

# Women with cerebral palsy: A qualitative study about their experiences with sexual and reproductive health education and services

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## Abstract.

**PURPOSE:** To explore the recalled experiences of women with CP regarding sexual health education and services they received.

**METHODS:** Semi-structured interviews and focus groups were conducted at four academic tertiary hospitals with 33 adult women with CP. Templates were used to ask about four key content domains: appointment planning (including planning for a gynecologic exam), accessibility of services, experiences with providers, and recommendations for improvement. Sessions were transcribed verbatim and analyzed to generate a coding dictionary. Blinded coding was carried out for each transcript, with duplicate coding used to confirm identified themes. Iterative analysis was used to identify and consolidate coding and key themes.

**RESULTS:** Similar barriers were discussed at the four sites, including lack of accessible exam tables, hospital staff unfamiliar with physical disabilities, and assumptions that women with CP are not sexually active. Many described the sexual education they received as brief, omitted, or mistimed. Self-advocacy was crucial, and recommended strategies ranged from pre-gynecologic exam medication to visit checklists.

**CONCLUSION:** Reproductive health education for young women with CP is frequently inadequate. Medical professionals lack relevant knowledge and awareness; medical facilities lack necessary infrastructure. Recommendations for improvements are made.

Keywords: Health education, sexual education, reproductive health, cerebral palsy

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## 1. Introduction

Cerebral palsy (CP) is the most common motor disability of childhood, with a worldwide average prevalence of 2.1 per 1000 live births that varies with gestational age and birth weight [1]. CP refers to a heterogeneous group of disorders which have in common abnormalities of movement and posture. Secondary features may include intellectual disability, seizure disorders, and sensory and musculoskeletal impairments [2]. Most children with CP live into adulthood and require appropriate preventative and holistic care as they transition to adulthood and across their lifespan. While studies have shown that people with disabilities are perceived as being asexual, not interested in sex, and not sexually active [3–6], few studies have focused in-depth on women with CP. Because CP is so prevalent and because individuals with CP often have co-occurring disabilities which make their care more complex, it is worth exploring the experiences of this particular population.

Adolescents with physical disabilities such as CP have been reported to be as sexually experienced as their non-disabled peers, but they often report receiving less sexual education and fewer sexual health services [7,8]. For example, young women with mobility impairments are less likely than women without disabilities to be asked about contraception by physicians, and they are also less likely to receive indicated Papanicolaou tests [9–11]. In a previous study by our group consisting of a national survey of women with CP, 70% of women were not asked about their desire to become pregnant during a physician visit, yet 20% experienced at least one pregnancy [3]. Overall low rates of education about sexually transmitted infections (STIs), human immunodeficiency virus (HIV), and condoms among women with disabilities potentially place them at greater risk of pregnancy and sexually transmitted infection. In the Netherlands, smaller studies of young adults with CP and without intellectual disability showed that a large proportion of women were dating, but 90% reported that their sexuality was not discussed during medical visits. In this same population, 80% reported CP-specific sexual problems and a desire to have these problems addressed [12–14].

The purpose of our study was to explore the recalled experiences of women with CP with regard to their access to information, interactions with providers, and healthcare services provided to support their sexual and reproductive health. We used a qualitative approach to more deeply understand the experiences and feelings of these women.

## 2. Methods

Semi-structured focus groups and individual interviews were conducted in the context of a larger study about the sexual health of women with CP across four academic tertiary care sites with specialized CP programs. One site is a freestanding children's hospital, and the others are large medical centers that serve adults. Institutional review board approvals were obtained at each participating site before commencing the study. Each participant was informed of confidentiality requirements and provided informed consent before participation.

Focus groups were conducted using semi-structured discussion templates (see example in Table 1). To maximize participation, individualized interviews were also conducted. To provide consistency across study sites, all focus group and interview sessions were facilitated by an experienced female moderator who is also a physical therapist. Due to transportation and mobility limitations, especially in more severe weather conditions, participants had the option of participating in person or by phone or Skype. The moderator reviewed informed consent and audio transcription consent as well as confidentiality principles and discussion guidelines (e.g., only one person speaking at a time, respecting other participants' perspectives) with each participant or group. She explained the purpose of the discussion as being to advise the research group to create best practices in clinics serving women with CP.

She then led informal discussions based on semi-structured interviews and group discussion templates, which varied in focus by site. The pediatric site focused mainly on reproductive and sexual health education. Groups at the adult sites discussed mammography, pregnancy care, and physical access to gynecology care. All, however, included templates designed to elicit information about experiences in key content domains: recalled sexual education, appointment planning, accessibility of services, exploration of potential barriers to care, experience with providers, and recommendations for improving care. Because the same moderator conducted all focus groups and interviews, we were able to use an iterative approach to explore common themes and expand upon them in subsequent discussions. Questions were not altered, but examples were provided to prompt discussion about points raised in prior focus groups and interviews as a means of theoretical sampling.

Interviews and focus group sessions were audio recorded on a digital device and transcribed verbatim. To retain confidentiality, transcripts were de-identified

Table 1

Example of qualitative interview moderator guidelines used at pediatric site (\*indicates questions used only at pediatric site)

*Questions:*

1. Do you remember the first time you talked with a healthcare provider about changes in your body at puberty, or your periods? What was that experience like?  
Follow up/probe:
  - Did you feel comfortable talking with your healthcare provider?
  - Did you think your healthcare provider felt comfortable?
  - Did s/he send you to a different healthcare provider?
2. Has your healthcare provider ever asked you whether you want to have children in the future?  
Follow up/probe:
  - What information do you wish you had about pregnancy?
3. Has your healthcare provider ever reviewed whether any of your medications could possibly interact with medications used for birth control? Would you feel comfortable talking about that with your healthcare provider?
4. \*Have you discussed information about HPV vaccination with your healthcare provider? What do you know about HPV vaccination?
5. \*Have you ever talked about condoms with a healthcare provider? What do you know about them?
6. \*How should healthcare providers ask patients about whether they are in a healthy relationship? That is, how should they ask about partner violence?
7. The following questions are about having a gynecologic exam, meaning a pelvic exam.
  - a. Tell me about what types of things you have to do to plan attending a medical appointment. Let's start at your home, on the phone with the provider, trying to schedule the appointment and go from there.
  - b. What expectations did you have for the appointment, and how did that compare with the experience?
  - c. Can you talk about what it is like to get on the exam table?
  - d. In what way could providers best prepare patients for gynecologic health visits?
  - e. Now I want you to think about your emotional response to these types of appointments – from set up to leaving; what do you feel when you need to attend a gynecologic appointment?
8. Are there any recommendations that you can think of that might help clinicians better understand your healthcare needs and the needs of women with cerebral palsy?
  - a. What recommendations do you have for providers?
  - b. What advice would you give patients?
  - c. What information would be helpful for you to have before, during, or after your visit?

by the removal of participants' names. Quotes were associated with participants by alphanumeric codes. De-identified data was stored centrally at the lead institution.

### 2.1. Participants

Women  $\geq$  18 years with CP were recruited to participate. Inclusion criteria were: 1) a confirmed diagnosis of

CP (ICD 9/10 codes 334.1/G11.4, 337.1/G99.0, 342.1, 343.0/G80.1, or 343.2-343.9/G80.0, G80.8, G80.2, G80.9, or by documented clinical history); 2) ability to attend a focus group session or individual interview at the host institution; and 3) capability of giving informed consent as determined by absence of intellectual disability or guardianship documented in the chart, or as determined by their attending physician. Information regarding motor ability was collected but did not influence inclusion or exclusion criteria. Motor ability was reported according to the Gross Motor Function Classification System (GMFCS), in which categories range from I (mild physical disability) to V (most severe physical disability, non-ambulatory) [15].

Recruitment methods varied between sites but in all cases reflected purposeful sampling. Some participants had previously participated in an online survey administered by this research group. One site has a pre-existing electronic research registry. The other sites used provider referral, clinic flyers, and referral from a local nonprofit serving people with CP. Due to the difficulty in identifying adult young women without intellectual disabilities who met study inclusion criteria at the pediatric site, two sampling methods were used there. First, a research coordinator used intensity sampling to identify eligible participants via a review of hospital clinical records. ICD codes relating to CP were used to generate the list for chart review. Potential participants were identified using the inclusion criteria and then invited to participate. Second, snowball sampling was used to identify eligible participants through provider referral: physicians were contacted and asked to refer young women whom they saw regularly and were diagnosed with CP. The goal was to recruit a small but diverse sample of women with CP.

### 2.2. Data analysis

Combined focus group and interview transcripts from all sites were read and analyzed by the co-PIs at the pediatric institution, after which semi-structured code lists and a coding dictionary were developed. Two team member coders performed duplicate coding, blinded to the other coder's results. Coding was performed using Dedoose (Dedoose Version 7.0.23, Los Angeles, CA). Our analysis was informed by grounded theory [16]. Iterative, thematic analysis was used to identify and consolidate coding, leading to the emergence of key themes and theoretical conclusions. Disagreements about coding or thematic analysis were resolved by consensus among members of the broader research

Fig. 1. Top quartile of codes (75–100%) across sites.

Rank	Code	Total observations
1	Access to gynecologic health care	202
2	Insufficient care	156
3	Identity	148
4	Doctor patient dynamics: Patient perceptions	110
5	Insufficient education	109
6	Disability	105
7	Providers	101
8	Relationships	99
9	Pregnancy and childbirth	97
10	Self-advocacy	94
11	Doctor patient dynamics: Experiences	93
12	Physical access	80
13	Uncertainty	78
14	Access accommodation strategies	76
15	Advice for health care providers	71
16	Exam lived experience	70
17	Doctor patient dynamics: Communication	66
18	Doctor patient dynamics: Knowledge	63
19	Participant need for info	60
20	Physical impact of CP on pregnancy/childbirth	60
21	Raising a child lived experience	58
22	Provider type gynecologist	54
23	Independence/privacy	53
24	Identity disability stereotypes	52
25	Access finding the right doctor	46
26	Advice for peers	44
27	Education timing	44
28	Pregnancy	44

team at the pediatric institution. Codes were tabulated and rank-ordered by frequency. Those in the top quartile (75–100%) were contrasted between focus group interview transcripts and across the different study sites (see Fig. 1).

### 3. Results

Thirteen individual interviews and a total of six focus groups were conducted across all sites between October 2015 and February 2016; one subject participated in a group interview by Skype. The 33 participants ranged in age from 19 to 72 years old, with a mean age of 38 years and a median of 36 years. Eighty-two percent of the subjects were white, 9% African American/Black, 6% Asian or South Asian, and 3% Hispanic/Latino. Forty-five percent of participants functioned at a GMFCS level I or II, indicating they could walk independently without a hand-held device (see Table 1).

Themes that emerged during qualitative analysis of the combined data included challenges accessing sexual

Table 2  
Participant demographics

	Participants (n)	Participants (%)
Site		
1	15	45.4
2	9	27.3
3	6	18.2
4	3	9.1
Race		
Caucasian	27	81.8
African American/Black	3	9.1
Asian/South Asian	2	6.1
Hispanic/Latino	1	3
GMFCS		
I	2	6.1
II	13	39.4
III	8	24.2
IV	10	30.3
V	0	0
Age (years)		
Range 19–72	Mean 38	Median 36
Interview type		
In person 23 (69.7%)	Phone 9 (27.3%)	Skype 1 (3%)

GMFCS levels: I = walks without limitations, qualitative differences in speed, balance and coordination; II = walks with limitations, may use handheld mobility or wheeled mobility over longer distances; III = walks using a hand-held mobility device and uses wheeled mobility for longer distances; IV = limited self-mobility, requires physical assistance or powered/manual wheeled mobility; V = dependent on manual wheeled mobility, limited anti-gravity head control [27].

health care, insufficient education received from health-care providers about sexual health, insufficient education of healthcare providers about CP, disappointing experiences of doctor/patient dynamics, and a recognition of the need for continued self-advocacy within a system that is not prepared to meet their needs. Participants frequently discussed an absence of continuity of care, a lack of CP-specific related services, and deficiencies in accommodations at provider offices as barriers to care. Participants felt disempowered by providers' lack of CP-specific knowledge in sexual health, especially pregnancy and family planning. Recommendations contributed by participants to improve care in this area included creating checklists for sexual and reproductive health care for healthcare providers and patients to inform each of important topics to address, equipping offices with specialized equipment including height-adjustable exam tables, and improving education for healthcare providers about sexual and reproductive health topics concerning CP.

#### 3.1. Challenges accessing sexual health care

Discussions about accessing health care began in response to questions about how participants identified

the right doctor for their reproductive health needs. Participants described challenges and strategies.

*“I can tell you that I Google-stalked the guy ... for a year before I was able to go to him, like just making sure that he was the right person” – Site 3*

*“I kind of judge people on their level of understanding ... I’m specifically going to tell you, “Okay this might be an issue.” And then they get frustrated. And then I’m like, “But I already warned you that this ... might be a problem.” So, it’s not like I was hiding anything from you. Um, so, you know, I’ve done my fair share of doctor shopping ... when necessary.” – Site 4*

*“None of the doctors like to touch anything with CP; they want you to go to the doctor that deals with CP, they don’t wanna have anything to do with you. It’s like CP is a taboo word. You say CP and they don’t know what to do.” – Site 1*

*“That’s why I’m still trying so hard to find the right doctor that I can be comfortable with because I just really feel that not only do I need that, but I feel like I have a right to it just as much as any other woman.” – Site 2*

Questions about the exam table in particular elicited frustration about physical access for many women with CP.

*“The biggest issue is table access and transferring ... providers tend to look at me when it’s time for the exam and go, ‘What next?’ Particularly in a gynecological setting, part of what I find inexplicable, like absolutely inexplicable, is if you go to a urologist appointment, I use a catheter, they have lifts for table access. The nurses are very well trained, but if you try to go the same place for gynecological, they don’t have access to those. Same hospital, no lifts. No training. So it just seems really odd in terms of women’s health.” – Site 2*

*“Getting on the table was no problem but after sitting ... in the position you had to be in for that exam, it’s a little hard for me to get off.” – Site 4*

Many participants commented on the barrier presented by their need for assistance. They reported that their practical need to have a family member with them to help with dressing or undressing created a conflict with their desire for confidentiality and privacy in the context of visits requiring gynecologic examination.

*“I don’t think I should have to choose between having the help that I need and having my privacy ... [you need] just a little bit more patience and willingness to accommodate.” – Site 2*

*“My mother was there so she was there to help me, but you know, I might not ... that’s the only appointment my mom was with me but usually my parents are not with me at my appointments.” – Site 4*

### 3.2. Insufficient receipt of sexual health education and information

Participants described sexual education they received from healthcare providers as often omitted, brief, or mistimed.

*“I do want to have children ... But ... the pediatrician never asked ... and neither did my adult doctor ask. Yet. Should I bring it up?” – Site 4*

*“The only thing I knew when I was a teenager was what I read. I used to read Essence Magazine and they told you that your gynecologist is supposed to ask you your health history, they’re supposed to find out if you’re sexually active, are you on birth control for whatever reason. I wasn’t asked any of those questions.” – Site 2*

*“Last year I did get pregnant but ... I didn’t go through with the pregnancy, so that’s when [my gynecologist] started talking to me about like, the future, birth control, and um, starting a family and stuff. So, that’s when I talked to him.” – Site 4*

In the context of wanting information and not always receiving it from their healthcare providers, many participants reported seeking out information from other sources, including family, friends, school, and the internet, with mixed (but often disappointing) results.

*“At the time ... I had friends with older sisters, so it was kind of like, you just went to them, and like, alright, so what’s the deal with this?” – Site 4*

*“I know like when I’ve gone to different CP-related websites, you know, you just kind of like browse around and see what’s there, so I’ve never really found anything even remotely related to that ... like I’ve had trouble just finding stuff for people over the age of 18 never mind like, family planning.” – Site 4*

### 3.3. Doctor/patient dynamics

Many participants commented that they perceived

that healthcare providers frequently assumed that women with CP were not sexually active and therefore did not need information about sex.

*“When I got to that doctor, they were like, ‘People with cerebral palsy have sex?’ And I was like, ‘Oh my god, yes we do.’ They’re like, ‘Are you sure that you’re in this relationship under your own consent?’ and I’m like, ‘I’m pretty sure.’” – Site 1*

*“Um, but, as I got older, maybe like in my twenties, I would have to bring up like the issues with my doctor...like, my general practitioner, myself. They would never bring it up. So every conversation I’ve had ... I’ve had to initiate it.” – Site 4*

### 3.4. A need for change: Self-advocacy strategies

Participants at all sites recognized the importance of self-advocacy among women with CP receiving sexual healthcare services. If they didn’t ask for services, they didn’t receive them, and often as young adults they felt intimidated by doctors who erroneously assumed that they knew the patient’s care needs best.

*“My parents were awesome, and the fact that from very young, they taught me you have a voice, and that is your strongest asset to make sure that you are being treated and cared for the way that you wanna be treated, whether you’re talking to a bully, whether you’re talking to a medical professional, whether you’re talking to your best girlfriend. Your voice is your strongest tool to get your needs and your desires across.” – Site 1*

*“Don’t be afraid to advocate for yourself, because I’ve been in situations where I’ve just had to open my mouth and say something ... and I know you’re the doctor and I know you went through medical school, but this is what works for me and this may work for this other person but you need to pay attention to me right now and we’ll make it work ...” – Site 3*

Many participants had very specific strategies for proactively getting what they needed out of doctor appointments.

*“I won’t necessarily request a longer appointment, but I’ll say ... here are my objectives for the appointment. Should it be a longer appointment, or do you think we’ll be able to get it done in the amount of time that they usually [do]?” – Site 4*

Another example of women acting proactively in-

involved using medications such as a muscle relaxant prior to a gynecologic exam to make themselves more comfortable rather than asking permission or waiting to be offered medication from doctors.

*“It’s kind of something I just kind of worked out myself ... it’s just easier to be like, ‘By the way, I took some Valium ...’ so yeah, it’s more I prep myself rather than other people have made the suggestion.” – Site 4*

Participants were creative about considering how gynecologic visits could be improved. One common suggestion for promoting self-advocacy was for a checklist of sexual health topics that should be touched upon during a visit for both patients and providers.

*“I think a checklist would definitely help ... and I mean even if it was available online you could just kind of print it off and walk into the doctor’s office with it and be like, ‘Wait, I gotta ask, you know, here’s the questions I need to ask.’ ‘Cause a lot of times when I have questions, I’ve gone and looked stuff up myself and then gone to a provider to see if the information that I got off the internet was correct.” – Site 4*

### 3.5. A need for change: Healthcare provider education about CP and sex

There was a repeated theme of perceiving that clinicians lacked education about CP in general as well as sexual health information specific to CP, placing the burden of providing education about CP on the patients themselves. They also reported provider discomfort discussing issues related to sexual health for women with CP.

*“When doctors and nurses don’t understand CP and don’t take my word for it ... I have to educate them ... which is fine, because let’s face it, most medical professionals have only had a chapter in a medical book, and that’s it.” – Site 1*

*“I do remember when I was starting puberty my orthopedic surgeon, um, that I used to see, he, you know, would do like the yearly ... check in, the whole thing and then his last question was, ‘and you started your period, right? Okay, all right then. See you in a year. Bye.’ And like, okay, you don’t really know where that came from and what that reasoning was, but he always just kind of like, asked. And then ran out of the room after if he got his answer.” – Site 4*

Participants expressed a desire for care tailored to their needs, and particularly appreciated doctors who were knowledgeable about CP, or acknowledged their lack of knowledge but committed to help find answers.

*“When I worked with . . . [my] OBGYN . . . she admitted that she didn’t have 100% of an idea of how it would go and wanted to make sure that there were no additional risk factors that she needed to worry about, just because she was unaware. She was like, ‘I just don’t wanna miss something because I don’t know.’ But I appreciated that. At least she was honest and not obnoxious towards me in the process.” – Site 1*

#### 4. Discussion

This study details many opportunities for improving sexual and reproductive health care and education for women with CP, starting in adolescence. The findings of this study document that barriers to women with CP receiving appropriate and timely information and care still exist, despite evidence that many of these disparities have existed for decades [17,18]. Results of this study can be used to inform interventions to improve reproductive health care for women with CP.

Barriers to accessing sexual and reproductive health service are broad for women with CP, and some are more easily remedied than others. Participants perceived that despite their efforts to seek out knowledgeable healthcare providers, most providers have had limited exposure to patients with CP, let alone reproductive health care related to CP, and did not know how best to meet their needs. Healthcare providers’ lack of expertise contributed to participants’ sense of urgency for self-advocacy. Importantly, women with CP expressed appreciation when they sensed a willingness from clinicians to learn about their condition so as to better meet their needs.

A common element that surfaces in all of the themes identified in this study is that healthcare providers often seemed to assume women with CP were not sexually active and did not provide them information in the area of sexual health. Our participants recalled that they needed to seek out sexual health education from a variety of sources. The education they received from their healthcare providers was frequently inadequate, and what they received from parents, schools, friends, and the internet often failed to meet their needs as well. This was either because they could not find essential information or because, when found, it was not tailored to

the unique needs of women with CP. These findings resonate with previous studies which have identified gaps in patient-centered information provided to adolescents and young adults with CP, including the lack of education with regard to prevention of sexually transmitted diseases or how the diagnosis of CP may impact sexuality and reproduction [12,19,20]. Additionally, in studies evaluating topics reviewed at clinical visits by primary care providers, documentation of sexual, menstrual and pregnancy information for adolescents and young persons with a disability compared to matched individuals without disabilities was much less frequent [21]. For example, sexual history was documented in 19.0% of those with a disability versus 73.8% without a disability [22]. Similar findings as to the lack of discussion of sexuality have also been identified for those seeing rehabilitation providers [13]. Young women with CP are more likely to discuss birth control with healthcare providers than parents, and more likely to discuss abstinence with parents than healthcare providers [23]. Even within the population of adults with CP, those with more significant mobility impairments reported significantly lower levels of sexual information compared to those able to walk [24].

Although women with CP experience considerable challenges and changing complex systems is often difficult, participants suggested concrete incremental ways to improve standard sexual and reproductive health care. They created a number of innovative solutions as “work arounds” to address deficiencies in care processes and lack of provider knowledge about CP. They suggested requesting longer appointments earlier in the day at the time of scheduling, depending on anticipated needs for the visit. They suggested offices should ask in advance about the need for assistance with positioning or disrobing so that appropriate staffing can be allocated for assistance rather than depending on family members which then interferes with privacy. Healthcare offices must also plan staffing and protocols to ensure safe transfers to and from exam tables, a need that could be anticipated at the time of visit scheduling. They suggested providers should prescribe medications for reduction of muscle tone to allow for a less painful pelvic exam either at the time of scheduling or after a visit in anticipation of the next.

Strengths of this study include a broad national representation of women with CP across the gross motor function spectrum, including women with significant mobility impairments. Limitations of the study include the bias of recruitment from select urban populations with access to care. There was also a relative

under-representation of Hispanic/Latino and African-American participants in the sample compared to the United States (US) population at large; such information is not readily available for US adults with CP, but under-representation could be inferred from a population-based study of children with CP [25,26]. Because disability and racial/ethnic minority status potentially affect the receipt and experience of healthcare services to such a large degree, patient voices at the intersection of disability and racial/ethnic minority status should be particularly sought out in future studies. In addition, the ages of the participants span a generational shift from a less to more open attitude towards sexual education, though even our youngest participants reported receiving little education in this area. Because the study was conducted with adult women ranging widely in age, recall bias may affect the description of education and services received when they were adolescents and young women. However, emotionally loaded memories are often amplified and rarely forgotten. Finally, women with intellectual disability were not represented in this sample due to the complexities of consent, and their valuable experiences are thus missing from this report.

Healthcare providers need education about the sexual and reproductive healthcare needs of women with CP, both to improve the care they provide individually and to be able to advocate for more CP-friendly healthcare facilities for their patients (e.g., motorized lifts on exam tables). Healthcare trainees would benefit from more teaching about CP-specific reproductive health needs (e.g., what birth control methods are safe for a woman who uses a wheelchair) and coaching to promote emotional intelligence to ask sensitive questions (e.g., ask about sexual abuse), topics which could be introduced into training curricula. Clinics and hospitals can move toward standardization of care by auditing the accessibility of their physical plant, training clinic staff to anticipate known needs of women with CP (e.g., assistance transferring to an exam table), and implementing questions about disability into routine pre-visit screening questions. Providers can be encouraged to use best practices through standardized electronic medical record templates incorporating sexual and reproductive health for patients with CP. The most important education that healthcare providers can convey in all settings is that conversations about sexual health should be part of routine health care for women with CP, as they are for all women.

Women with CP also need access to accurate and CP-specific health information. Study participants iden-

tified the value of having a sexual health needs checklist to refer to, which could help them to prepare for their medical appointments and to advocate for their needs. Some participants implied that having such a checklist essentially gave them “permission” to raise these topics with providers. As follow up of the themes and recommendations from this project, each research site team developed educational interventions. One site developed patient sexual health checklists and patient educational videos to prepare for gynecology appointments. Another site developed a guide for preparing for pregnancy. A third site developed a provider education video regarding communication with women with disabilities before and during mammography appointments. The pediatric hospital site developed a conversation guide to help script conversations about sexual health for younger patients with CP, as well as a guide for pediatric healthcare providers less well-versed in conversations about sexual health to help them initiate discussion with patients. All of these materials are available at <https://cpresource.org/topic/womens-health>. More research is needed to validate these educational materials and to evaluate their impact on care.

## 5. Conclusions

Women with CP identify that healthcare professionals lack awareness of the sexual and reproductive health needs of women with CP and that healthcare facilities are often deficient in readiness to care for them. Medical professionals require education to address these gaps. Young women with CP need access to information about best practices so that they feel empowered to ask for and receive what they need. Both providers and patients with CP may benefit from scripted tools to ensure comprehensive care. While systems change can be challenging, a number of specific attainable recommendations were made by the participants of this study that could be incorporated into standard care.

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## Conflict of interest

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