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“They had the lunch lady coming up to assist”: The experiences of menarche and menstrual management for adolescents with physical disabilities

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Abstract

Background: Menarche is a pivotal time in an adolescent’s life but can be experienced differently by those with physical disabilities. Parents typically serve as the primary educators and support for their daughters during this time. Little is known about the parent’s perspective of their daughter’s experience preparing for menarche and learning to manage menses.

Objective: We sought to understand the parent’s perspective of the experience of their daughter with a physical disability around menarche and their preferences for health care provider support.

Methods: Individual semi-structured interviews were conducted with 21 parents of a daughter with a physical disability ages 7–26. Interviews were coded by 2 reviewers using Grounded Theory, with disagreements resolved by consensus.

Results: Six themes emerged regarding the parent’s perception of the experiences, including 1) variation in emotional responses to menarche, 2) parent’s perception of their daughter’s experience with menses and menstrual symptoms, 3) cross-section of disability and menstrual management, 4) menstrual management at school, 5) parental knowledge correlating to daughter’s preparation for menarche, and 6) desires for health care provider support.

Conclusions: All parents reported that their daughters faced challenges during menarche, ranging from emotional distress to dealing with the inaccessibility of hygiene products. Managing periods at schools was particularly burdensome. Parents who were better educated about what to expect were better able to prepare their daughters, but had difficulties finding informed, supportive providers. Health care providers should provide both anticipatory guidance and holistic, respectful, and equitable options for the management of menstrual symptoms.

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Keywords

disability; menstruation; adolescence; cerebral palsy; spina bifida

Introduction

The anticipation of menarche is a source of anxiety for many parents, including parents of adolescent girls with physical disabilities.¹ Mothers serve as the primary source of menstrual support for their daughters.^{2, 3} Their ability to educate their daughter is correlated with their daughter's sense of preparation of menarche.^{2, 3} However, current studies suggest mothers feel unequipped to prepare their daughters with a physical disability.⁴⁻⁶ Congenital and acquired physical disabilities, such as cerebral palsy, spina bifida, and spinal cord injuries, are associated with variable physical and for some cognitive disabilities. These conditions may be associated with precocious or early puberty as well as the exacerbation of medical conditions such as epilepsy.⁷⁻¹⁰ Additionally, future menstrual hygiene is a concern to many parents.⁵ The lack of reproductive health education specific to the considerations of adolescents with physical disabilities may further exacerbate the parent's anxiety.^{8, 11-14} Consequently, up to half of these parents seek anticipatory guidance from health care providers prior to menarche.⁴⁻⁶

Currently, most reports about the experience of menarche and learning to manage menses for these adolescent girls and the efforts of parents to support them is limited to chart reviews and viewpoints from health care providers.^{4-6, 12, 15-17} It is imperative to understand these experiences from the family's perspective to learn how to best equip them in supporting their daughters.

In this context, we performed an exploratory qualitative study of parents of adolescent girls and young women with physical disabilities. Our aims were to learn about 1) the parent's perspective of their daughter's experience with menarche and learning to manage menses and 2) the parent's experiences with and desires for health care provider support.

Methods

Institutional Review Board approval from the University of Michigan Institutional Review Board was obtained before participant recruitment (HUM00209888).

Research Team

The research team was composed of 8 female members: a pediatric urologist (CS), a Research Manager (JK), three adolescent gynecologists (SE, EQ, and MR), a certified sex therapist, licensed social worker, and sexual health researcher (DW), and a clinical and rehabilitation psychologist (CK). All team members are clinical or research experts in sexual health for women with disabilities. CS, JK, DW, and CK have expertise in qualitative research. One member of the research team has a physical disability and was involved in all steps of the research study.

Study Sample

A biologic or adopted parent or guardian of a daughter with a physical disability aged 7–26 years old was eligible to participate. Both parents could participate if interested. To capture the experiences of parents anticipating their daughter’s menarche, daughters did not need to have started periods for parents to participate.

Recruitment

Recruitment was conducted using convenience, purposive, snowball, and theoretical sampling between 4/6/2022 and 9/2/2022. First, parents of a female child ages 7–18 years with a diagnosis of spina bifida, cerebral palsy, or spinal cord injury in a single institution were mailed an approved recruitment letter explaining the study and offering an incentive of \$25 for participation, with intentions to stagger the letters to eligible participants ages 19–26 later for ease of scheduling. However, due to similar experiences among participants due to the availability of pediatric gynecologists at our center, theoretical sampling was used to elicit a broader range of perspective.¹⁸ JK and providers at two southern tertiary referral centers contacted several parents they thought could add important viewpoints to gauge interest. Interested parents were emailed the recruitment letter. Finally, at the end of each interview, participants were asked if they knew of other parents who may be willing to participate.

Interested parents contacted the Research Manager (JK) who explained the study, screened for eligibility, obtained secure online or phone consent, sent the participants an electronic survey, and set up a time for the interview. Of 38 interested parents, 26 completed screening and 21 participated. Those who did not participate did not follow up.

Online Survey

After consent was obtained, parents were sent a link to an online survey via RedCap. The survey was designed by the study team to assess the daughter’s disability type and physical and cognitive abilities, as these were hypothesized to impact menarche and learning menstrual management (Appendix 1). Race was not assessed as it was not hypothesized to impact the findings.¹⁹

Qualitative Data Collection

Semi-structured interview guides were developed based on the investigators’ clinical experience with adolescents with physical disabilities (CS) and sexual health research (DW), then reviewed by the study team member with a physical disability and two parents of an adolescent girl with spina bifida. The interview guides were iteratively modified during the study (Appendix 2). This was a part of a larger interview also probing experiences and desires for sexual health education.

One-on-one semi-structured in-depth interviews were performed via the institution’s secure Zoom account by the Research Manager (JK). Interviews were recorded and transcribed verbatim. Each participant was assigned a study identification number to ensure anonymity.

Data Analysis

The interviews were analyzed by 2 authors (JK and CS) while data collection was ongoing using constructivist grounded theory procedures.²⁰ This inductive approach was chosen for this exploratory study as there is limited foundational knowledge on this topic from the perspective of the families.

The coders participated in reflexivity to acknowledge their own experiences with menarche. Each transcript was reviewed line by line by both authors and meaningful quotes related to the research questions were given a short descriptive phrase that conveyed the meaning of the quote using NVivo (QRS International) to record the coding. The codebook was iteratively refined during the analysis based on memos and team discussion to ensure all codes were clear and not redundant. Next, focused coding was performed by the JK and CS to synthesize overlapping concepts of the most common and relevant codes. Finally, theoretical explanations for the data were developed using abductive logic whereby theory was postulated based on the data and informed by the background of the analysts and then checked and refined using additional interview data.²¹ The 2 coders reviewed all interviews together and discussed codes and theories until consensus was reached. Thematic saturation was reached after 21 interviews, meaning all concepts for each theme were well understood and supported by the data.²² Trustworthiness of the data was ensured by the ability to reach thematic saturation, the diversity of disability severity of the daughters, the investigators lived and clinical experience, rigorous discussion of findings, and consensus on the results.^{23, 24} Member checking and repeat interviews were not performed.

Results

Participants

Twenty-one parents, all females, participated. Fourteen of the daughters entered menarche at a median age of 11 years [interquartile range (IQR) 3, range 8–13], while the seven who had not entered menarche were a median age of 9 (IQR 4, range 7–13). The daughters current ages were 7–26 years (median 13, IQR 4.5). As this data describes their experiences specifically around the time of menarche, the term “adolescent” will be used.²⁵ Nine adolescents had cerebral palsy, 10 had spina bifida, 1 had a spinal cord injury, and 1 had another congenital cause of a physical disability (Table 1). Thirteen use a mobility assistive device at school. Eight had a learning disability. Ten were on catheterization for bladder management and eight wore pull-ups to school. Two were parents of patients of CS and two personally knew JK.

Six themes were identified regarding the parent’s perception of their daughter’s experience with menarche and learning to manage menses and parent’s preferences for support (Table 2).

Variation in emotional responses to menarche

Parents reported their daughters experienced a range of emotional responses to menarche. Some parents felt their daughters’ responses were like any other adolescent. Other parents reported their daughters had strong responses, such as shock and embarrassment.

“She actually [hid] everything...because she didn’t want to tell us...she just cried because she [was] not ready.”

– Participant 7

Some parents reported their daughters viewed their period as an illness, whether due to difficulties understanding periods related to their cognitive ability or their frequent health concerns.

“...she felt like it was almost like a sickness... she thought I got to go to the hospital, and she still [does].”

– Participant 2

Other parents reported they or their independent daughters viewed menses as a burden.

“it’s more just the planning and...extra things to help [my daughter] do what other kids would do [on their own].”

– Participant 10

“The primary thing of managing her spina bifida is self-cathing. And she does do enemas... so adding on her period is something else she [has] to manage..”

– Participant 3

Parent’s perception of their daughter’s experience with menses and menstrual symptoms

Parents perceived their daughters experienced a range of difficulties with menses and menstrual symptoms soon after starting their periods. Some felt their daughter’s experience was no different than their own experience or that of siblings. Others reported their daughters had irregular periods, whether infrequent or especially frequent and heavy.

“...it became very heavy and irregular even at age eight...sometimes three weeks out of the month, she had her period...”

– Participant 10

Several parents reported their daughters experienced sudden gushes of bleeding. While not exclusive to girls who used wheelchairs, those who did tended to experience this with transfers.

“We would change her right before she went to therapeutic riding...[one of the] young men...[lifted] her out of her wheelchair...and all of a sudden a big...gush. She was completely covered in blood... that was embarrassing for the guys, embarrassing for her...”

– Participant 10

Parents felt period-related symptoms were similar to any other adolescent who recently entered menarche, but often perceived as more severe or harder to manage. Several mothers noted their daughters had more intense labile emotions compared to older siblings.

“When it starts getting time with her PMS...she definitely gets very moody. She’s...our third daughter... she is more agitated...we call her our Mr. Jeekyll and Dr. Hyde.”

– Participant 20

Parents of daughters with epilepsy worried about cyclical seizure activity. One mother started her daughter on period suppression immediately after menarche and her daughter had not experienced any seizures. Parents also reported their daughters commonly complained of cramping. One parent noted her daughter’s bowels were looser during menstruation, but other parents did not notice changes in bowel and bladder symptoms. A parent of a daughter who had not entered menarche worried about worsening autonomic dysreflexia and urinary tract infections with periods.

“...she’ll have her cycle and she’ll have a wet diaper and a messy diaper...She does get quite a few UTIs as it is...how [are we] going to make sure [she doesn’t] get...an increase in those infections.”

– Participant 9

Cross-Section of Disability and Menstrual Management

Nearly every parent, including those who described their daughter’s disability as “mild,” felt they and their daughters struggled initially to find the best option for period management due to the inaccessibility of the products. Products all required two hands to place and change.

“My daughter is just affected on one side...but trying to do some of these tasks one-handed, you don’t realize how hard it is until you do it that way too.”

–Participant 27

Parents felt menstrual pads were uncomfortable and ineffective, especially for daughters who used pull-ups. Although many placed pads within the pull-ups, they tended to not stick, get caught in pubic hair, cause chafing in girls who primarily sit, and fall out the leg of the pull-up. Leaking was also common for those using pull-ups.

“[Her period] can be so heavy that it’ll leak down the leg hole, not through the pull-up itself, but it just will happen so suddenly and so rapidly...”

– Participant 21

Parents shared helpful tricks, such as avoiding pads with wings and using reusable pads, which are gentler on the skin. Period underwear was frequently noted to be the most accessible method, but insufficient on heavier days and difficult to change independently. Despite these tricks, many daughters required assistance with managing periods even if they were independent in toileting.

Conversely, one mother reported her daughter’s body awareness made it easier to learn to use tampons compared to her sister.

“She started using tampons quite early on. And it just took one time because she’s used to self-cathing.”

– Participant 3

Menstrual Management at School

Learning to manage menses while at school was often challenging. All parents perceived that their daughters developed an increased desire for privacy and care from only females at menarche. Some parents felt their daughters did not like being helped with their period, even if they already received assistance with toileting.

“She’d be on her period...at the end of the day she comes home drenched and...her period terrible all over her clothes and her wheelchair... [the teacher would say], ‘oh well, she was combative, she didn’t want us to change her so we didn’t change her.’...she can’t talk [so] instead of saying, ‘I don’t feel comfortable with Mr. Rob changing me,’...she was spitting and being combative.”

– Participant 9

Respectful care from females was difficult to secure at some schools due to their overall level of support and staffing limitations.

“They had the lunch lady coming up to assist in the changing because they had nobody else in the building.”

– Participant 9

Private bathrooms were often desired if needing assistance or if undressing was required, such as for daughters using period underwear, but were often not available.

“there’s privacy concerns...if you’re changing in a five-stall... public bathroom at school.”

-Participant 19

Even if schools were supportive, parents reported not liking to ask the schools for help.

“...there’s always that guilt as a mom, like okay I’m sending her to school and the aids are going to have to take care of [her period] for her...”

– Participant 2

Some mothers chose to not to have anyone help at school to guard their daughter’s privacy. They chose products that could typically last all day or came to the school themselves to help.

“...I was... opposed to [anybody] at school wiping her bottom. It’s very intimate.”

– Participant 21

Parental knowledge correlating to daughter’s preparation for menarche

Some parents felt they had sufficient knowledge to support their daughter during menarche. For some, this was because they anticipated the experience to be similar to their own or that of her older siblings. Others learned about how a disability could impact menarche from other parents, their own research, or their professional experience as a teacher or nurse. This prompted them to seek anticipatory advice.

“I actually was proactive when she was very young because I’m a special ed teacher. I’ve seen puberty hit real early and I’ve seen it mess with seizure activity. So, I began speaking with her neurologist and also my gynecologist.”

– Participant 5

These parents transferred their knowledge to preparing their daughters prior to menarche, whether by informal conversations or by reading books on puberty.

In contrast, some parents felt completely unprepared for menarche. For many, this was due, at least in part, to menarche starting earlier than expected.

“...we weren’t prepared for it to happen that early...at school, we have [sex ed] programs...[but she had not] even had that class yet.”

– Participant 20

Other parents were unaware of what to expect or how to explain periods adequately to their daughters. This translated into difficulties supporting their daughters.

“I wasn’t aware of how hard it would be for her to, you know, change a pad...”

– Participant 19

“So we’re trying to figure out how do you explain puberty to a child who probably wouldn’t comprehend it...”

– Participant 8

Desires for health care provider support

Parents desired anticipatory guidance from their health care providers about what to expect at menarche and tips for menstrual management.

“...just giving some advice on things to do or look for or try...having some direction of a child with disabilities trying to manage this stuff would have been nice.”

– Participant 19

Parents felt most providers were knowledgeable about period suppression, but not menstrual products or non-medical symptomatic treatment. Parents had mixed but strong opinions about the use of contraceptives for their daughters. Some reported both they and their daughters thought contraception was beneficial for preventing seizures, improving hygiene, decreasing embarrassing leaks, avoiding panic over periods, eliminating the need to rely on schools for assistance, and improving mood and other menstrual symptoms.

“It has alleviated all of, for the most part all the bleeding, discomfort, and just the hassle of it all...it has helped with the seizure control.”

– Participant 5

Parents reported daughters using oral contraception, medroxyprogesterone acetate injections, and intrauterine devices. Some tried several types of period prevention before settling on one that worked best. Some parents had to make decisions about contraceptive use on behalf of their daughters with significant cognitive delay. However, they appreciated those providers

who demonstrated respect by speaking directly to their daughters during consultations and offering a confidential interview.

Other parents wanted to avoid contraception. For some, this was due to a concern that their daughter was too young or their own personal history of poor tolerance of contraception.

“I wasn’t comfortable with putting an 11-year-old on birth control at that age...”

– Participant 19

Whether parents and daughters wanted to learn about options for contraception or avoid medical intervention, many experienced provider resistance. Parents wanted their daughters to have the same access to choose or decline contraception as any other girl and to have their decisions respected.

Discussion

In this study, parents reported their perception that they and their daughters faced multifaceted challenges at menarche. While some parents felt equipped to support their daughters, many felt surprised and unprepared for challenges such as precocious puberty, inaccessible products, or difficulties explaining periods or managing hygiene. Menstrual management while at school was particularly challenging. Parents wished health care providers provided better anticipatory guidance and offered a holistic, respectful, and equitable reproductive health care.

The parent’s perspective of their daughter’s experience of menarche and learning to manage menstruation can be understood using a socio-ecological model (Table 3). This model recognizes the intersectionality of five levels that impact this experience, including intrapersonal (knowledge, self-concept), interpersonal (individual relationships), institutional (systems and community), policy (policies and laws), and societal (cultural norms).²⁶ For many, the experience with menarche and decision about how to manage menses was a result of the intersectionality of all levels of factors. For example, one parent recognized her daughter’s desire for privacy at menarche and therefore did not want to have anyone at school assist with menstrual hygiene. However, the lack of accessible products meant that assistance with hygiene was necessary. Therefore, the parent decided to come to school personally to provide assistance.

These findings both align with and expound upon prior reports. Consistent with some parents in this study, Gray et al reported parents of adolescents with cerebral palsy often find the anticipation of menarche to be worse than the actual experience.¹ However, other parents in this study perceived menarche more challenging than anticipated. Grover and Wilbur have reported that some parents feel they have maximized what they can handle prior to the onset of menarche, with the additional need of managing menses becoming overwhelming for parents.^{8,14} In this study, this was true not only for some parents, but also one independent daughter. Prior studies have reported similar indications for seeking menstrual suppression as this study.^{6, 8, 12, 27, 28}

This study provides new insight to the parent's perspective of the experiences of daughters who are independent with their bladder and bowel hygiene. Although prior studies have reported that these adolescents who are independent with toileting can typically become independent with their menstrual hygiene, several parents noted their otherwise independent daughters required assistance due to the lack of accessibility of menstrual products.²⁹ Finally, experiencing more labile emotions around the time of their periods compared to their siblings or peers was described by parents for daughters with a range of disabilities. These emotional changes have primarily been previously described in adolescents with cognitive disabilities.^{6, 12, 16}

The use of contraception in this study was in accordance with established guidelines.^{30, 31} Adolescents and women with disabilities should be given autonomy and never coerced in reproductive decision-making, but also afforded the same access to women's health care as those without disabilities.^{30,31} Shared-decision making about contraception should occur after menarche. If a woman cannot make an independent or supported decision due to significant cognitive disability, parents or assigned decision-makers should make decisions in their best interest.^{30, 31} Contraception should start with the least risky and invasive reversible option available and tailored to the next best reversible option if not tolerated or effective.³⁰ Parents and daughters in this study sought contraception for ethical reasons such as seizure prevention, heavy and unpredictable periods, and a desire to avoid being touched by others for assistance at school.³¹ Providers started with the least invasive option such as the "mini pill" and progressively tried other reversible options such as injections or an IUD if indicated.^{30, 31}

Together, this supports the importance of health care providers proactively discussing menarche with parents and their daughters with a physical disability.⁷ Parents who felt prepared for what to expect felt more confident in supporting their daughter through menarche, consistent with prior studies.² Providers can equip parents by educating both the parents and daughters about the possibility of early menarche, potential challenges with menstruation, options for menstrual hygiene, and the options for non-medical and medical management of symptoms.^{7, 12} This also sets the foundation for future proactive, empowering discussions about sexual and reproductive health. If a provider feels ill equipped to facilitate such conversations, they should proactively refer families to adolescent gynecologists or other providers familiar with the challenges these adolescents and families may face. Additionally, our team is developing an online video-based disability-specific curriculum for adolescents and young people with disabilities to learn about puberty, periods, and other reproductive health topics. It will also have a curriculum for parents to learn how to support their daughters, which has been informed by this study. The goal is to supplement and facilitate education from providers and sex ed teachers.

This demonstrates the need for accessible hygiene products. Current products require dexterity of both hands and the ability to balance. Period underwear were viewed by many to be the most accessible, but on heavy days required changing at least once, which was difficult and embarrassing to do in school bathrooms. Additionally, this is not an option for adolescents and women with incontinence. Finally, this work also demonstrates the need for policies to ensure respectful, gender-aligned care support and private bathrooms at schools.

There are several limitations to this study. First, the findings are limited by the perspectives of parents who decided to participate, which may be different from non-participants in important ways. Nonetheless, the purpose of qualitative studies is to obtain an in-depth understanding of the experiences of participants. This represents the perspective of parents of daughters with a wide range of abilities. This did not capture the perspective of the adolescents themselves. The purpose of this work is to inform the parent portion of our developing intervention with the goal of equipping them to support their daughters during adolescence. We have previously interviewed adolescents and women about their reproductive health to inform the adolescent portion of the intervention.^{11, 32, 33} While this study was open to all parents, only women responded. This is likely due to mothers typically taking primary responsibility in this area.^{2, 3, 34} Finally, the sexual and gender identities of the daughters were not elicited.

Conclusion

Parents perceive that their daughters with a physical and, for some, coexisting cognitive disability face challenges at menarche. These can be understood as an intersectionality of intrapersonal factors (e.g., the daughter's knowledge, cognitive abilities, and new desire for privacy), interpersonal factors (e.g., the parent's knowledge and ability to prepare their daughters), institutional and policy factors (e.g., lack of school support), and societal factors (e.g., inaccessible products). These experiences could be improved by better educating adolescents around the time of menarche and equipping their parents to support their daughters, providing proactive, holistic, and equitable health care, implementing policies that ensure schools provide respectful, gender-aligned caregivers and private bathrooms, and developing accessible hygiene products.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Disclosures:

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Table 1.

Characteristics of Daughters

Participant	Age at Menarche	Current Age	Diagnosis	Assistive Device Used at School	Use of Birth Control	Bladder Management	Pull-Up at School	Educational Support
1	N/A	13	Spina Bifida	None	N	None	N	N
2	13	17	Cerebral Palsy	Wheelchair	Y (OCP)	CIC	Y	IEP/Special Ed
3	12	14	Spina Bifida	Shoe Insert/ Lift	N	CIC	N	N
4	N/A	12	Spinal Cord Injury	Wheelchair, Braces/AFOs	N	CIC	Y	N
5	11	18	Cerebral Palsy	Wheelchair, Braces/AFOs	Y (Depot)	CIC	Y	IEP/Special Ed
6	12	12	Cerebral Palsy	None	N	None	N	N
7	10	11	Cerebral Palsy	Braces/AFOs	N	None	N	N
8	N/A	9	Spina Bifida	Wheelchair, Braces/AFOs	N	None	Y	Special Ed
9	8	13	Cerebral Palsy	Wheelchair, Stander	Y (IUD)	Other	Y	IEP/Special Ed
10	N/A	9	Spina Bifida	Wheelchair, Braces/AFOs	N	CIC	Y	N
11	N/A	8	Cerebral Palsy	None	N	None	N	N
12	N/A	7	Cerebral Palsy	Braces/AFOs	N	None	N	N
13	13	14	Spina Bifida	None	N	Medications only	N	N
14	13	13	Cerebral Palsy	None	N	None	N	Lower Grade for Age
15	N/A	12	Spina Bifida	None	N	CIC	N	N
16	9	20	Spina Bifida	Walker	N	CIC	N	N
17	9	15	Spina Bifida	None	Y (OCP)	CIC	N	IEP
18	12	18	Spina Bifida	Wheelchair	Y (Depo)	CIC	Y	IEP
19	11	13	Cerebral Palsy	Braces/AFOs	N	None	N	Special Ed
20	10	12	Spina Bifida	Wheelchair, Crutches	N	CIC	Y	N
21	Unk ("mid-teens")	26	Other congenital cause	None	N	Other	N	IEP/Young Adult Program

AFOs- ankle foot orthosis; Unk- unknown; OCP- oral contraceptive pills; IUD- intrauterine device; Depo- Depo-Provera shot; IEP- Individualized Education Program

Table 2.

Theme Definitions

Theme	Definition	Axial Themes	Representative Quote
Parental knowledge correlating to daughter's preparation for menarche	Parental awareness of the possibility of early menarche and how to manage periods with a disability correlated to their ability to educate and physically prepare their daughters	<ul style="list-style-type: none"> • Timing of periods • Daughter's preparation of periods • Preparing daughter with education • Preparing daughter with supplies • Impact of pandemic on sex education 	"I made sure we were prepared. I made sure to get books and read them and keep us informed, but I don't think doctors were." -Participant 13
Variation in emotional response to menarche	Parents and daughter's perception of periods and emotional response to starting and managing periods	<ul style="list-style-type: none"> • Daughter's understanding of period • Daughter's preparation for period • Emotional distress of having to manage periods 	"...as parents, we had not... explained to her what was happening in her body, and it scared her to death." - Participant 20
Parent's perception of their daughter's experience with menses and menstrual symptoms	Daughter's physical experience of menses and cyclical physical and mood-related symptoms	<ul style="list-style-type: none"> • Physical impact of periods on health • Difficulties with periods • Irregular periods • Impact on whole family 	"...she lashes out at her sisters...it's not an all-the-time thing...it's just when we know it's getting time [for her period]...But right now...it's not affecting her at school...or we would have already explored some options." -Participant 34
Cross-section of disability and menstrual management	Disability-related difficulties and adaptations for menstrual management	<ul style="list-style-type: none"> • Accessibility for managing periods • Devices/supplies for managing periods 	"It's terrible. It's awful... the tape [on the pad] don't stick... to the pull-up. They move all around...Then the tape gets stuck in her pubic hair..." - Participant 2
Menstrual management at school	Experience of managing periods while at school	<ul style="list-style-type: none"> • Lack of school physical/emotional support • Helpful physical/emotional support • Preferences for support at school • School's perception of child's disability • Concerns about relying on others at school to care for periods 	"...it's impossible [for her] to change [her tampon or underwear] by herself at school...I [plan to] be there...I can hold her body...to help her." - Participant 7
Desires for healthcare support	Parental experiences with and preferences for education prior to menarche and period management support	<ul style="list-style-type: none"> • Knowledge of providers regarding disability and puberty • Providers initiating conversations on sexual and reproductive health • Providers not initiating conversations on sexual and reproductive health • Desire for parent preferences to be respected 	"...her pediatrician... [should have] stated, "[Daughter's Name], you've managed your spina bifida this far...you're gonna be able to do this.'" - Participant 3

Table 3.

Parents perspective of factors that influenced their daughter's experience of menarche and learning to manage menstruation using a socio-ecological theoretical framework

Level	Parent's Perspective of Relevant Factors
Intrapersonal (personal knowledge, self-concept)	<ul style="list-style-type: none"> • Education/knowledge about periods prior to menarche • Cognitive ability to understand periods • Emotional response to periods • Age at menarche • Sense of burden by current health management routines (e.g., bladder and bowel routines) • Desire for privacy • Desire for care from only females • Relevant health history (e.g., epilepsy)
Interpersonal (individual relationships)	<ul style="list-style-type: none"> • Parent's ability to educate daughter about what a period • Parent's knowledge about best menstrual products • Parent guilt to ask school caregivers for assistance • Parent preference not allow school caregivers to help with menstrual management • Parent sense of burden by current health management routines (e.g., bladder and bowel routines) • Knowledge of daughter's health care provider • Support of daughter's health care provider
Institutional (systems and community) and Policy (politics and laws)	<ul style="list-style-type: none"> • Lack of health care provider knowledge • School support • Availability of female caregivers at school • Lack of private bathrooms at school
Societal (cultural norms)	<ul style="list-style-type: none"> • Lack of accessible products • Lack of disability-specific sexual health education • Societal avoidance of being discrete/not talking about periods (postulated by authors)