my friends complained about how, when they were pregnant, the world would descend upon them and touch them and talk about everything... I kept waiting for that to happen. No one ever said a thing except, “Were you raped?” and “How did that happen?” and “Are you really pregnant or is that just a part of your disability?” A lot of very different questions were asked of me than of my

friends...It was an “I did not see what I just think I just saw” thing. It was like, “Oh, my god, you must have been raped.” ...

I would get these questions when I was pregnant, “Well, is your child okay?” “What do you mean is she okay?” “Well, you know.” “Well no, I don’t know.” “Is she going to have a ... ?” And I’d look at them and say, “Well, you know, the hardest thing about delivery is when I have to deliver the wheelchair first. That’s going to be harder than the baby, for sure.” ...

After I had her, I can’t tell you the number of people that would come up to me that I didn’t know and ask, “Is that your child? Is that your baby?” “Yes.” “I know, but is that really your baby?” “Yeah, this is my baby.” “You know what I mean. Is that really your baby?” And I would say, “You mean did I give birth to her?” “Well, yeah.” And I’m like, “Yes, I did.” And then the response is, “Well, how did that happen?” My response was always, “I had sex. That’s what I did. I had sex. If you’re going to be this rude to me, I’m going to give it back to you because I don’t think it’s any of your business anyway. And yes this is my child.” And now when I tell people that I’ve had a child they’re always like, “You’re kidding me!” – like it’s this stupendous thing that I’ve done. It’s a challenge. Anybody can be a parent. It’s a challenge to be a good parent, but I think that the general public just completely doesn’t know how to handle it at all, not at all. Even today I have people ask me, “Is she yours? Because you look alike, but I’m not sure if she’s yours.” “Well, she’s calling me mommy, isn’t she? Yes, she’s mine.”

Other women also reported situations where they felt that strangers’ curiosity became intrusive. Nicole “even had a couple people assume that I was riding in the wheelchair because I was pregnant ... and I told them, ‘I’m fine.’” She perceived the questions of a minor acquaintance as too personal when he said, “I wasn’t sure how to ask you that, but I didn’t know you could like even do that, and how did that happen?” And I’m like, ‘Same way it happens for every other woman. Use your imagination here, and stop looking at me like that.’”

Hostile

Several interviewees perceived hostile attitudes and accusatory statements, with strangers suggesting the woman’s baby would become a burden to society. An example came from Margie (late 20’s, white, arthrogryposis, walks with leg braces), who described trips to Walmart while pregnant with her son. “Some people were thrilled and other people just gave me the most disgusted looks. Some people even had the nerve to come up and [say] ... ‘What do you think you’re doing? How you can do this?’ People would say, ‘You’re just a waste to society. Why would you bring a baby into that?’” On the street, Margie recalled getting “dirty looks,” which said to her “how horrible I am to bring a baby into this world when I’m not even fit to be a mother – just very hateful things like that.”

Some of these situations involved primarily facial expressions or non-specific negative statements, but with contextual details that women interpreted as targeting her pregnancy. “I had one woman say something, and I bawled my eyes out,” remembered Hannah (severe long-term injuries from car crash, walker). “She very specifically looked at me and at my

stomach and turned to [her husband or boyfriend] and said, ‘Why would you ever do something like that?’ I was flabbergasted that, you know, anyone would ever say anything like that.”

Annemarie reported that strangers sometimes made hostile comments within earshot but not directly to her. Nonetheless, she felt compelled to respond:

The worst one that I heard was, “Oh good. Another child I’m going to have to pay for.” ... I was about seven-and-a-half months pregnant and into the bitchy mommy stage. And I turned around, and I looked at her, and I said, “I have two college degrees. How about you?” And she looked appalled, and I said, “Really? Can’t actually talk to me to my face about it?” And she walked away. But it was an automatic defense mechanism that I try not to do. I try very hard to be politically correct and let people have their own opinions and walk away. But I was so hormonal, and it kind of came out.

Questioning competence

A few women indicated that strangers questioned their competence to be parents, specifically to care safely for a child. Christine (early-30’s, white, college educated, cerebral palsy, pushed by others in manual wheelchair) has three children under 3 years of age, including a newborn. “I live in Minnesota now, and everybody’s really polite,” said Christine. “The worst I usually get is strange looks and ... [people saying] okay, she’s in a wheelchair. Oh, she’s pregnant.” But Christine nevertheless said she feels judged by strangers, especially when she hires help to care for her children.

A lot of people think you can’t handle it ... If you ask for help or if you hire a babysitter, hire a nanny even though you’re at home, ... people look at you strangely and say, “Well, why are you having so many babies if you can’t take care of them?” And you’re like, “Well, what do you do with your babies? You send them to daycare from 9 to 6, and you go to work. So who’s taking care of your kids then? Somebody else.” So it’s kind of the same situation.

Bethany (late 30’s, white, some college, spinal cord injury, manual wheelchair) also has 3 children, all under 8 years old. As did Christine, Bethany perceived that strangers questioned both her pregnancy and her abilities:

I’d be obviously pregnant and ... going to the store or going to the mall ... and you’d get these people that just – I had one old lady walk by me, and she just had this look of disgust on her face like, “Someone would have sex with you?” ... It was like totally judgmental, and I’m like, “Yep, look lady, it’s there.” It’s just so hard for people to comprehend that people with disabilities will have sexual needs or desires or that they’d want to have children ... Curiosity and disability go hand in hand with rudeness a lot of times. Somebody was just shocked that I would consider having a baby because how could I possibly take care of a child?

Other women shared similar experiences after giving birth. Jennifer (early 30’s, white, Charcot-Marie-Tooth, scooter) was upset when her husband reported that a neighbor had approached him, raising concerns that she would drop her newborn: “I was floored. ... I felt

like, you're watching me and judging me. How dare you?" Nicole and her husband, Justin, were walking in a park, with Justin holding their newborn daughter in his arms while Nicole pushed an empty stroller. When they reached the crest of a hill, Nicole decided to roll quickly downhill in her wheelchair, still pushing the stroller.

A guy like literally jumped out and screamed at me ... "How dare you put that baby in danger?" He's lucky my husband didn't throw him in the [river] ... because Justin was like, "I have my baby." I almost felt like Justin ... felt that was a slap at him, too. "I'm here, too, and I'm protecting my family." ... It's not a good feeling to think that somebody thinks that you're not a ... good parent or thinks that you're not capable of being a good parent ... That's my number one goal in my life is to make sure I'm as wonderful a mom as I could possibly be. And so any time anybody questions that, even if it's ... not for a good reason, ... it makes me feel a little like, "I got this. I do. I can do this."

Oblivious

Sometimes strangers seemed oblivious to the possibility that a woman with physical disability could be pregnant or mother of an infant. Women perceived these strangers as failing to recognize or misinterpreting the evidence in front of them. Francie (early 30's, white, partial spinal cord injury, power wheelchair) said, "Whenever I went into Babies Are Us, they would ignore me ... You know, when somebody is sitting, they look less pregnant than when they're standing up. So I think that part of it was that I didn't look as pregnant as I was because I was sitting down." When Francie was seven months pregnant, she went to a free breast pump class offered by the store and store personnel asked, "'Who are you doing this for?' And I'm like, 'For me. Who else? My husband?'" After Tanya was born, Francie said, "People stop me all the time about whatever. They also assume she's adopted."

Angela (early 30's, white, muscular dystrophy, power assist manual wheelchair) went shopping for maternity clothes when she got big. "The lady at the store was like, 'You don't need to buy these clothes. The regular size section is over there.'" But I'm like, 'I'm pregnant.' 'Oh, you are?' 'Yeah.'" The store clerk then assisted her. Angela believes that "people don't think of people with disabilities having babies. When I go down the street with my chair, I can push a stroller, too ... I've had people almost stop their car in the middle of the street trying to watch it. One time someone said, 'Damn girl. I didn't know that was possible.'"

Nan (late 30's, white, cerebral palsy, power wheelchair) had twins. "I remember going to the grocery store with my ... childcare worker, who then acted as my PA [personal assistant] ... post-birth." She recalled people turning to her PA and saying, "Oh, boy. You have your hands full! You have two *and* her?" indicating Nan, and the PA replying, "They're not mine. They're hers."

Lauren (early 30's, white) uses a manual wheelchair because of osteogenesis imperfecta; she describes herself as a "little person," as is her husband Paul. "I was hugely pregnant, and we went to Babies R Us, one of our last times to get like a few last things," Lauren recalled. "We asked where something obscure was, and the lady led us to it and asked, 'Oh, are you

going to be parents?’ And we said, ‘Yeah, we’re going to be parents very soon.’ She just like grabbed her heart and said, ‘I’m so glad they let people like you adopt.’” Lauren replied, “‘What? Do you not see my giant stomach?’” Despite being seated, Lauren stated that her pregnancy “was definitely visible because I pretty much only gained weight there in my mid-section, and it went straight out ... But I think people just can’t compute. The stares were a lot longer and just a lot more, I think, confused. I think they were trying to figure it out, ‘Could that be?’”

After Lauren gave birth to Lilly, she confronted questions about whether she could really have a newborn. A male neighbor “came over and said, ‘Is that your baby?’ And we said, ‘Yeah.’ And he said, ‘Well, where does she live?’ And we said, ‘Here, with us.’ He said, ‘She’s in there with you guys?’” Lauren describes her neighborhood as culturally diverse because of the large international corporation based nearby.

They bring in people from all over the world ... we have a lot of people from the Middle East and Asia. And this one group of ladies that would walk all the time, they were in traditional headgear ... I would push Lilly around our loop there. I had been doing it for weeks, and one of them came over and said, “Oh, she is real.” And I was like, “Yeah.” They thought I was pushing a doll that whole time, that I was just some crazy person pushing a doll. So I don’t know. For the most part I find amusement in that stuff, just because it’s so ridiculous.

Positive

Finally, several women perceived receiving positive reactions. Notably, for some of these women, their views of strangers as positive specifically arose from their expectations of strongly negative responses: i.e., these women interpreted the absence of the negative as indicating something positive. Kayla (mid-30’s, black, spinal cord injury, power wheelchair) had strangers on the street say, “‘Oh my gosh, are you pregnant?’ ‘Oh my gosh, you’re so cute.’” When these strangers transitioned to the standard curiosity question – “‘Oh my gosh, how’d that happen?’” – Kayla would “just tell them it happened the old-fashioned way. You’re in love, and one thing leads to another. And that’s what happened.”

Maureen (early 30’s, white, doctoral degree, power wheelchair) was born without any limbs except 7” of one arm; her limb loss occurred “in utero likely because of a botched abortion attempt by my birth mother.” As a teenager and young woman, Maureen never had a boyfriend despite “having a pretty face.” After exercising for a year to ensure peak physical conditioning, Maureen conceived her child through a sperm bank. Her pregnancy did not show until late because of her position in her wheelchair.

I’m used to always being looked at – it’s been that way since I was a child. But I looked the best that I’ve ever looked when I was pregnant. It was great pregnancy. I felt like I looked beautiful, that I was glowing, and I think people saw that I was happy, and people were happy for me. I sometimes had people say congratulations to me.

Discussion

Nearly all 22 women in this study described being accustomed to stares or comments from strangers because of their mobility disability. They have grown accustomed to handling or deflecting these public reactions, including by using humor, irony, and sarcasm. But when they became visibly pregnant or mothers of newborns, more than two-thirds of the women perceived new and different responses from the public. The interviewees saw that common thread as strangers viewing the co-occurrence of disability and pregnancy (or newborn babies) as something requiring their comment, most often questions about how the pregnancy had happened. The sentiments expressed varied, ranging from curiosity to outright hostility, with strangers sometimes virtually demanding responses through persistent questioning. Many interviewees said they could not imagine nondisabled women being subject to the same public reactions and queries.

Little is available in scholarly publications about how the public reacts to women in general who are visibly pregnant. An informal search of the Internet finds websites for pregnant women devoted to public reactions to their “baby bumps,” offering generally upbeat advice for dealing with these interactions. While recognizing that the attention is unsolicited, one website suggests that women relax and enjoy the expected solicitude, which includes offers: to open doors; to relinquish seats on crowded public transportation; to lift or carry packages; of food, constantly; and of baby care advice, which one website suggests might be valuable when from older women. These websites seemingly treat public responses as typically positive and congratulatory, with notable downsides of uninvited belly touching and pats.

The limited scholarly literature reflects on how the pregnant female body is viewed, not only by health care professionals but also by family, friends, and the public. Writing about her own pregnancy experience, an Australian academic described “my body be(com)ing a public space,” recalling strangers, acquaintances, students, relatives, and friends rubbing her belly “for luck” uninvited.²⁵ She “insisted on wearing clothing that may be deemed sexy by onlookers,” evoking stares and comments and being viewed as having a “provocative and even dangerous maternal body.”²⁵ She also “was surprised at how many people offered to help me when I was lifting objects which may be deemed heavy in my ‘condition’, and even more shocked at the appalled looks that I got from people when I refused their help. I was measured in terms of unspoken rules about what not to do when a woman is pregnant...”²⁵

Our study was not designed to compare the statements of strangers to visibly pregnant women with and without mobility disability. Nonetheless, as the interviewees said, it is hard to imagine the same intrusive questions and sometimes hostile responses being directed toward nondisabled women, although critical exceptions might exist (e.g., visibly pregnant young teenagers). Somewhat ironically, one prototypical, putatively “positive” public response is moot: 18 interviewees appear in public already seated, in wheelchairs or scooters, so giving up seats on crowded public transport is unnecessary. Since women with mobility disability typically cannot lift and carry heavy objects, that form of solicitude is also moot even if women would reject such offers. Furthermore, even if they dressed in today’s “sexy” maternity fashions,²⁵ it seems unlikely that most women with mobility

disabilities – typically viewed as “asexual” anyway¹⁻³ – would be seen as sexy. Dressed in that style, they might even experience more negative responses.

Given that it is likely that women with mobility disability experience more negative reactions when out in public, the question becomes why does this matter? As women themselves said, they are already subject to stares and unsolicited comments. Why should intrusive questions or perceived hostility during pregnancy be important? It is easy to suggest that how these uninvited comments affect an individual woman depends on how she responds. For example, some interviewees relished their chosen role as educator and laughed off preposterous public reactions. Others reported experiencing stress in responding to strangers. Putting the onus on women to “respond well” to public statements might represent practical reality: regulating public behavior is impossible. But it also imposes burdens on pregnant women with mobility disabilities.

Our analysis has limitations. We only interviewed 22 women, and their demographics do not represent those of the average pregnant woman with chronic mobility disability.⁹ They were disproportionately white, well-educated, and higher income. We recruited most participants through social media, starting with postings by disability rights advocates. Therefore, our participants might have stronger linkages to the disability advocacy community than might other women. We could not find qualified participants with certain conditions common in reproductive age, notably multiple sclerosis.

In addition, although the interview protocol addressed wide-ranging issues relating to pregnancy, it did not consider all potential topics in depth because of length concerns. For instance, we asked questions about strangers speaking to interviewees but not about touching or other physical contacts. Finally, we could not validate women’s assertions about their experiences or the perceived reactions of strangers. Nonetheless, the consistency and authenticity of women’s reports over the course of 2-h interviews suggest the validity of the interview data as representing the women’s “lived experiences.” While in a few instances up to 9 years had elapsed since their last birth, the level of detail of participants’ recollections suggests that their memories are vivid and the experiences had a lasting impact on them.

Relatively little research has explored pregnancy experiences of women with chronic mobility disability. Our findings suggest that women with mobility disability who become pregnant should anticipate unwanted interactions with the public and plan, to the extent they can, how they wish to respond. Even though, in an ideal world, the onus would not fall on the woman, preparing in advance how she wants to handle intrusive situations may relieve some stress. Peer-to-peer support, including through the Internet, might also assist; sometimes sharing stories can help women laugh off or disregard intrusive and even hostile comments.²⁶ Stores that cater to pregnant women and prospective parents should train their staff to expect customers with disabilities and address them respectfully, as they would other customers.

Clinicians providing obstetrical care should also seek to understand how women with mobility disability experience the public’s response to their pregnant bodies. One challenge is that obstetrical clinicians may themselves harbor societal biases, consciously or

unconsciously. Recognizing and addressing those biases will be essential for clinicians to provide the highest quality care to women during their pregnancies. In particular, developing strategies to minimize stresses as they interact with strangers might help women with mobility disability continue to participate as fully as they wish in community life throughout their pregnancies.

Acknowledgments

The Eunice Kennedy Shriver National Institute of Child Health and Human Development funded this study (Grant No. 1R21HD068756-02).

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Table 1Interviewee characteristics (*n* = 22)

Characteristic	<i>n</i>
Age in years (mean, standard deviation)	34.8 (5.3)
Age category	
25–29 years old	1
30–34 years old	13
35–39 years old	4
40–49 years old	4
White race ^a	20
Hispanic ethnicity	2
Marital/partner status a time of pregnancy ^b	
Married or partnered ^c	17
Boyfriend (broke up after pregnancy)	4
Single	1
Education	
High school	2
Some college	5
College degree	7
Graduate degree	8
Low income at time of birth ^d	8
Medicaid coverage at time of birth ^e	11
Geographic region at time of birth ^f	
Northeast	7
Midwest	7
South	5
West	3
Number of children	
One ^g	16
Two ^h	4
Three	2
Age of youngest child	
Up to 2 years old	12
3–5 years old	4
6–7 years old	3
8–9 years old	3
Condition causing disability	
Cerebral palsy ⁱ	4
Spinal cord injury	8
Other condition ^j	9

Characteristic	<i>n</i>
More than one condition ^k	1
Mobility aid(s) or other assistive technology used at time of pregnancy ^l	
Cane or crutches	4
Walker	2
Manual wheelchair ^m	12
Scooter	1
Power wheelchair	5
Leg braces or ankle-foot-orthotic	2

^aBlack = 1; Native American = 1.

^bMost recent pregnancy or birth if has >1 child.

^cTwo women are married to men who also had physical disabilities; 1 woman is now divorced.

^dLow income defined as <\$20,000/year. All other women self-described as “middle income.” Employment histories were too complicated to summarize, with women frequently changing schooling and employment status once or twice around the time of pregnancy.

^eAll women had some health insurance. Four women had been dually eligible for Medicaid and Medicare.

^fStates 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.

^gOne woman was 10 weeks pregnant with her second child at the time of the interview.

^hOne woman was 24 weeks pregnant with her third child at the time of the interview. One woman had had twins.

ⁱOne woman with cerebral palsy had a stroke during her first pregnancy, which complicated her second pregnancy.

^jArthrogryposis (2 women); Charcot-Marie-Tooth (1); congenital myasthenia (1); missing all four limbs, congenital (1); multiple bone injuries from car crash many years ago (1); NARP (neuropathy, ataxia, and retinitis pigmentosa) (1); osteogenesis imperfecta (1); spina bifida (1).

^kIncomplete spinal cord injury + mitochondrial disease.

^lAll women used at least one mobility aid or assistive technology, and some used more than one type (e.g., cane inside home and manual wheelchair outside). Some women started using the mobility aid during their pregnancy and continue to use it post-partum.

^mTwo women used a manual wheelchair with power assist.