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“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

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Abstract

Background—Although pediatric urologists have taken responsibility for initiating discussions on sexual and reproductive health (SRH) with spina bifida (SB) patients, research shows that very few females with SB have ever discussed this topic with any physician.

Aim—We sought to better understand pediatric urologists’ gaps in knowledge and training needs in the SRH education of women with SB with the goal of creating a toolkit to equip providers to have these discussions.

Methods—In this qualitative study, pediatric urologists were interviewed separately about their current practices, perceived barriers, knowledge gaps, and recommendations for the toolkit until thematic saturation was reached. The interviews were recorded and transcribed verbatim, then analyzed using Grounded Theory by three independent reviewers.

Outcomes—To evaluate the perspectives and practices of pediatric urologists, we identified the overlapping themes of the interviews. Consensus on themes was reached.

Results—Ten pediatric urologists participated in the study, including 5 males, 5 females, of whom 4 were fellows, and 6 were attending physicians (mean years of practice 18, range 6–31). The mean number of patients followed in the respective SB clinics or by the provider was 434 (range 24–1500). The following themes regarding pediatric urologists’ experience providing SRH education to women with SB emerged. Pediatric urologists’: 1) lack of formal training, 2) knowledge gaps such as SB sexuality, fertility, and pregnancy experience, 3) barriers to having SRH conversations such as lack of comfort and lack of time, 4) facilitators of these conversations such as a long-term relationship with the patient and the patient’s own initiative, 5) desire to learn and provide competent care, 6) recommendations for a web-based toolkit that would include content to address the knowledge gaps and training about how to start SRH conversations.

Clinical Implications—These findings can provide the beginning concepts for the development of training on providing SRH education for pediatric urologists’ care for women with SB.

Conflict of Interest

All authors report no conflicts of interest.

Strengths & Limitations: This study gives the perspectives of 10 pediatric urologists with a diversity of backgrounds, but all of whom care for a large number of SB patients. This does not give the perspectives of the SB women themselves, which will be evaluated in the next phase of the study.

Conclusions—Pediatric urologists are not trained and do not feel prepared to provide SRH education for young SB women. However, they do see it as their scope of practice and wish to acquire competence in this area.

Keywords

Spina bifida; Myelomeningocele; Sexual health; Reproductive health; Sexuality; Urologist
Urology

Introduction

Like their able-bodied peers, young women with spina bifida dream of having intimate relationships and starting families. While up to 48% of young women with spina bifida are sexually active by age 25,¹ up to 92% are interested in becoming sexually active and up to 76% are interested in having children.^{1–6} However, these women are viewed by society as being asexual.^{7–10} Such a stigma is not only harmful to their own self-image,¹⁰ it has led to a potentially dangerous lack of education and access to necessary health care for these women. As few as 5% of young women with spina bifida have ever received sexual and reproductive health (SRH) education from a physician.¹¹ While these women may receive sex education in school or from their family, many women assume that this education does not apply to them due to their disability.⁷ Additionally, they lack the opportunity to learn about sexuality and disability through less formal methods such as the media or from their able-bodied peers.¹⁰ Most research on sexuality in patients with spina bifida is focused on males, limiting the women's ability to seek information independently.¹² As a result, as few as 9% of sexually active women with spina bifida use contraception, some assume they cannot get pregnant because of their disability, others have reported unintended pregnancies, and some assume that they cannot get sexually transmitted infections.^{1,6,13} Additionally, women with disabilities have difficulties getting access to routine and necessary gynecologic care.¹⁴

As most women with SB now survive well into adulthood and are interested in or currently developing their sexual and reproductive lives, the need for improved SB specific SRH education is clearer.¹⁵ Research shows that significantly more women with spina bifida are now having babies; however, over a quarter of these women deliver by age 22, at an age when 59–76% of pregnancies are unintended.^{16,17} Additionally, these women may be particularly vulnerable: research shows that women with physical disabilities are four times more likely to be victims of sexual abuse, while those with intellectual disabilities have seven times the risk.^{18,19} Therefore, topics specific to these women, such as using latex-free barrier contraception, continence during intercourse, fertility, potential pregnancy complications, as well as the difference between healthy and potentially abusive relationships should be discussed by physicians.^{20,21} Conversations on SRH could help to better deal with sexual abuse risks, unintended pregnancies and sexually transmitted

diseases.^{20,22} According to the American College of Obstetricians and Gynecologists, these conversations should occur by age 13–15 or before the patient becomes sexually active.²³

As genitourinary providers who care for these patients through adolescence and young adulthood, pediatric urologists have assumed responsibility for providing sexual and reproductive health (SRH) education for these women.^{24–26} Their investment and expertise that come from caring for women with spina bifida make pediatric urologists particularly well-positioned for this responsibility. Paradoxically, while these responsibilities are often discussed by providers at national meetings, discussions with patients about SRH are not taking place and research on how these conversations should proceed is not conducted. As a result, neither these young women with spina bifida nor their providers have a solid grasp on sexuality and reproductive health as it is experienced by women with spina bifida. As such, both patients and providers are subject to potentially dangerous misconceptions about SRH in women with spina bifida which can lead to adverse outcomes such as unintended pregnancies, sexually transmitted infections and sexual abuse.¹ Without these conversations and understanding of what young women with spina bifida need, these women do not have access to routine and much needed preventive care and reproductive counseling.

This study is part of a larger research project that has the ultimate goal of assisting pediatric urologists and other providers to discuss SRH with women with SB, by creating an online toolkit. Data from an online survey, as well as input from women themselves, will inform the development of this education intervention. However, given the lack of research and uncertainty about how these conversations might proceed, this study follows a qualitative methodology and aims to explore pediatric urologist's experience of discussing SRH with their female patients with SB. Specifically, the study aims to understand the providers' perceptions of the barriers to these conversations and their recommendations for what further training pediatric urologists deem necessary to equip them to initiate these discussions.

Materials and Methods

This exploratory qualitative study used individual semi-structured interviews as a method for data collection. Institutional Internal Review Board approval from a large Midwestern medical center was obtained prior to participant recruitment.

Research Team

The principal investigator (CSS) is a female pediatric urology fellow (M.D., M.S.) with training in mixed methods study (Masters in Health and Health Care Research). The senior author (DW) is a female licensed social worker and certified sex therapist, educator, and health services researcher with expertise in mixed methods research methodology (PhD, MSW). The project coordinator (CS) is a college senior pursuing a degree in neuroscience and gender and health who was trained in mixed method studies during the project. Due to the small number of practicing pediatric urologists nationally, CSS knew nine of ten study participants prior to the interviews from interactions at national meetings or work affiliations.

Study Sample

Participants in this study were pediatric urologists and pediatric urology fellows. Inclusion criteria were: currently practicing and actively participating in the care of female patients with spina bifida. Providers were excluded if they were not currently practicing or do not follow patients with spina bifida. Fellows were included due to their ability to describe the most recent training pediatric urology fellows receive on this topic as well as their experience watching multiple providers discuss this with patients. No minimal years of practice was defined in order to capture experiences and education of both recent graduates and experienced urologists.

Procedure

Purposeful snowball sampling recruitment procedure was used to recruit participants. The Principal Investigator sent an email invitation to participate without an incentive to providers at institutions with large spina bifida programs. The email described that the goal of the study was to identify current practices of whether providers discuss sexual and reproductive health as well as their knowledge gaps and training needs. Those participants who responded to the email also had the opportunity to recommend the study to other eligible providers. After thematic saturation was reached, recruitment was closed.

Data Collection and Analysis

Participants were asked to provide demographic data which included years in practice, years of fellowship education, and number of patients with spina bifida they followed. Semi-structured interviews were developed, based on the review of literature and the investigators' expertise in spina bifida (CSS) and sexual health (DW) (Appendix A). Examples of questions were: "can you walk me through your sense of how well prepared you feel to discuss sexual and reproductive health with your female spina bifida patients?" and "what do you think the patients want to know or need to know, and what do you wish you knew more about regarding the sexual and reproductive function of young women with spina bifida?". The open-ended nature of the interviews allowed the participants to reflect on their experiences and express their views about what they had and had not learned, what was difficult about these conversations and what training was necessary. The one-on-one interviews were conducted either in person or by phone by one of the investigators (CSS).

The interviewer performed the interviews in a closed room to ensure confidentiality of the interviews. Prior to initiating the interview, CSS again described the goal of the interview. All interviews were recorded and transcribed verbatim. Each participant was assigned a study ID number and no participant name was recorded or transcribed to ensure anonymity. Field notes were collected, noting the participant's comfort and openness in discussing the topic, evidence of particular biases, novel concepts, and evidence of previous practice or thought about SRH in these patients.

The interviews were analyzed by three authors (CSS, CS, DW) independently, using Grounded Theory²⁷ procedures. Little is known about how pediatric urologists think about discussing sexual and reproductive health with spina bifida patients or what training gaps they identify. Therefore, this exploratory study intended to compose concepts where there is

no existing theory, making Grounded Theory the most relevant method for analysis. Meaningful phrases, based on the research questions, were coded with open codes. Codes that were related thematically were combined into axial codes and further categorized into higher level concepts representative of the new developing knowledge about pediatric urologists knowledge and training gaps with respect to sexual and reproductive health of young women with spina bifida. Each interview was reviewed for the emergence of new codes which were then applied to both previous and future interviews. A codebook was created, based on the increasingly higher level of coded categories until meaningful high-level themes, representative of the findings was reached. The authors reviewed each interview together and discussed the codes until consensus was reached. Thematic saturation was reached after 10 interviews, as all pediatric urologists described inexperience and a lack of knowledge in this area and could not provide richer data. and No repeated interviews were conducted due to clarity of the initial interviews. Trustworthiness of the data was assured by the investigators' prolonged exposure to the experience of spina bifida and sexual health (CSS and DW), separate coding by the investigators, rigorous discussion of the findings and consensus on the results.

Results

Sample characteristics

Ten pediatric urologists participated in the study, including 5 males, 5 females, of whom 4 were fellows and 6 were attending physicians. Two fellows were in their 2nd year of pediatric urology training, one was in the 3rd year, and one recently graduated from a 2-year program. Mean years of practice for attending physicians was 18, ranging from 6 to 31. The providers practice in seven different states representing all geographic regions of the United States. The mean number of spina bifida patients followed in the respective spina bifida programs was 494, ranging from 245 to 1500. Attending physicians personally followed a mean of 269 spina bifida patients (range 24–700). One physician who initially volunteered to participate dropped out due to time constraints.

Interview findings

Review of the individual semi-structured interviews revealed six common themes regarding pediatric urologists' experience of being trained and of providing SRH education to young women with spina bifida. These included pediatric urologists': 1) lack of formal training, 2) knowledge gaps, 3) barriers to discussing SRH, 4) facilitators to discussing SRH, 5) desire to learn and provide competent care, and 6) recommendations for a training toolkit. Examples of how our data was developed into these themes is provided in Table 2.

Lack of formal training

When asked to describe the training they had had to talk to young women with spina bifida about their SRH, nine of the ten providers stated they had had no training whatsoever. One provider described learning how to have discussions during fellowship from an attending who cares for adult spina bifida patients, but not from her pediatric urology mentors. Another provider commented that urologic training provides adequate training to discuss SRH with men, but no training for how to have these discussions with women.

“...so I think urology residency with its focus on male genital issues prepares you pretty well to talk to men about sex... But through no part in that training do I remember there being any kind of focus or formal teaching about how to talk to women about sexuality...” [female participant 10 (F10), 7 years in practice (7y)]

Some commented that everything they learned about the SRH of women with spina bifida is from their own initiative, and not from formal learning during training.

“I think any... conversations that I will have or advice that I will give to my spina bifida patients will be gleaned from my personal research and interest, not based on something that I’ve been taught in fellowship...” (F8, fellow)

Indeed, several participants mentioned that they had pursued knowledge about this topic on their own. They identified lectures at various conferences, research articles, and people such as pediatric gynecology providers, female pediatric urology colleagues, and patients themselves as their sources of information.

Overall, despite taking the initiative to learn about the topic on their own, pediatric urologists did not feel their training equipped them to discuss SRH with their female patients with spina bifida.

Knowledge gaps

Providers identified many general and specific knowledge gaps regarding the SRH of women with spina bifida. There was a consensus that much about the SRH of women with spina bifida remains unknown.

“There’s a lot that needs to be known. I think that void is pretty significant.” [male participant 4 (M4), 25y] Additionally, providers felt that they were not up-to-date on any research regarding the SRH of these women. “...the more I talk about it, the more I realize I don’t know anything.” (M5, fellow)

Several sub-themes were identified of specific areas pediatric urologists felt they lacked knowledge and desired more information, including female sexual function and sensation, the impact of self-image on intimate relationships, fertility potential, pregnancy, delivery, transition into motherhood, and abuse.

The providers felt they lacked even the most basic understanding of sexuality for women with spina bifida.

“...I think I would like to know, I mean, almost everything. What is their desire? When do they start showing sexual interest? When do they start having sex? How young are they? Do they have pleasurable sex? Are they forced into sex?” (F3, 6y)

One provider stated that this knowledge gap is not unique to pediatric urologists, but instead is due to the lack of research on this topic.

“...whole stuff about female sensation that nobody talks about and there’s almost no data on...” (M1, 20y)

Pediatric urologists also want to know more about how having spina bifida and often having undergone multiple surgeries impacts women's self-image and how they relate to their partners.

"The fact that you catheterize your bladder—does that bother you?... abdominal scars and stomas... how does it affect you, the way you view yourself? How you relate to other people?" (M2, 17y)

Physicians expressed a lack of knowledge about all aspects of reproductive health from fertility rates to issues that may arise during pregnancy to how to best manage delivery.

"...we have to have... a better understanding... on pregnancy and what happens during pregnancy... and... the technical challenges of carrying a child." (M9, 31y)

They also reported they were not prepared to counsel women on issues such as birth outcomes for their child and how to prepare for motherhood as a woman with spina bifida.

"...what are some unique challenges that the patient would face as a parent who has spina bifida?" (F6, fellow)

Finally, physicians did not know how prevalent abuse is among these women. They also felt they would need training to learn how to screen for abuse and to talk to the women about their risk for physical and sexual abuse.

"...I would like to have more information on how many of these women are actually in some type of abusive situation where they either realize what's going on or they don't even realize what's going on." (M9, 31y)

Pediatric urologists reported a lack of basic understanding of most aspects of SRH specific to women with spina bifida. They agreed that this was due both to a lack of research and to a lack of training during fellowship. Many expressed embarrassment about their lack of knowledge. One physician commented, "I hope other people are saying that and I'm not just and idiot". (F6, fellow)

Barriers to discussing sexual and reproductive health with patients

Physicians identified a number of distinct barriers, some structural, others knowledge based. Structural barriers included the limitations of clinic visits and characteristics of patients and providers that could make the conversations awkward. Knowledge based barriers included the training and knowledge gaps that made providers feel ill-equipped to facilitate conversations about SRH.

Both patient and provider structural factors were identified as barriers to having these conversations with women with spina bifida. Several male and female physician participants perceived that women feel less comfortable discussing the topic with men, but also felt that this sentiment was mutual, with male providers feeling less comfortable talking to women.

Many providers mentioned that time constraints of a busy clinic limited their ability to have these discussions, especially if the patient has other issues that need attention. Most felt that

their lack of knowledge and training prevented them from bringing up the conversation since they did not know how to bring it up and or what to mention during the discussions.

“Because it’s uncomfortable, because you don’t really know what to say, because... it may lead you to even more uncomfortable places or places where you feel like you’re out of your realm of expertise...” (F10, 7y)

Physicians also did not know when to initiate conversations based on patient age and cognitive ability.

“the level of processing and cognitive abilities vary from child to child so I think that it’s not just a strictly a chronological age-dependent thing... I’m not sure as a urologist I can effectively assess what their... cognitive abilities are” (M2, 17y)

Parents were seen as a primary barrier to starting conversations. As one participant stated, “... the biggest barrier is parental buy-in. Having parents be willing to have these really difficult conversations about really intimate topics” (F3, 6y). Physicians felt they did not know how to determine if parents were comfortable with this type of conversation, when to include them in the discussions versus speak with the patients alone, or how to ask the parents to leave the room, particularly for patients who are very attached to their parents.

Some also felt that many pediatric urologists do not bring the topic up because they are not aware of its importance to the patient and their family.

Facilitators of discussing sexual and reproductive health with patients

Pediatric urologists described factors that make the conversations easier. Several experienced urologists reported that their long-term relationship with the patients and their families made the conversations seem natural.

“so many of these patients I’ve known for so long... and know the families, that for the right families it’s appropriate. So I feel comfortable.” (M1, 20y)

Urologists who do generally address this topic reported that the parents actually appreciated the conversations. “I find they appreciate it because I’m worried about the patient as a whole.” (M1, 20y)

Providers were also more likely to discuss this topic if the young women were otherwise doing well, if they had a higher level of functioning, or if they mentioned having a partner or brought their partner to clinic. Some patients brought up the subject themselves and were very forthcoming, which also made the conversation seem more natural. One physician noted the importance of asking the patients about their social life and interests, as an opening that can lead to conversations about SRH.

The likelihood of bringing up the topic of SRH, as perceived by the physicians, appear to rely most on patient factors and the physician’s relationship with the patient and family.

Desire to learn and provide competent care

Along with acknowledging knowledge gaps and barriers to these discussions, providers expressed a desire to learn how to best have these conversations.

“...I do think that it’s a really important topic and something I want to learn more about...” (F8, fellow)

They felt that this was an important topic to address in order to provide these women with competent and comprehensive care.

“...I think getting to know a little bit more about the sexual function of teenagers with spina bifida... we’ll be in a much better position to take care of these kids.” (M4, 25y)

Interestingly, several senior urologists described changing their practice to discuss this topic. While they were not formally trained in how to do this and remain frustrated with the current research gaps, they nonetheless were made aware of its importance to the women and therefore decided to start addressing SRH with their female spina bifida patients. Some of these providers were made aware of the need for these conversations by their colleagues or by patients who described its importance at national meetings. Others had heard of and others witnessed adverse events that occurred from the lack of conversations, such as sexually transmitted illnesses and unintentional pregnancies.

“I’ve just been made aware of the issues and therefore taking it upon myself to address it” (M1, 20y)

“I have been learning over the last several years... [discussing sexual and reproductive health] was not a part of my practice five years ago. It’s become more so right now.” (M4, 25y)

Even those providers who have started addressing SRH with their patients felt more training and a better knowledge of the topic could help improve the care they provide.

“I think I could do a better job... if I had some form of preparation I think I would be better prepared to talk to these women.” (M4, 25y)

Pediatric urologists in this sample clearly indicated that they would welcome and utilize training and resources to help them discuss SRH with their spina bifida patients.

Recommendations for a training toolkit

When asked what should be included in the toolkit and what format it should take, pediatric urologists had several overlapping ideas for both its content and format. Most wanted to explain when to bring it up first, what to discuss with patients by their age and cognitive ability, and how to best handle parents. Overall, they felt that the toolkit should make having these discussions as easy and approachable as possible.

“I would love to have this be something that we can get practitioners to really engage in and realize that it’s not that difficult...” (F3, 6y)

Most desired an online format with printable resources and physician algorithms or checklists that could help facilitate the conversations. Several mentioned having a patient questionnaire that could gauge the patient's current sexual activity as well as their interest in the topic. One mentioned that having homework for the patient may better facilitate conversations.

"...the patient comes in ahead of times knowing that at this visit we're going to discuss some issues on sexuality so they actually have some homework where they can explore things... then they may be better prepared to ask some questions themselves." (M9, 31y)

Most felt that a toolkit should be designed as a resource for both patients in addition to physicians: for providers to learn how to have the conversations and for patients to be able to seek information independently and possibly interact through a forum. Several felt that this topic should be addressed either at an independent conference or as a panel at an existing conference.

Pediatric urologists indicated their wish to have resources that will enable them to start and conduct a conversation about SRH. They also recommended a number of formats they thought would facilitate well provider education.

Discussion

The aim of this qualitative exploratory study was to understand what barriers that prevent or limit pediatric urologists from discussing SRH with their young female SB patients and what knowledge or training they would like to equip them to initiate these discussions. We discovered that pediatric urologists do not feel adequately trained to discuss SRH with young women with spina bifida. Specifically, they expressed a lack of knowledge about most aspects of sexuality, pregnancy, delivery, and sexual abuse in these women. Providers also described uncertainty about how and when to start the conversations. Nonetheless, they felt that initiating these conversations should be a part of their practice and desired resources and training to learn how to incorporate it into their usual care of these patients. In this study, pediatric urologists seemed to have very similar experiences with regard to their training, knowledge gaps and desire to fill those gaps so that they might be able to provide competent SRH care for their young female patients with spina bifida.

Pediatric urologists are not alone in their discomfort with this topic. Over 40% of primary care providers do not feel adequately trained to discuss SRH and desire further training on this topic.²⁸ Patients are able to perceive this discomfort. In a study of 500 patients, 71% thought their physician would dismiss any concern about their sexual health and 68% felt that bringing up any issues would make their physician uncomfortable.²⁹ However, neglecting to discuss SRH with these women leads to persistence of their misconceptions and potential resultant health risks such as STDs, future cervical cancer, unintended pregnancy, and the possibility of sexual abuse. A lack of these conversations also reinforces the stigma experienced by people with disabilities that regards women with spina bifida as asexual.⁸ This stigma is not only frustrating for these women and potentially harmful to their self-image, but it also prevents them from getting the information and care they need.

^{7,8,10} There is little research in the area of sexuality and reproduction and disability, especially for women, and providers are not trained in how to discuss SRH with people with this population, which serves to reinforce the stereotype.^{7,9}

The strengths of this study include the variety in practice experience of the physicians who participated, the ability to interview enough providers to reach thematic saturation, and the development of concepts. Specifically, we established what prevents pediatric urologists from discussing SRH with their female spina bifida patients, including a lack of training and knowledge about the topic, discomfort with the discussions, uncertainty as to when to bring it up based on patient age and cognitive ability, limited time in clinic, and perceiving parents as a barrier. We also determined what training they desire to feel prepared to have these conversations, including an online toolkit with an algorithm for discussions and printable materials to facilitate the talks. The limitations of this study is the lack of data about the women's perspectives. It is currently unknown what or how these women have learned about their own SRH or how they would like their pediatric urologists to address this topic. This will be addressed in the second phase of this study when we will interview women with spina bifida to discover their experiences with such education and ask for their feedback. Findings from these studies will inform an online survey for all urologists to generalize the knowledge gaps and training needs of pediatric urologists to provide the sexual and reproductive health education these women desire. This foundational knowledge will be crucial to create a relevant web-based toolkit that equips providers to have discussions about SRH with their spina bifida patients. Trainees in medical school, residency, and fellowship can then learn from seeing this modeled by their attendings, helping change practice to improve care for women with spina bifida in future generations.

Conclusions

This study highlights the barriers that limit or prevent discussion about SRH between pediatric urologists and their female spina bifida patients. These barriers are primarily due to a lack of knowledge about the SRH of these patients and a lack of training as to how to facilitate the discussions. Nonetheless, these providers expressed a clear and strong desire to provide SRH to their patients in order to better care for these women. Together, this suggests that an educational toolkit would be an effective intervention to pediatric urologists' and other providers' competence and confidence to discuss SRH with their female spina bifida patients.

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Appendix A

Semi-structured interview guide.

Pediatric urologist's current practices

1. What kind of training did you have to learn how to talk to these young women with SB?

PROBES: Residency or fellowship

Classes

Conference

Other

2. Can you walk me through your sense of how well the training prepared you for the conversations?

3. What do you think patients want to know or need to know?

PROBES: How the body works sexually

The effect of SB on sexual function

Managing relationships

Being able to say "no"

Family planning/birth control

Safety

Fertility

Folic acid supplementation

Gynecologic exams

4. Tell me about how you address the topic of sexuality and reproductive health with your adolescent and young adult female patients with spina bifida.

PROBES: Who do you talk to? (male, female, wheelchair)

Do you have a certain age in mind when you broach the subject? What is your thinking behind that?

Can you tell me about any circumstance when a young woman brought it up herself?

Since young women may already be in a relationship, how do you address it?

How do you bring it up the first time?

With or without parents in room

Introductory statements you use

5. If you have these conversations, how do they go for you?

PROBES: What is easy to approach

What is challenging:

Starting the conversations

Knowing what is relevant at what age

Ability to answer questions – lack of knowledge about sexual function, impact of disability, pregnancy, contraception, relationship with a boyfriend/partner

Embarrassment/personal discomfort

6. Where do you get help if you if a young woman asks you a question you don't know the answer to?

PROBES: Literature review

Call a different specialist

Talk to a colleague

Referral

7. What topics regarding sexuality and reproductive health do you typically cover with your adolescent and young adult female patients with spina bifida?

PROBES: The impact of SB on sexual functioning

- How the body works sexually
- How it is different for someone with SB than in someone without SB

Relationships

Reproduction

Sexual health maintenance through:

- Regular gynecologic exams
- Pap smears
- STD screening
- HPV vaccination

Reproductive health

- Fertility – is it the same or different with SB?
- Contraception methods
- Family planning

Knowledge Gaps and Barriers

1. What do you wish you knew more about regarding the sexual function of young women with SB?

PROBES: Their feelings about being sexual, readiness to have a sexual relationship

Self-esteem about being sexual with a partner

Differences from women without SB

Sensation

Overcoming mobility limitations

Spasms

Management of the bladder and bowels during sexual activity

Contraception

2. What do you wish you knew more about regarding the fertility and reproductive function of young women with SB?

PROBES: Contraception

Fertility potential

Risk of having a child with SB

Dosing of folic acid needed

3. If you were to give guidance for pediatric urologists to discuss this topic with young women with SB, what would be important to include?

PROBES: Young women's psychological /emotional development with respect to sexuality and fertility

Evidence regarding women with SB and self-esteem/stigma of physical disability and how it affects sexuality and read

Education about how to talk to young women with SB about sexual function, relationships and safety

How to discuss the value of gynecological follow-up, screening for various issues, contraception and family planning

4. What would make the conversations easier?

PROBES: Education on topic

Education on how to bring it up

Class/conference

Practicing the words and conversations

Tips for how to start the conversations

Case discussions

Closing opportunity for spontaneous input

1. Is there anything else that you would like to add?

Abbreviations:

SRH	Sexual and reproductive health
SB	Spina bifida

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Table 1.

Demographics of physician participants

Participant	Gender	Years in Practice	Number of Current SB Patients
1	M	20	700
2	M	17	50–75
3	F	6	40
4	M	25	400
5	M	Fellow	500
6	F	Fellow	300
7	F	Recent Fellow Graduate	1500
8	F	Fellow	400
9	M	31	400
10	F	7	24

Table 2.

Coding process.

Raw Data	Open Coding	Axial Coding	Theoretical Coding
<p>Q: What kind of training have you had to learn how to talk to these young women with spina bifida about sexual and reproductive health? A: None (1,2,3,4,5,6,7,8,10)</p> <p>Q: ...do you recall at any point in your training, whether in residency or fellowship... ever seeing one of your attendings talk to a young woman about their sexual and reproductive health? A: I feel like as a resident and during training the only time that really comes up... in the setting of, oh, I got to be present at this C section... (10)</p> <p>Q: Tell me how you've seen your mentors address the topic of sexuality and reproductive health with the adolescent young female patients with spina bifida. A: I mean I've never seen them talk about it (6)</p>	<p>No training to talk to women with spina bifida about SRH</p> <p>Mentors only taught residents about SRH in context of helping with c-sections</p> <p>Mentors did not talk about SRH with their SB patients</p>	<p>Never had training</p> <p>Deficit in mentorship</p> <p>Deficit in mentorship</p>	<p>Lack of formal training</p>
<p>Q: What do you wish you knew more about regarding the sexual and reproductive function of young women with spina bifida? A: Um, I think I would like to know, I mean, almost everything. What is their desire? When do they start showing sexual interest? When do they start having sex?... Do they have pleasurable sex? Are they forced into sex? (3)</p> <p>Q: What do you wish you knew more about regarding the fertility and reproductive function of these women? A: I think there's very little information on fertility and parenting in patients with spina bifida. I think getting to know exactly what their risks are: the risk of getting pregnant and the risk of um having children... All these issues are not very well known.</p> <p>Q: ...are [there] any areas you wish you knew more about regarding their sexual function...? A: Yeah... their sexual sensation and orgasmic function. We just know nothing about that. (1)</p>	<p>Would like to know more about the sexual function and experience of women with SB</p> <p>Feels there is little research on pregnancy and parenting in women with SB</p> <p>Wants to know about sexual sensation of women with SB</p>	<p>Lack of knowledge about sexuality</p> <p>Lack of knowledge about reproductive health</p> <p>Lack of knowledge about sexuality</p>	<p>Knowledge Gaps</p>
<p>Q: ...what else could make these conversations easier...? A: So, one I think it's difficult for men to have this conversation with female patients. And number two I think it's difficult for me to have this conversation because I just don't know enough. (6)</p> <p>Q: ...why do you think your mentors didn't bring it up? A: Because it's uncomfortable, because you don't really know what to say, because the downstream effect of bringing it up may lead you to even more uncomfortable places or places where you feel like you're out of your realm of expertise..." (10)</p> <p>Q: ... what barriers are there....? A: ... I'd saw the biggest barrier is parental buy-in. (3)</p> <p>Q: ...what would you say are the biggest barriers from having any dialogue? A: ... time is another thing. You know, we're just so busy, so usually with my clinic it's so fast paced, I try not to sort of kind of ask them. (2)</p>	<p>Hard for men to talk with female patients and for her to have conversations due to lack of knowledge</p> <p>Lack of comfort with addressing sexual health and lack of knowledge prevents conversations</p> <p>Parental buy-in limits conversations</p> <p>Lack of time in a busy clinic prevents conversations</p>	<p>Gender makes conversations hard Lack of provider knowledge prevents conversations.</p> <p>Lack of provider knowledge prevents conversations</p> <p>Parents limit conversations</p> <p>Lack of time prevents conversations</p>	<p>Barriers to discussing sexual and reproductive health with patients</p>

Raw Data	Open Coding	Axial Coding	Theoretical Coding
<p>Q: ... do you have a certain way that you usually bring up this topic...?</p> <p>A: Well, I think you know, things are going well from a urinary and bowel standpoint, then I'm more likely to do it for two reasons: one, they're doing well, and number two is that I have more time... (1)</p> <p>Q: ... how did you know [those patients] were sexually active?</p> <p>A: ... I think what also helped get to that topic was that their boyfriend or partner when they came so like in the clinic it was like you have a boyfriend, I should ask about this." (5)</p> <p>Q: ... when you saw those conversations take place in residency, um how did it go?</p> <p>A: ...they were both very assertive females. So they like had opinions, they were strong. When you asked them questions, they were honest and forthcoming. Um it wasn't like they felt ashamed or indifferent, if anything they were more than happy to share the information. (5)</p>	<p>More likely to discuss SRH if patients are doing well urologically</p> <p>Having women bring their partners to clinic prompted conversation about SRH</p> <p>Talking to assertive/ forthcoming women made conversation easier</p>	<p>Conversations more likely if women doing well</p> <p>Conversations more likely if woman brings partner</p> <p>Conversations more likely is woman is assertive</p>	<p>Facilitators of discussing sexual and reproductive health with patients</p>
<p>Q: What do you wish you knew more about regarding the sexual function of these young women?</p> <p>A: ... so I think getting to know a little bit more about the sexual function of teenagers with spina bifida... we'll be in a much better position to take care of these kids... (4)</p> <p>Q: ...how well-prepared do you think you feel to have that kind of conversation?</p> <p>A: I have been learning over the last several years. I think that was not a part of my practice five years ago. It's become more so right now. I think I can do a better job. I think if I had some form of preparation I would be better prepared to talk to these women. (4)</p> <p>Q: ... is there anything else you'd like to add or any other thoughts on this?</p> <p>A: ...I think it's really important, and I think that it's something that we should be at least asking</p>	<p>Better knowledge of sexual function in SB would help urologists take better care of patients</p> <p>Changed practice to start addressing SRH with patients, but feels he can improve the education.</p> <p>Feels it is important to talk about SRH with patients</p>	<p>Better knowledge leads to better care</p> <p>Took initiative to change practice and address SRH</p> <p>Importance of addressing SRH to providers</p>	<p>Desire to learn and provide competent care</p>
<p>Q: ... What do you think would make the conversations easier?...?</p> <p>A: I find that having some sort of pathway or algorithm is helpful... (3)</p> <p>Q: Um, so if you were to give guidance to pediatric urologists to discuss this topic, what would be important to include?...?</p> <p>A: ...I would like to... see a kind of checklist of, okay, those are the questions that need to be asked in a teenager with myelomeningocele. (4)</p> <p>Q: Alright so in creating this online toolkit, are there anything you feel like we should make sure to cover, like any kind of guidance you want?</p> <p>A: ...Like for example if the kid's cognitive abilities are such-and-such and we know, so what would be the appropriate way to address this sexuality issue?</p>	<p>Would like an algorithm/ pathway for how to approach SRH with patients</p> <p>Would like a checklist of questions to ask teenagers with myelomeningocele</p> <p>Would like information on the best way to address sexuality based on patient's cognitive ability</p>	<p>Recommendation for an algorithm</p> <p>Recommendation for a checklist of questions</p> <p>Recommendation for addressing topic based on cognitive status</p>	<p>Recommendations for training toolkit</p>