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## "He told me it would be extremely selfish of me to even consider [having kids]": The importance of reproductive health to women with spina bifida and the lack of support from their providers

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### Structured Abstract:

**Background:** As more women with spina bifida (SB) enter their reproductive years, the number having children is significantly increasing. However, little is known about their understanding of their ability to get pregnant or their experiences in considering, planning, or interacting with providers during a pregnancy.

**Objective:** We sought to determine what women have been told and understand about their reproductive health, their attitudes towards having children, and their experiences interacting with providers when seeking reproductive health care.

**Methods:** In this exploratory study employing qualitative research methods and following Grounded Theory, interviews with women with SB 16 years or older were transcribed verbatim and analyzed by three coders.

**Results:** Interviews of 25 women with SB ages 16-52 (median 26) revealed the following themes about their reproductive health perceptions and experiences: 1) poor understanding of reproductive health and potential, 2) interest in having a family, 3) facing provider's opposition to their reproductive goals, 4) going into pregnancy and delivery unprepared, 5) the importance of provider support for reproductive goals. Five women experienced an unintended pregnancy.

**Conclusions:** Although having children is important to most women with SB in this study, they report a poor understanding of their reproductive potential with several noting unintended

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pregnancies. They feel uninformed and unprepared during pregnancy and face discouragement from providers. Those experiencing supportive providers report a more positive experience. This demonstrates the urgent need to educate women with SB about their reproductive health and the providers who care for them how to support and counsel these women.

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## Introduction

Over the last several decades, advancement in the care of children with spina bifida (SB) has improved such that now 85% survive well into adulthood.<sup>1</sup> For the first time in history, there are now more adults with SB than children.<sup>2</sup> Not surprisingly, as more women with SB are entering adulthood, rates of pregnancy and live births have also been increasing,<sup>3,4</sup> in some western countries as much as fourteen fold since 1989.<sup>3</sup>

The growing body of literature on pregnancy in women with disabilities points to substantial inequities in healthcare quality and experience of stigma and bias. For example, they are twice as likely to start prenatal care after the first trimester and receive inadequate care compared to their non-disabled peers.<sup>5</sup> Clinicians face their own ambivalence and limited knowledge of disability in providing necessary care.<sup>6</sup> Their ambivalence reflects broader societal expectations that women with disabilities are asexual and that pregnancy is highly improbable.<sup>7,8</sup> It is therefore not surprising that women with disabilities are no different than their non-disabled peers in their desire or intention to have children, but are almost twice as likely to be uncertain if they will be able to realize their intention.<sup>9</sup>

Despite more women with SB pursuing motherhood and the expanding research on pregnancy in women with disabilities more broadly, little is known about the experiences of women with SB specifically in considering, planning, or experiencing a pregnancy. Given the congenital nature of their disability and potential hereditary nature of spina bifida, with a risk of SB is 1-5% for children with one parent with SB and up to 15% for those with both parents, it is possible that their experiences and concerns are unique.<sup>10</sup> However, current literature on pregnancy in spina bifida is limited primarily to small case series strictly about their obstetric outcomes.<sup>3,4,11-13</sup> Even health care providers specializing in SB feel they lack a basic understanding of the topic.<sup>14</sup>

In this context, we conducted an exploratory qualitative study to learn about women with SB's understanding of their ability to get pregnant, their interest in having children, and their experience seeking reproductive health care and having children. This foundational knowledge will be used to create and education and decisional support reproductive health toolkit for women with spina bifida and their providers.

## Materials and Methods

Institutional Review Board approval was obtained from a large Midwestern medical center before initiating this exploratory qualitative study.

## Study Sample

Women with the diagnosis of SB ages 16 years and older were eligible to participate. They were excluded if they did not speak English or had evidence of intellectual disability impeding their ability to understand or appropriately answer questions.

## Recruitment

We identified all participants followed at a large Midwestern tertiary referral center with the diagnosis of SB or SB occulta (ICD-10 Codes: Q05.9, Q05.4, Q05.8. ICD-9 Codes: 741.91, 741.00) using the electronic medical record. Women with SB occulta were included as these women have higher rates of cesarean delivery and complications of delivery than the general population, indicating that their reproductive health experiences may be different.<sup>15</sup> Letters were sent to 132 women explaining the goal of the study and inviting them to participate with a \$25 incentive. Additionally, a Facebook advertisement inviting women to learn about the study was run for a total of 6 weeks. The advertisement connected interested women to a description of the project on our institution's research webpage.

Interested women contacted the project coordinator who answered questions about the study and screened those interested in participating according to the inclusion and exclusion criteria. She then scheduled eligible women for an individual interview either in-person or over the phone, instructing them to make sure they were in a private place to avoid being overheard if they elected to be interviewed over the phone. Per the IRB-approval, participants were consented prior to the interview using a secure online survey program (REDCap<sup>®</sup>), phone consent, or a written consent.

The research team included four female members including the principal investigator (CSS; a practicing pediatric urologist), the senior author (DW; a licensed social worker, certified sex therapist, sexual health, and mixed methods researcher) and two undergraduate students (CS and VG) who were provided with appropriate training for data collection and analysis. Interviews were conducted by three of the authors (CSS, CS, and VG).

## Data Collection

Semi-structured interview guides were created by the first and senior authors (CSS and DW), based on their combined clinical experience working with this patient population, expertise and knowledge of the sexual and reproductive health research literature. The guides focused on four general topics: what had women been told and understood about their ability to get pregnant, their attitudes towards having children, their experience planning a pregnancy, and their experience during pregnancy and delivery. Interview guides were refined during the study iteratively, based on new information learned during interviews. Questions were open-ended so women could reflect on their own thoughts and experiences, such as, "What was it like discussing getting pregnant with your doctor for the first time?" (see questions in Appendix 1). All interviews were audio recorded and professionally transcribed verbatim, with any identifying information removed. Field notes were taken for each interview to record observations of participant comfort level, openness, and new ideas or concepts.

## Development of Coding Structure and Qualitative Data Analysis

Three investigators (CSS, CS, DW) independently reviewed all interviews using Grounded Theory procedures to develop new concepts in an area without foundational knowledge in this specific patient population.<sup>16</sup> Meaningful phrases related to the research questions were independently coded with open codes, or phrases that described the content of the quote, by two investigators (CSS and CS). Open codes were transformed into axial codes, or short phrases reflective of the themes or ideas through discussion of three investigators (CSS, CS, and DW). Axial codes were then categorized into higher level constructs summarizing the themes. Discrepancies were discussed until consensus was reached. The diversity of the disability severity of the participants, the investigator's experience of studying sexual and reproductive health (DW) and caring for SB patients (CSS), independent coding by the investigators, rigorous discussion of the findings and codes, and consensus on the results helped ensure trustworthiness of the data.

## Results

### Sample Characteristics

Twenty-five women with SB ages 16-52 (median age 26) participated in the study (see Table 1). Twenty-four were recruited from the research institution and 1 through Facebook. One woman who had been recruited from the research institution was excluded because she was uncertain if her diagnosis of SB was accurate. Recruitment was closed after 25 women because thematic saturation was reached.

Six of these women had at least one previous pregnancy, of whom 4 delivered vaginally and 2 underwent a cesarean delivery. Two of the women who had children required no bladder management or ambulatory assistance; three, both bladder management and ambulatory assistance; one, bladder management but no ambulatory assistance. Five of these six women (83%) had an unplanned pregnancy as they did not think they could get pregnant. The one woman with an intended pregnancy required bladder management but no ambulatory assistance. She underwent IVF to become pregnant. Twelve had some sort of conversation about reproductive health specific to SB with their doctor, although for three this occurred after they became pregnant. In six instances the women initiated the conversation themselves.

### Interview Themes

Coding of the interviews revealed five themes regarding the women's understanding of their reproductive health and experiences seeking professional guidance in order to get pregnant: 1) poor understanding of their pregnancy potential, 2) interest in having a family, 3) facing provider's opposition to their reproductive goals, 4) going into pregnancy and delivery unprepared, and 5) the importance of provider support for achieving reproductive goals.

### Women's poor understanding of their pregnancy potential

All women reported a deficient understanding of their reproductive health or capability to get pregnant. Education from schools' sexual education curriculum, parents, doctors, or searching online was felt to be insufficient, leaving them with many basic unanswered

questions about their ability to become pregnant, what pregnancy would be like for them, and what their outcomes may be (see Table 3 for common unanswered questions).

“I don’t know if I’m going to be able to someday have kids because of my back I don’t know how much it can take... if I do get pregnant will [the pain] be worse than a regular person’s back because my back is broken...?” Participant 15, 19 years (requires bladder management and ambulatory assistance)

“is [my spina bifida] affecting my chances of... being able to conceive, does it affect ovulation...?” Participant 7, 32 years (no bladder management or ambulatory assistance)

Five participants had an unintended pregnancy because they assumed they could not get pregnant, either because a physician told them that they could not get pregnant or they were told it would be extremely difficult to become pregnant, which the women interpreted as being unable to get pregnant.

“Basically that’s what they made it seem like—like I couldn’t get pregnant. If I did, it would be very difficult.” Participant 2, 24 years (requires bladder management and ambulatory assistance)

“...medical doctors have looked at me for years and always told me I would never bear a child, ever.” Participant 21, 27 years (requires bladder management and ambulatory assistance)

“That’s what they said, I’m not gonna get pregnant so I don’t have to worry about [using birth control].” Participant 25, 52 years (requires bladder management and ambulatory assistance)

Without adequate education, women with SB were left with unanswered questions about reproductive health specific to their diagnosis. These women received potentially incorrect information that they could not get pregnant and for them, this resulted in unplanned pregnancy.

### **Interest in having a family**

No matter their age or relationship status, the majority of participants (80%) had considered having children. Three had considered adoption, for one due to concerns about her back during a pregnancy and for another who wanted to adopt an older child due to concerns about her ability to care for an infant. Two had not thought about having children.

“I’ve always, always wanted to be a mother ever since I was little.” Participant 21, 27 years (requires bladder management and ambulatory assistance)

“...I would like have to... be able to carry them... out of their crib and change their diapers and that would be a lot for me...” Participant 15, 19 years (requires bladder management and ambulatory assistance)

Despite a desire to have children, eight of the women expressed fear about how pregnancy would impact their own bodies, the potential for miscarriage or inability to carry a pregnancy, or the risk of passing SB on to their child.

“And then there was a huge fear of if I did get pregnant, would my body be able to make it and you go through this absolute sheer terror of I don’t know if I can handle my body not being able to get the child here, and losing it.” Participant 24, 36 years (requires bladder management and ambulatory assistance)

Three women did not want children. For one, this was because she felt she was now too old and missed her chance, for another this was due to her fear of passing SB on to her child, and for the third, this was because she never had a desire for children, although this decision was a struggle for her at times.

“... each time that my sister got pregnant it was so emotional for me because it was just a reminder that I was never gonna have kids, and I was comfortable with that decision that I had made to have the hysterectomy, but... it was just kind of like the finality of you’re never gonna do this.” Participant 23, 36 years (requires bladder management and ambulatory assistance)

Having a child was very important to most of the women, although not without associated fears. For those who decided not to have children, this decision was difficult and they often felt ambivalent.

### **Facing provider’s opposition to their reproductive goals**

Women experienced opposition from providers from the time they considered pregnancy to the time of transition to motherhood. Women experienced relatively common discouraging feedback from physicians, such as that pregnancy could hurt their back or cause their bladder to rupture, the risk of passing on SB to their child, or simply because they felt the women had too much else going on or could not take care of a baby.

“...so he told me that he wanted [to be] nowhere near me if I ever decided that I was going to have kids because he said it would be extremely selfish for me to even think about it...” Participant 20, 23 years (requires bladder management and ambulatory assistance)

“...it felt like [the doctor] thought that... the value of my life was worth less and therefore it should be avoided for future people...” Participant 13, 29 years (no bladder management; requires ambulatory assistance)

Of the six women who had children, four were advised to terminate their pregnancy due to their SB. All women who became pregnant experienced disapproval from a physician.

“Yes, every time that I got pregnant that was the first words that came out of their mouth, I think you should think about abortion.” Participant 25, 52 years (requires bladder management and ambulatory assistance)

“...once I did get pregnant, I kind of felt like a little discouraged... from the doctors because they made me feel like it was just the worst thing that could happen to me.” Participant 2, 24 years (no bladder management or ambulatory assistance)

One woman said that her doctors told her that they did not think she could care for her baby and worried that her baby would be taken away.

“...I felt when I was in the hospital having my child almost like someone was gonna take him away because they felt I couldn’t take care of him and that scared me even worse.” Participant 25, 52 years (requires bladder management and ambulatory assistance)

Physicians’ biases included an assumption that the bodies of women with SB could not sustain a pregnancy, that having a child with SB would be undesirable, and that they would not be good mothers because of their disability.

### **Going into pregnancy and delivery unprepared**

Women felt their doctors, whether obstetricians, primary care physicians, or SB specialists, were unprepared to counsel them about what to expect during pregnancy and delivery. The fear of the unknown caused significant anxiety during pregnancy for some.

“They didn’t have a clue what to do with me being pregnant, and that was the scariest part because they had no idea.” Participant 21, 27 years (requires bladder management and ambulatory assistance)

Women felt their physicians did not know how their labor might be different and how to lead a woman with SB through a delivery. Some had large groups of providers present during their delivery who the women felt completely ignored their own concerns and preferences, making it a frightening and isolating experience.

“..I kept saying that I was just feeling restless and... my cervix was hurting... they looked and [my baby’s] feet were in the birth canal...” Participant 12, 35 years (requires bladder management; no ambulatory assistance)

“They actually did not ask me any way of how I wanted to deliver... anything I wrote down on a piece of paper they ignored basically.” Participant 3, 26 years (no bladder management or ambulatory assistance)

“They constantly wanted to give me an epidural and I kept saying I don’t want an epidural... They came in with latex gloves, and I’m allergic to latex.” Participant 25, 52 years (requires bladder management and ambulatory assistance)

“...when I delivered my daughter I just felt like what was supposed to be my best moment was the worst moment, I don’t feel like those doctors... were hearing me, were listening to me, or anything.” Participant 25, 52 years (requires bladder management and ambulatory assistance)

Women did not feel that their physicians were prepared to care for them during pregnancy and delivery, which caused some to feel anxious and alone during these crucial and vulnerable times.

### **The importance of provider support for reproductive goals**

While all six women who had a pregnancy had negative experiences of being discouraged by a physician at some point, some ultimately found providers who made them feel well supported. Interestingly, it was not the clinical experience of the provider that made them

feel well cared for, but the provider's willingness to care for them and support her reproductive goals.

"[My obstetrician]... handled the situation of [my pregnancy even though] I don't think he had ever had a SB patient before... and he did great." Participant 24, 36 years (requires bladder management and ambulatory assistance)

"...I didn't feel like anybody was particularly prepared because my particular situation is not something they normally come up against... But the nurses... were amazing. There were 14 people in the room when I gave birth." Participant 12, 35 years (requires bladder management; no ambulatory assistance)

"...I think what I liked most about [my obstetrician] was she never questioned [my decision to have a baby]... She was really kind of like my cheerleader, like you can do this..." Participant 25, 52 years (requires bladder management and ambulatory assistance)

"...it was actually the head of the department who happened to deliver [my baby] but... it was the one resident who was just amazing and took special interest in me because she was just very compassionate... and now she's my obgyn..." Participant 12, 35 years (requires bladder management; no ambulatory assistance)

Women who found supportive providers felt well cared for during their pregnancy and delivery, no matter the experience of the provider with pregnant SB patients.

## Discussion

In this study we found that women with SB lack a basic understanding of their ability to become pregnant and how pregnancy may be different for them due to difficulty finding any source of information specific to SB. Indeed, this topic was not properly addressed, completely ignored, or false information was given by providers, including obstetricians, primary care physicians, and SB specialists. As a result, the women with SB in this sample reported a poor understanding of their potential for fertility and pregnancy. This led to uncertainty about their ability to get pregnant; 83% of first pregnancies in our study sample were unintended. Most women desired to have a child, although many were fearful of how the pregnancy would impact their health and the possible risks for their child. They experienced physicians actively discouraging them from considering having children, even when they were already pregnant; most who became pregnant were advised to terminate their pregnancy. Women felt their doctors were unprepared to guide them through pregnancy and delivery due to their lack of experience and bias. For some, that resulted in too many providers being involved in their pregnancy and delivery, drowning out the women's own voices and desires. This left women feeling anxious and isolated. The women who ultimately found more supportive providers felt reassured through the process of pregnancy and delivery, regardless of the provider's experience.

Although there is little information about the experiences of women with SB in the literature, these findings are consistent with reports of women with disabilities more generally. Unintended pregnancies occur at a higher rate among women with disabilities



than those without, although exact rates remain unknown.<sup>17</sup> In one study, nearly half of 25 pregnancies among women with disabilities were unintended.<sup>18</sup> In a study of young people (14 – 23 years) with SB, three of 27 women experienced a pregnancy, all of which were unplanned.<sup>19</sup> It is alarming that the vast majority of first-time pregnancies in this current study were not only unintended, but also the result of misinformation or misleading information given by their physicians.

The resistance women in this study felt from providers regarding their reproductive goals aligns with the broader literature on women with physical disabilities. In a survey of 126 women with physical disabilities who had given birth, 35% of women said their health care provider (primary care physician, obstetrician, or midwife) had a negative reaction to their interest in becoming pregnant and 46% had to see multiple obstetrical providers before finding one who would care for them during pregnancy.<sup>20</sup> Other smaller qualitative studies have also reported that women are frequently encouraged to avoid pregnancy, terminate their pregnancies, or give their babies up for adoption.<sup>6,21,22</sup>

Similar to the women in this study, other women with disabilities have also felt unprepared for their pregnancy due to a lack of sufficient education from their providers. In Mitra et. al.'s study of 126 women who delivered a child, 52% wanted to know more about how their disability may impact their pregnancy and 65% wanted to know more about how their labor and delivery may be different.<sup>20</sup> Similarly, qualitative studies have also shown that women have felt that their providers were not able to give them adequate information about their reproductive health in general and what they should expect during a pregnancy.<sup>6,18,21,22</sup> Some felt their provider's lack of knowledge about how to care for them led to negative birth experiences where they felt their preferences and concerns were ignored.<sup>6,21,23</sup> In a large survey of 881 women with physical disabilities who had a baby, only 65% felt they were involved in decisions about their perinatal care<sup>24</sup> and in another large survey of 1,482 women with disabilities, only 65% felt they were involved in decisions during delivery.<sup>25</sup> Although little is known about the training obstetricians receive to care for women with SB during pregnancy, pediatric urologists, who have taken responsibility for initiating conversations on sexual and reproductive health with their adolescent and young adult SB patients, admit to avoiding the topic because they feel unprepared to do so. However, they did express a desire to learn to be able to better support SB women's sexual and reproductive goals.<sup>14</sup>

As the first study to specifically address women with SB's experiences contemplating, planning, and going through pregnancy, this investigation breaks new ground in an area of healthcare that is essential for all women, but has been inadequately addressed in this population of women. The limitations of the study include a relatively small sample, recruitment from a single Midwestern tertiary referral center in the United States and exclusion of women who did not speak English or had learning disabilities. Additionally, while this data suggests that women with spina bifida and all different severities of disability face challenges, further large-scale studies are needed to explore outcomes of pregnancy in this population and elucidate any differences by spina bifida type. This initial work, strengthened by a diversity of disability severity and personal experiences, lays the

foundation for work to improve reproductive health education, pregnancy decision making and the training of clinicians to address the needs of their patients with SB.

## Conclusions

This study's results suggest that women with SB feel a lack of understanding of their potential for and risks during pregnancy. Moreover, the women's negative experiences with health care providers when discussing pregnancy goals and being pregnant highlights an urgent need to educate health care providers about fertility, pregnancy, and delivery outcomes specific to women with spina bifida. The enduring stigma and discrimination many women with disabilities face in discussing and pursuing their reproductive goals must be addressed and its adverse impact on healthcare quality mitigated. Women with SB wishing to become mothers through childbirth deserve what all women deserve – well educated health care providers who are able to address their needs for information and to support their autonomy in making these decisions with compassion and openness.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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## References

1. Shin M, Kucik JE, Siffel C, et al. Improved survival among children with spina bifida in the United States. *The Journal of pediatrics*. 2012;161(6):1132–1137. [PubMed: 22727874]
2. Ouyang L, Grosse SD, Armour BS, Waitzman NJ. Health care expenditures of children and adults with spina bifida in a privately insured U.S. population. *Birth defects research Part A, Clinical and molecular teratology*. 2007;79(7):552–558. [PubMed: 17335056]
3. Auger N, Arbour L, Schnitzer ME, Healy-Profitos J, Nadeau G, Fraser WD. Pregnancy outcomes of women with spina bifida. *Disability and rehabilitation*. 2018:1–7.
4. Shepard CL, Yan PL, Hollingsworth JM, Kraft KH. Pregnancy among mothers with spina bifida. *J Pediatr Urol*. 2018;14(1):11.e11–11.e16. [PubMed: 28943353]
5. Mitra M, Clements KM, Zhang J, Iezzoni LI, Smeltzer SC, Long-Bellil LM. Maternal Characteristics, Pregnancy Complications, and Adverse Birth Outcomes Among Women With Disabilities. *Medical care*. 2015;53(12):1027–1032. [PubMed: 26492209]
6. Walsh-Gallagher D, Sinclair M, Mc Conkey R. The ambiguity of disabled women's experiences of pregnancy, childbirth and motherhood: a phenomenological understanding. *Midwifery*. 2012;28(2):156–162. [PubMed: 21570753]
7. Iezzoni LI, Mitra M. Transcending the counter-normative: Sexual and reproductive health and persons with disability. *Disability and health journal*. 2017;10(3):369–370. [PubMed: 28395909]
8. Iezzoni LI, Wint AJ, Smeltzer SC, Ecker JL. "How did that happen?" Public responses to women with mobility disability during pregnancy. *Disability and health journal*. 2015;8(3):380–387. [PubMed: 25944504]
9. Shandra CL, Hogan DP, Short SE. Planning for motherhood: fertility attitudes, desires and intentions among women with disabilities. *Perspectives on sexual and reproductive health* 2014;46(4):203–210. [PubMed: 25209449]

10. Visconti D, Noia G, Triarico S, et al. Sexuality, pre-conception counseling and urological management of pregnancy for young women with spina bifida. *European journal of obstetrics, gynecology, and reproductive biology*. 2012;163(2):129–133.
11. Arata M, Grover S, Dunne K, Bryan D. Pregnancy outcome and complications in women with spina bifida. *The Journal of reproductive medicine*. 2000;45(9):743–748. [PubMed: 11027084]
12. Jackson AB, Mott PK. Reproductive health care for women with spina bifida. *TheScientificWorldJournal*. 2007;7:1875–1883.
13. Greenwell TJ, Venn SN, Creighton S, Leaver RB, Woodhouse CR. Pregnancy after lower urinary tract reconstruction for congenital abnormalities. *BJU international*. 2003;92(7):773–777. [PubMed: 14616465]
14. Streur CS, Schafer CL, Garcia VP, Wittmann DA. "I Don't Know What I'm Doing... I Hope I'm Not Just an Idiot": The Need to Train Pediatric Urologists to Discuss Sexual and Reproductive Health Care With Young Women With Spina Bifida. *The journal of sexual medicine*. 2018;15(10):1403–1413. [PubMed: 30195565]
15. Shepard CL, Yan PL, Kielb SJ, et al. Complications of Delivery Among Mothers With Spina Bifida. *Urology*. 2019;123:280–286. [PubMed: 29908216]
16. Charmaz K *Construction Grounded Theory: A Practical Guide Through Qualitative Analysis*. 2 ed: London, Thousand Oaks, New Delhi: SAGE Publications; 2006.
17. Rowen TS, Stein S, Tepper M. Sexual health care for people with physical disabilities. *The journal of sexual medicine*. 2015;12(3):584–589. [PubMed: 25739683]
18. Mitra M, Long-Bellil LM, Iezzoni LI, Smeltzer SC, Smith LD. Pregnancy among women with physical disabilities: Unmet needs and recommendations on navigating pregnancy. *Disability and health journal*. 2016;9(3):457–463. [PubMed: 26847669]
19. Sawyer SM, Roberts KV. Sexual and reproductive health in young people with spina bifida. *Developmental medicine and child neurology*. 1999;41(10):671–675. [PubMed: 10587043]
20. Mitra M, Akobirshoev I, Moring NS, et al. Access to and Satisfaction with Prenatal Care Among Pregnant Women with Physical Disabilities: Findings from a National Survey. *Journal of women's health (2002)*. 2017;26(12):1356–1363.
21. Lipson JG, Rogers JG. Pregnancy, birth, and disability: women's health care experiences. *Health care for women international*. 2000;21(1):11–26. [PubMed: 11022446]
22. Smeltzer SC, Mitra M, Iezzoni LI, Long-Bellil L, Smith LD. Perinatal Experiences of Women With Physical Disabilities and Their Recommendations for Clinicians. *Journal of obstetric, gynecologic, and neonatal nursing : JOGNN*. 2016;45(6):781–789.
23. Smeltzer SC, Wint AJ, Ecker JL, Iezzoni LI. Labor, delivery, and anesthesia experiences of women with physical disability. *Birth (Berkeley, Calif)*. 2017;44(4):315–324.
24. Malouf R, Henderson J, Redshaw M. Access and quality of maternity care for disabled women during pregnancy, birth and the postnatal period in England: data from a national survey. *BMJ open*. 2017;7(7):e016757.
25. Redshaw M, Malouf R, Gao H, Gray R. Women with disability: the experience of maternity care during pregnancy, labour and birth and the postnatal period. *BMC pregnancy and childbirth*. 2013;13:174. [PubMed: 24034425]

**Table 1.**

Participant clinical and reproductive characteristics.

Patient	Age	Bladder Management	Ambulatory Status	Previous Pregnancy	Current or Previous Partner	Desire for Family
1	19	None	No assistance	N	Y	N
2	24	None	No assistance	Y	Y	Y
3	26	None	No assistance	Y	Y	Y
4	26	None	No assistance	N	Y	Y
5	30	None	No assistance	N	Y	Y
6	32	None	No assistance	N	Y	Y
7	32	None	No assistance	N	Y	Y
8	33	None	No assistance	N	Y	Y
9	17	CIC (urethra)	No assistance	N	Y	Y
10	21	CIC (urethra)	No assistance	N	Unk	Y
11	22	Medication only	Unk	N	Y	Unk
12	35	CIC (urethra)	No assistance	Y	Y	Y
13	29	None	AFOs/Wheelchair	N	Y	Y
14	16	CIC (urethra)	AFOs	N	N	Y
15	19	CIC (bladder channel)	Wheelchair	N	Y	Y
16	19	CIC (bladder channel)	Wheelchair	N	N	N
17	22	CIC (urethra)	AFOs	N	Y	Y
18	23	CIC (bladder channel)	Wheelchair	N	N	Y
19	23	CIC (urethra)	Crutches/wheelchair	N	Unk	Y
20	23	CIC (bladder channel)	Crutches	N	Y	Y
21	27	CIC (bladder channel)	Wheelchair	Y	Y	Y
22	35	CIC	Wheelchair	N	Y	Y
23	36	Urostomy	Wheelchair	N	Y	Y
24	36	CIC (bladder channel)	AFOs	Y	Y	Y
25	52	Urostomy	Wheelchair	Y	Y	Y

**Table 2.**

Summary of participant clinical characteristics

	<b>Yes</b>	<b>No</b>	<b>Unknown</b>
<b>Bladder Management Program</b>	16	9	0
<b>Ambulatory Assistance</b>	13	11	1
<b>Both Bladder Management and Ambulatory Assistance</b>	12	12	1

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**Table 3.**

## Participants' unanswered reproductive health questions

<b>Women's unanswered questions</b>	<b>Participants</b>
How am I different from other girls/what I learned in sex ed?	3, 14, 18, 21, 24
Can I get pregnant?	2, 7, 9, 10, 13, 15, 21, 24, 25
If I got pregnant, what would happen to my body?	7, 10, 21
Could I physically carry a child with my back abnormalities?	15, 17, 7
What is the risk of spina bifida or other abnormalities in my child?	6, 8, 9, 17, 19, 20, 21, 24

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