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Labor, Delivery and Anesthesia Experiences of Women with Physical Disability

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Abstract

Background—Although many women with physical disabilities report poor quality reproductive health care, little research has addressed labor, delivery, and anesthesia experiences of these women. This study was conducted to explore these experiences in women with significant mobility disabilities.

Methods—A qualitative descriptive study was conducted with 22 U.S. women who had delivered newborns within the prior 10 years. All had significant mobility disabilities. Two-hour, in-depth telephone interviews were conducted using a semi-structured, open-ended interview protocol, which addressed many topics, including labor, delivery and anesthesia experiences. We recruited most participants through social networks, interviewing women from 17 states. Conventional content analysis, facilitated by NVivo software, was used to identify major themes.

Results—The women's mean age was 34.8 ± 5.3 years. Most women were white, college-educated, and used wheeled mobility aids. Four key themes emerged from participants' narratives of laboring and giving birth with a disability. These included women's preferences for type of delivery; clinicians and some women expected no labor pain; fears prompting active advocacy, and positive experiences. As participants discussed their experiences with anesthesia, four additional themes were identified: importance of consultation with the anesthesia team; decisions regarding epidural/spinal vs. general anesthesia; failed epidural with repeated efforts; and fear of injury related to anesthesia.

Conclusions—The responses of women in this study suggest that there is need to make intrapartum care better for women with physical disabilities and to improve their experiences with labor, birth and obstetric anesthesia care.

Keywords

Pregnancy; disability; obstetrical anesthesia; labor and delivery

Introduction

The World Health Organization reports that 10% of women with disability worldwide are of childbearing age.¹ Almost 145,000 U.S. women with severe mobility disability become pregnant every year,² many of whom have difficulty obtaining quality obstetrical care.^{3–5} Few studies have focused specifically on labor, delivery and anesthesia experiences of women with physical disability. Those few studies have typically had small samples or described case studies of women with specific disabling conditions, such as spinal cord injury (SCI), spina bifida, osteogenesis imperfecta, Charcot-Marie-Tooth disease and mitochondrial disease.^{6–9} Although recent research has addressed issues related to pregnancy care for women with physical disability more broadly,^{10–12} labor, birth, and anesthesia care for these women remains understudied.

A qualitative descriptive study was conducted to explore labor, birth, and anesthesia experiences of women with physical disability; this approach is particularly useful for examining issues of interest to clinicians.^{13–14} Given the minimal knowledge on these issues, we aimed to increase understanding that could lead to improved obstetrical care for women with physical disability and identify topics requiring further investigation.

Methods

Women with physical disabilities agreed to telephone interviews after being screened for study eligibility and informed about the interview process and human subjects protections. Massachusetts General Hospital/Partners HealthCare Institutional Review Board (IRB) approved this study, including use of verbal agreement to indicate implied informed consent.

As detailed elsewhere,¹⁵ eligibility criteria included using mobility assistive technology (cane, crutches, walker, manual or power wheelchair or scooter) or having limited arm or hand movement at the time of pregnancy (Tables 1, 2 and 3). After unsuccessful attempts to recruit women from Massachusetts General Hospital obstetrical practices and local disability organizations, we obtained IRB approval to recruit participants through social media sites used by women with disabilities. Within several days of posting information about the study, 45 women expressed interest; we included the first 21 women who met inclusion criteria. Subsequently, one woman referred by her Massachusetts General Hospital obstetrician was interviewed.

We used a semi-structured interview guide (available upon request) developed from existing literature and our previous research findings,^{16–19} which covered 8 broad pregnancy-related topics. After obtaining verbal informed consent, L.I.I. conducted all 22 telephone interviews

in late 2013; interviews averaged two hours in length. Women received \$50 for participating. A professional transcription service transcribed the interviews verbatim from audio recordings. We assigned pseudonyms and slightly changed details to protect participants' confidentiality.

The investigators used traditional content analysis²⁰ and independently read the interview transcripts to identify major topics participants raised in response to interview questions. Codes developed from these topics were used to code all interview transcripts with NVIVO 10 (QSR International). Through discussion, we reached consensus on the resulting themes captured by the codes. Selected quotations support the themes and subthemes and amplify women's experiences. Texts coded for labor, delivery and anesthesia experiences and selected quotations were analyzed for the findings reported here. Details about other experiences are addressed elsewhere.^{10,15,21–22}

Results

Most women who participated in this study were white, non-Hispanic, and college-educated; they resided in 17 states. Sixteen of the 22 women had at least one child three years of age or younger. Eighteen used wheeled mobility aids. Twenty-one received obstetrical care from an obstetrician (several were high-risk obstetricians) and one from a nurse midwife. Fourteen women had cesarean deliveries, 8 planned.

Themes Related to Labor and Birth Experience

Women's labor and birth narratives generated four themes that help to explain how women with physical disabilities experienced labor and delivery. These themes included: women's preferences for type of delivery; clinicians and some women expected no labor pain; fears prompting active advocacy, and positive experiences.

Most participants had clear preferences about type of delivery they wanted, often made in consultation with clinicians, based on women's perceptions of how their disability might affect labor, delivery and the immediate postpartum period. For example, Becky (SCI) preferred cesarean delivery to avoid an episiotomy:

After researching it, I decided for me that a C-section would be a better idea anyway because if I tore, how am I going to take care of that? That's almost like a pressure sore."

In contrast, Gabriella (SCI) stated:

I wanted to avoid a C-section...I didn't want to be laid up in bed with a C-section that would be below my level of injury, since my circulation is worse there and it would be weeks and weeks to heal.

Gabriella worried about caring for her baby through prolonged recovery.

Although several women preferred vaginal delivery, they feared that their obstetricians would recommend cesarean section because of their disability rather than for obstetric indications. Jennifer, who has Charcot-Marie-Tooth disease, was afraid of being pressured

into cesarean delivery. She elected to deliver at a birthing center with a nurse midwife and described her delivery as quick and easy:

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?

Several women with SCI preferred cesarean section because of risk of autonomic dysreflexia. Becky, who had a history of autonomic dysreflexia, reported that her obstetrician dismissed this concern:

He [obstetrician] didn't know anything about autonomic dysreflexia... I had learned in my research a vaginal birth would mean I would need to deal with this. He was like, 'Oh, that's not an issue.' I'm like, 'Actually it's a really big issue.'

Becky brought her obstetrician medical journal articles about autonomic dysreflexia in vaginal delivery with SCI, feeling that was the only way "to communicate with him and it worked."

Several women wanted to be awake during birth and had specific delivery and anesthesia preferences. Lauren (osteogenesis imperfecta) described her approach to ensure she was awake despite her cesarean section:

We did a lot of work on the front end...it was really important...that I have a C-section, if possible with an epidural, so that [husband] could be in the room too. I really wanted to be a part of it too, especially with the concern that [baby] could have [osteogenesis imperfecta]. We... wanted to make sure there was an advocate the whole time.

To inform their preferences, these women sought information from various sources. Despite viewing themselves as knowledgeable, they would have preferred for their clinicians to have discussed these issues with them.

Several women indicated that their clinicians expected that their disability precluded them having painful contractions. As a result, the women did not anticipate pain or discomfort during labor, leaving them unprepared for the pain that occurred. Most women, including those with altered lower-body sensations, detected labor through muscle spasms, abdominal tightening and pressure, or "autonomic dysreflexia headache." Becky (SCI) experienced autonomic dysreflexia symptoms with contractions and wishes she could have been prepared better.

Gabriella (SCI) was uncertain if she would detect contractions. She found clinicians and others to have erroneous perceptions about pain sensations and SCI:

People think, aren't you already paralyzed? You know, you can't feel anything anyway. They never really...realize that, you know, just like my legs would spasm if there's pain.

Cecelia, who had CP, described atypical contractions of her uterine muscles, which surprised her obstetrical team:

My uterus...would contract in one side and then contract in another, and then not contract at all at the bottom or whatever. ... [The clinicians] saw, when I was in active labor with my previous baby, that my uterus wasn't doing what it was supposed to do, so they weren't sure how to deal with that.

Women viewed their clinicians as uninformed about labor in women with disabilities. However, even when clinicians were knowledgeable, they did not share that information with their patients, leaving women uncertain about what to expect during labor.

Fears about labor and delivery outcomes for themselves and their infants prompted women to become active advocates. Women viewed their clinicians as lacking knowledge about how disability affects pregnancy and identified the need to advocate for themselves, and in some cases, to educate their physicians. During labor and delivery, women sought advocacy from spouses and others to avoid poor outcomes. To advocate for themselves, some women chose to remain awake during delivery. Francie (mitochondrial disease) feared she would receive intravenous lactated ringers solution contraindicated in her disease;⁶ she arranged for a labor and delivery nurse with the same condition to be present to prevent errors:

Nobody seemed to be on top of the medical issues. ... I was...more worried that I was going to die because nobody knew what was going on. I had seen too many patients [with mitochondrial disease] die because of doctors who just aren't informed.

The women who feared negative outcomes for themselves or their infants indicated that having knowledgeable clinicians would have reassured them and diminished their fears.

Several women described positive labor and delivery experiences. They reported positive relationships with their obstetric clinicians, who willingly answered their questions and provided trusted input. According to Nan (CP):

[My obstetrician] knew...that I wasn't talking out of fear...that I had some knowledge and education to support my decisions. She really believed I knew my body the best and was willing to help me....She listened and she read my chart and she said 'I see this is what you want ...you and your baby to come out of this healthy and fine.' ... And she's like 'you have every right...'

Bethany (SCI) appreciated a perinatologist's thorough explanation about why vaginal delivery was likely not possible:

'Your pelvis is too small. Let me explain why.' And he says that typically when a woman experiences SCI before puberty, their hips do not form properly.... Not just the width, but at an angle to allow a child to pass through the pelvis.

She was satisfied with his explanation and receiving information specific to her circumstances resulted in a positive experience for her.

Themes Related to Obstetrical Anesthesia

Labor and delivery anesthesia narratives generated four themes. These were the importance of consultation with the anesthesia team; decisions regarding epidural/spinal vs. general anesthesia; failed epidural with repeated efforts; and fear of injury related to anesthesia.

Several women discussed the importance of consulting formally with anesthesia providers prior to the onset of labor, especially when their disability presented challenges to pain control. Several who had prior consultations received the anesthesia they had preferred, while others did not. Most women who anticipated anesthesia difficulties had taken steps to inform their anesthesia team (e.g., provided scans, x-rays) about their specific concerns and their anesthesia preferences. Rachel (SCI) was worried about aspects of her spinal injury:

Because of the rods in my back and where my injury is, I knew that an epidural may or may not be an option for me... If something were to happen and I needed a C-section, I felt I needed to know what my options were. So I met with the anesthesia team.

Nan's anesthesia consultation went poorly, with the anesthesia clinician telling her:

'I don't even know why you're in here and you just have no idea what you're getting into.'

Those women who did not receive the anesthesia approach they preferred despite such consultation were dissatisfied: they felt their anesthesia preferences were ignored. Furthermore, the anesthesia teams failed to communicate with them about their decisions.

Women described having preferences about receiving epidural/spinal or general anesthesia, which was related in part to their desire to be involved in decision making about the anesthesia approach used. Several women had conducted literature searches about anesthesia options given their disability. Others had to be proactive to ensure that the anesthesia approach was appropriate for them and enabled them to be awake for the delivery if that was their preference.

Becky (SCI) indicated that an anesthesiologist said the risks of autonomic dysreflexia during labor and delivery meant "We'll just have to put you out then. We're going to give you a general." Becky indicated that she was fortunate that she had a different anesthesiologist for delivery who had previously provided anesthesia for women with a disability and ensured that she remained awake during the birth of what would be her only child. Most women had preferences for anesthesia approach, but the anesthesia received was not always what was planned or anticipated.

Failed epidural, often with repeated efforts, was reported by several women. They described receiving inadequate anesthesia, a frightening experience for them and their family members. Women reported repeated efforts to insert an epidural catheter hampered by skeletal abnormalities or presence of skeletal hardware in the affected area. Even if the catheter was eventually inserted, the epidural was ineffective.

Lauren (osteogenesis imperfecta) prepared extensively to ensure that she would remain awake during delivery. She met with the anesthesia team late in pregnancy and provided spinal x-rays showing skeletal hardware inserted with a spinal fusion. Nevertheless, efforts to establish an epidural line were unsuccessful.

They tried like 23 times and it was terrible. ...they just kept hitting metal. And to counteract that pain, they just kept giving me more pain meds through my IV. So I was...getting more and more confused and I don't respond really that well to narcotics anyway...When they did the incision I could feel it, so they immediately flooded my IV and knocked me out then.

She was unconscious during delivery, a great disappointment for her. Lauren felt the anesthesia team underestimated the complexities of her situation:

I remember them comparing how many spinals they had done on people with scoliosis. ...So I think they were not informed about [osteogenesis imperfecta] bones, and apparently it's a different fusion and there's more hardware in there than they expected, even though they had x-rays... They were pretty confident with themselves. They were like, 'Oh, we know we can do it. We've done it before.'

Sara (spina bifida), with previous surgeries for scoliosis, also described unsuccessful efforts to establish an epidural line:

I have a rod in my back from...two scoliosis surgeries....it's got scar tissue ... And where I was kind of small-boned and crooked, I really didn't think it would go smoothly, and I don't think they did either. They said, 'Well, let's give you an epidural, and maybe you can at least be awake during the surgery.' But it didn't take because of all my scar tissue.

The final issue addressed by women was their fear about injury related to anesthesia. Several women reported being afraid of injury and other negative outcomes from anesthesia. Nan (CP) reported fear about complications of an epidural:

My biggest fear, and I told the doctor this, was that if you gave me an epidural I was never going to walk again.

Cecelia feared becoming paralyzed if she moved during insertion of an epidural catheter during cesarean section:

In the back of my head I'm thinking 'Oh my God, I hope I'm not paralyzed.'

Women indicated that their fears about possible injury with anesthesia were related to their own inadequate knowledge and information.

Discussion

The study participants with physical disability recalled vivid details about their labor, delivery and anesthesia experiences even if they occurred several years ago. Participants reported positive as well as negative experiences. They described steps they employed to have positive labor, delivery and anesthesia experiences, although their plans were often derailed as they approached labor and delivery.

The experiences reported by participants support previous findings about problematic care during pregnancy^{3-4,10-12,23} and reflect women's perceptions about labor, delivery, and anesthesia care. Most participants had specific preferences for type of delivery and anesthesia. Despite preplanning, several women reported having little input into decisions about their care or having their input ignored, which is consistent with research findings that women with physical disability are less involved in decisions about their care than other women.²⁴ Although women without disabilities have also reported that decisions about type of delivery and anesthesia are made for them rather than with them,²⁵ lack of input or disregard of their input is of particular concern to women with physical disabilities who believe that many clinicians lack knowledge about obstetrical care needs of women with physical disability.

Fourteen of the 22 women in this study had cesarean sections; only 5 of which were planned. Changes in plans from vaginal delivery to cesarean section and from epidural to general anesthesia were likely based on lack of progression of labor and obstetrical complications (fetal distress, preeclampsia). Nevertheless, receiving general anesthesia and not being conscious for their newborn's birth were great disappointments to several women. More open communication between these women and their clinicians could have addressed their hopes, expectations and reasons why alternate approaches were necessary, perhaps decreasing their dissatisfaction with their anesthesia care.

Several descriptions of multiple unsuccessful attempts to place an epidural catheter suggest the need for more clinician training, including not only technical skills but also communication and shared decision-making. Several women had provided x-rays or scans of the sites of previous spinal surgeries, however, they believed that anesthesia providers were overly confident and minimized the effects of skeletal changes and the presence of skeletal hardware on epidural catheter placement. Although adequate epidural anesthesia is successful in almost 99% of patients in labor,²⁶⁻²⁷ more than half of the women in this sample reported failed epidural anesthesia. This may relate to women's underlying conditions or prior treatments (e.g., spinal fusion) as failed epidural anesthesia occurred most often in women with osteogenesis imperfecta, SCI and spina bifida. Successful administration of epidural anesthesia in women with significant changes in the neuroaxis anatomy due to these disorders has been reported in studies with very small numbers of women.⁷⁻⁹ The risk of autonomic dysreflexia with labor and delivery is common in women with SCI²⁸⁻²⁹ and requires special consideration because of possible serious outcomes if not prevented or adequately treated. Several women reported having to convince clinicians about its importance.

Several women believed that anesthesiologists did not recognize the importance women placed on being awake for delivery and ignored their anesthesia preferences. Although decisions to abandon efforts to administer epidural anesthesia and to administer general anesthesia were likely made in response to failed efforts to insert epidural catheters, lack of progression of labor, or maternal or fetal complications,³⁰ women reported receiving inadequate explanations about these decisions. Although prevention of complications that affect women and their newborns during labor and delivery is of paramount importance,

explanations to women about these complications and their seriousness should be communicated to women.

A recent review of reproductive health care of women with disabilities indicated that although the U.S. has comprehensive disability legislation, no national strategy specifically addresses the intrapartal needs of women with disability.³¹ The responses of our study participants are consistent with those reported in the review and indicate unmet needs of women with disability related to pregnancy and the importance of education and training of clinicians to address these needs. This training should address communication and shared decision making with the goal that patients and clinicians are well informed and satisfied with the ultimate course of care, even if circumstances during labor and delivery require changes in obstetric or anesthesia management. Further strategies to develop informational resources on pregnancy for women with disability are needed. The findings are also consistent with previous studies in which individuals with disabilities, pregnant or not, report that their clinicians do not communicate adequately with them. Women with physical disabilities view clinicians as lacking understanding of the complex health issues of individuals with disabilities, and believe that clinicians fail to make efforts to increase their knowledge and understanding of those issues.^{10–12,18–19,32} Further research is needed to examine these issues and to evaluate strategies to address them.

The ability of women to recall and report vivid details about their experiences is a strength of this study. Even if women's reports of their experiences are not completely accurate in every detail, their perceptions of what occurred and how they were made to feel at the time remain relevant. With some exceptions, many of the unsatisfactory experiences described here could occur in other groups of pregnant women, including those without disability, and may not relate only to their physical disability. As with all qualitative studies, the sample was not a representative sample. Women did not represent all types of disabilities, and race/ethnicity diversity was limited. Also, women who had negative birth experiences may have been more interested in sharing their experiences than women whose experiences were positive.

Conclusions

The responses and experiences of women in this study clearly suggest the need for education and training of clinicians to provide more effective care of women with physical disability during pregnancy, including knowledge and technical skills. Further, greater attention of clinicians is needed to address the informational needs of women with physical disabilities and their desire to be informed and consulted about treatment decisions made during pregnancy. More effective communication with women about these issues would likely increase their satisfaction with obstetric and anesthesia care, an important consideration given the growing number of women with disability who elect to become parents, and would likely result in positive experiences and good maternal and infant outcomes.

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Table 1

Participant Characteristics and Pregnancy Outcomes n = 22

Characteristics and Pregnancy Outcomes	n
Age in years at time of interview (mean, standard deviation)	34.8 (5.3)
Age category at time of interview	
25–34 years old	14
35–39 years old	4
40–49 years old	4
White race ^a	20
Hispanic ethnicity	2
U.S. geographic region at time of delivery	
Northeast	7
Midwest	7
South	5
West	3
Number of children per participant	
One	16
Two	4
Three	2
Condition causing disability	
Cerebral palsy	4
Spinal cord injury	8
Other condition ^b	9
More than one condition ^c	1
Gestational diabetes	4
Eclampsia	1
Pre-eclampsia ^d	3

^aBlack = 1; Native American = 1^bArthrogryposis (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); neuropathy, ataxia, and retinitis pigmentosa (1); osteogenesis imperfecta (1); spina bifida (1)^cIncomplete spinal cord injury and mitochondrial disease^dClinicians disagreed about one woman's pre-eclampsia diagnosis; one woman mentioned only high blood pressure that led to early delivery

Table 2**Causes of Disability Among Study Participants**

Arthrogryposis: nonprogressive congenital disorder that affects the joints; characterized by multiple joint contractures.

Cerebral palsy (CP): neurologic disorder caused by damage to the brain either during pregnancy or shortly after birth; affects ability to control muscle movement.

Charcot-Marie Tooth disease: inherited disorder of peripheral nervous system with progressive loss of muscle strength and touch sensation.

Congenital myasthenia: inherited disorder in which the transmission of impulses from the nerves to the muscles is blocked, resulting in fatigue and weakness.

Mitochondrial disease: neuromuscular disease caused by abnormalities of intracellular structures that produce energy; symptoms usually involve weak or spontaneous muscle contractions.

Muscular dystrophy: is a group of inherited, progressive muscle disorders; all forms involve progressive weakness and degeneration of the muscles that control movement.

Osteogenesis imperfecta: genetic disorder characterized by short stature and bones that break easily, often from little or no apparent cause.

Spina bifida: defect in which the neural tube, the embryonic structure that eventually develops into the brain and spinal cord, fails to develop or close properly; consequences depend on the level of involvement of the spinal cord and nerves.

Spinal cord injury (SCI): damage to any part of the spinal cord or nerves at the end of the spinal canal; often causes permanent changes in strength, sensation and autonomic functions below the site of the injury. Level of the spinal cord and the complete or incomplete status of SCI determine function and sensation. Autonomic dysreflexia (AD) is a potentially dangerous clinical syndrome that develops in individuals with SCI at or above the T6 (thoracic 6th level), resulting in acute, dangerously elevated blood pressure.

Table 3

Demographic Characteristics of Women with Physical Disabilities and Their Experiences related to Labor, Delivery and Anesthesia

Demographic Characteristics and Disability	Mobility Assistance Used	Planned/Actual Type of Delivery; Planned/Actual Anesthesia	Women's Description of their Labor, Delivery and Anesthesia Experiences
Becky, 45–49 years old, white with thoracic SCI	Manual wheelchair	Vaginal/Cesarean Spinal	Deemed high risk (because of age, history and SCI); decided abdominal incision would be easier to manage than episiotomy; concerned about autonomic dysreflexia; pre-term contractions temporarily halted; baby's presentation required cesarean delivery; premature but normal birthweight.
Gabriella, 30–34 years old, white with thoracic SCI	Power-assist manual wheelchair	Vaginal/Vaginal Epidural	Strong desire to avoid cesarean section; hospitalized twice for urinary tract infections during pregnancy; headache similar to autonomic dysreflexia as earliest sign of labor.
Nicole, 30–34 years old with thoracic SCI	Manual wheelchair	Vaginal/Cesarean Epidural/General	Contractions several weeks early; extreme discomfort with spasms that occurred with contractions; unsuccessful epidural.
Jennifer, 30–34 years old, white, with Charcot-Marie-Tooth (CMT) disease	Scooter and forearm crutches	Vaginal None	Desire to avoid medicalization of birth; care provided by nurse midwife; supported by doula; quick and easy delivery.
Lauren, 30–34 years old, white with osteogenesis imperfecta	Manual wheelchair	Cesarean/Cesarean Epidural/General	23 unsuccessful efforts to insert epidural; patient and spouse wanted to be able to advocate for baby in OR if born with osteogenesis imperfecta; unable to do so because of need for general anesthesia for cesarean section; slighter larger incision than usual to accommodate baby in case baby had osteogenesis imperfecta. Described delivery as "It was very scary, after that...it wasn't an experience I would want to do again."
Bethany, 35–40 years old, white with partial SCI since age 2; paraplegia	Manual wheelchair	Cesarean/Cesarean Not reported	Third pregnancy after two cesarean sections; appreciated honesty of clinician with no previous experience providing care for women with disabilities but a willingness to learn.
Christine, 30–34 years old, white with cerebral palsy (CP)	Manual wheelchair; cane	Vaginal/Cesarean Epidural/General	Two previous emergency cesarean sections for placenta previa; complicated delivery after being hospitalized for several weeks; ineffective epidural.
Francie, 30–34 years old, white with mitochondrial disease; incomplete cervical level SCI due to car crash	Power wheelchair	Vaginal Epidural	Ineffective placement of epidural; used BIPAP (form of noninvasive positive pressure ventilation to support ventilation); weight gain of 57 lbs (had not been weighed throughout pregnancy); 20 hrs of labor; feared dying if lactated ringers infusion given; feared risks of general anesthesia because of mitochondrial disease; previous ICU stay with previous general anesthesia; operative vaginal delivery due to muscle weakness.
Margie, 25–29 years old, white with arthrogryposis and scoliosis	Leg braces	Vaginal/Cesarean Epidural/General	Failed epidural; described sense of "bolt of lightening" through her body with insertion of epidural catheter; catheter kinked; received general anesthesia after half day of labor without progression.
Nan, 35–40 years old with CP	Power wheelchair	Cesarean/Cesarean Epidural	Feared epidural would result in her never being able to walk again; negative interaction with anesthesiologist; described major seizures; chaotic delivery.
Samantha, 45–49 years old, white with congenital myasthenia; has tracheostomy	Manual wheelchair, walker	Cesarean/Cesarean Epidural/General	Failed efforts to insert epidural catheter due to skeletal abnormalities resulting from scoliosis surgery; very weak from disability; had pre-existing tracheostomy, which developed mucus

Demographic Characteristics and Disability	Mobility Assistance Used	Planned/Actual Type of Delivery; Planned/Actual Anesthesia	Women's Description of their Labor, Delivery and Anesthesia Experiences
Maureen, 30–34 years old white with congenital absence of both legs and most of one arm	Power wheelchair	Vagina/Cesarean Epidural	plugs and other complications; physical therapy during hospitalization. Cesarean section shortly after due date after 20 hours of labor without progression; expressed concern about being unable to push in absence of legs.
Rachel, 45–49 years old, white with low thoracic high-lumbar level SCI	Manual wheelchair	Vaginal/Vaginal None	Bleeding shortly before due date; resulted in short hospitalization prior to onset of labor; had hardware in spine; had consult with anesthesiologist with plan for epidural if needed.
Kayla, 35–39 years old, Black with cervical level SCI quadriplegia	Power wheelchair	Vaginal/Vaginal Not identified	About 2 months early; went from doctor's office to hospital in labor; described contractions as similar to "the most severe menstrual cramps ever"; post-delivery eclampsia.
Angela, 30–34 years old, white with muscular dystrophy	Power-assist manual wheelchair	Cesarean/Cesarean Epidural or spinal	Used intermittent positive-pressure ventilation (form of noninvasive positive pressure ventilation to support ventilation) during surgery and postpartum; difficulty breathing; 1 hr needed to place epidural/spinal catheter; difficult to assume position for placement of catheter when unsupported; pulse-ox monitored postoperatively because of difficulty breathing.
Adriana, 30–34 years old, Hispanic with spastic quadriplegia due to CP	Power wheelchair	Vaginal/Cesarean Epidural and spinal	Preeclampsia/eclampsia; hospitalized several days to control blood pressure; delivered several weeks preterm.
Ceceilia, 30–34 years old, Hispanic with CP	Cane	Vaginal/Cesarean Epidural	72-hour nonprogressing labor; terrified that epidural would cause SCI; had doula support during labor.
Nina, 35–39 year olds, white with low thoracic SCI, with damage to cervical spinal cord; scoliosis	Manual wheelchair	Vaginal/Vaginal Epidural	Previous surgeries and bone spurs at lumbar level of spinal column made epidural difficult (ineffective); catheter dilation attempted without success; experienced convulsions immediately after water manually broken; fetal distress; described delivery as chaotic
Hannah, 30–34 years, white, multiple bone injuries from trauma	Walker	Vaginal/Vaginal Epidural	Ineffective epidural.
Annmari, 40–44 years old, white with arthrogryposis, arm and leg weakness	Power wheelchair	Vaginal/Cesarean Not reported	Preference was for vaginal delivery because of time required for recovery from cesarean section; preeclampsia several weeks preterm; nonprogressing labor.
Kachina, 30–34 years old, Native American with thoracic level SCI	Manual wheelchair	Vaginal/Vaginal None	Weight gain resulted in being barely able to do weight shifts.
Sara, 30–34 years old, white with spina bifida	Manual wheelchair; crutches	Vaginal/Cesarean	Cesarean section required because of baby's transverse position; previous spinal surgeries precluded epidural