Published in final edited form as:
*Child Care Health Dev*. 2015 November ; 41(6): 963–969. doi:10.1111/cch.12282.

# What young people with spina bifida want to know about sex, and aren't being told

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## Abstract

**Objective—**To examine sexual knowledge, concerns, and needs of youth with spina bifida (SB) to inform the medical community on ways to better support their sexual health.

**Methods—**As part of the Video Intervention/Prevention Assessment (VIA) – Transitions, a prospective cohort study, 309 hours of video data were collected from 14 participants (13–28 years) with SB. Participants were loaned a video camcorder for 8–12 weeks to shoot visual narratives about any aspects of their lives. VIA visual narratives were analyzed with Grounded Theory using NVivo.

**Results—**Out of 14 participants, 11 (6 females) addressed issues surrounding romantic relationships and sexuality in their video clips. Analysis revealed shared concerns, questions, and challenges regarding sexuality gathered under 4 main themes: romantic relationships, sexuality, fertility and parenthood, and need for more talk on sexuality.

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Conflicts of interest: None declared. Permission for video excerpts has been provided by all participants by means of signed release forms.

**Conclusions—**Youth with SB reported difficulties in finding answers to questions regarding their sexuality, romantic relationships, and fertility. This study revealed a need for help from the medical community to inform and empower youth with SB in the area of sexual health. Through sexual and reproductive health education with patients and parents starting at an early age, medical providers can further encourage healthy emotional and physical development in adolescents transitioning into adulthood.

### Keywords

Qualitative; spina bifida; sexual health; adolescent; chronic condition

## Introduction

Adolescents with chronic disease (Suris & Parera, 2005; Suris et al. 1996) and physical disabilities (Maart & Jelsma, 2010), including spina bifida (SB) (Lassmann et al. 2007; Sandler et al. 1996; Visconti et al. 2012), have been shown to engage in sexual activity as much as their able-bodied peers, but are often inadequately informed about how their chronic condition affects their sexuality and sexual health (Verhoef et al. 2005). Standardized sex education in school and/or by parents (Verhoef et al. 2005) is typically insufficient for those with physical limitations; adolescents with complex medical histories often lack the context necessary to interpret and apply general sexual health information to their unique bodies and physical realities (Sawyer & Roberts, 1999). SB-specific issues such as neurologic capabilities, fertility, and heredity are rarely discussed (Verhoef et al. 2005).

Adolescents with SB have a high risk of precocious puberty (Gatti et al. 2009) and sexual dysfunction due to neurological impairment (Visconti et al. 2012). Bladder and bowel incontinence can make sexual contact physically and psychologically challenging (Verhoef et al. 2005) and latex allergies can compromise their use of condoms (Visconti et al. 2012). Despite these negative aspects, they still experience sexual desire and find ways to engage in sexual activity (Gatti et al. 2009). Many young people with SB are dissatisfied with their sex lives, reporting sexual satisfaction rates around 50% (Verhoef et al. 2005). A high prevalence of unwanted sexual contact or sexual abuse of adolescents with SB (Sawyer & Roberts, 1999; Verhoef et al. 2005), physical disabilities, or a chronic condition (Suris et al. 1996), indicate a need for focused sexual abuse prevention with these populations of children and adolescents. There is a necessity for better understanding sexual health among adolescents living with SB. The aim of this qualitative study was to examine the sexual knowledge, concerns, and needs of adolescents and young adults with SB through their own voices in order to inform the medical community on ways to better support their sexual health.

## Methods

Three hundred and nine hours of video data were collected from 14 participants (7 females) with SB aged 13–28 years (median age 17 years). This qualitative study was part of the Video Intervention/Prevention Assessment (VIA) – Transitions study, a prospective cohort design using VIA methodology (Rich et al. 2005) to follow young participants with chronic function-limiting conditions longitudinally through the transition into adulthood and adult-oriented medical care.

The VIA method of generating and analyzing participant-created visual illness narratives has been described previously (Rich et al. 2000; Rich & Patashnick, 2002). The VIA protocol and informed consent were approved by the Boston Children's Hospital (BCH) Committee on Clinical Investigation. Adolescents and young adults with SB were recruited by their clinician from the BCH myelodysplasia clinic. Patients aged 13 to 28 with all levels of SB and abilities were eligible; mobility of included participants ranged from using crutches and leg braces to wheelchairs. After enrolling and consenting (or assenting with parental consent if under 18 years), participants were loaned a video camcorder for a period of 8 to 12 weeks and trained to shoot visual narratives (Rich et al. 2005). Participants were encouraged to record any and all aspects of their lives that they wanted to share, with the knowledge that the videos would be used to educate the medical community about their experience living with SB.

To encourage the creation of their VIA visual illness narrative, participants were provided with written prompts, including (a) Daily Talk Suggestions – ideas to help them get started (e.g. Tell us what happened today); (b) Interview Questions – general and medical questions for family members or friends (e.g. What is spina bifida?); (c) General Suggestions – important experiences and aspects of their lives with SB (e.g. Record a doctor's appointment). Participants were free to use all or none of these prompts. Only one prompt in the Daily Talk Suggestions was directly related to our subject: "*Talk about a friend or girlfriend/boyfriend*". The Field Coordinators made regular visits to participants' homes to make sure the cameras were working properly, to pick up fully recorded tapes and distribute new ones, and to perform interviews with participants.

VIA visual narratives were analyzed with the established VIA method (Rich et al. 2005)] using NVivo (Qualitative Solutions and Research, Pty, Ltd., Victoria, Australia, 1998) qualitative analysis software to manage visual data. Visual illness narratives were screened 2 to 4 times, objective scenes recorded, dialogue transcribed verbatim, and notes/memos made on contextual and subjective aspects observed by the coder. Grounded theory (Glaser, 1992) was used to develop, structure, examine, and code an array of prevalent themes from an emic point of view. This study focused specifically on themes of sexuality, romantic relationships, sexual health and concerns as they emerged from the data.

## Results

Out of 14 participants, 11 (6 females) addressed issues surrounding romantic relationships and sexuality in their video clips. Four participants explicitly discussed their specific sexual activity and 3 of these were physically intimate with people who also had disabilities. The other 7 discussed sexual health matters and concerns, possibilities of having children, crushes they had, as well as dating on a hypothetical level, but did not mention that they had ever been in a sexual or romantic relationship. Notwithstanding their actual sexual activity, analysis revealed shared concerns, questions, and challenges regarding sexuality, grouped into four main themes.

## Romantic relationships

Participants were in different romantic situations at the time of the study.

Three participants were in long-lasting 'serious' relationships: "*Yesterday, I went out with my boyfriend… we just enjoyed each other's company. I've had my boyfriend for 4 years.*" (Participant A, female 19); "*Nothing really serious happened 'til [girlfriend's name] though… with [girlfriend's name], it's getting pretty serious.*" (Participant B, male 28). They talked about positive aspects of their relationships: "*I think I just needed to be loved and she does a good job at loving me, ya know.*" (Participant B, male 28), but also negative ones: "*My boyfriend and I had a huge fight… I just didn't know how to deal with it.*" (Participant A, female 19).

The other participants expressed various feelings regarding romantic relationships or flirting/dating situations or possibilities. A 16 year old male disclosed self-confidence issues around girls: "*it's always been an awkward thing for me… it's just something I have never been comfortable with… talking to girls sometimes…*" (Participant C). Three participants showed or talked about a school dance to which they went with a date: "*We are prom day so we are going to show you [Participant D] wearing her dress and scandals…*" (Mother of Participant D, female 13).

Some had previous dating experience. One male participant mentioned that he had a girlfriend once, but she broke up with him because of his wheelchair and ethnic background. Two participants revealed current or past crushes: "*I wrote her a little love letter, I had a silly crush on her…*" (Participant E, male 17); "*I do have a little crush on a guy named Sean at my school, but I did find out he had a girlfriend, but I still have a crush.*" (Participant F, female 18).

Each participant expressed a desire for a romantic partner: "*You want your heart filled 24/7. I need a real girlfriend. I need love… I want romance.*" (Participant E, male 17); "*Friend: Do you have a boyfriend? Participant G: No. Friend: And do you want a boyfriend? Participant G: Yes, why not!*" (Participant G, female 13 and a girlfriend); "*How about a boyfriend/girlfriend?* [reading the prompt to the camera] *I wish!!*" (Participant E, male 17).

Some participants saw SB as a direct barrier to romantic relationships: "*I'm in a chair and I can't get a girlfriend. No one looks at me! They see me and think I am f***ing retarded.*" (Participant C, male 16). Two participants reported going online to chat and meet up with some girls as a way to counter the fact that they were in a wheelchair and dependent on others to go out: "*Don't tell my mom but I've found this site and you can go and search for profiles and then they have these pictures… and then if I like the picture of a certain girl, I'll talk to her.*" (Participant E, male 17).

Some parents expressed worries on camera about their child not having typical adolescent experiences such as dating. For instance, a mother explained a gap between her son's chronological age and his 'social and emotional age': "*He doesn't go to malls, he doesn't go to movies, he doesn't date… he has no typical life of a 17 year old…*" (Mother of Participant E, male 17); another mother teased her 16 year old son about getting a date: *Mother: "Is* *there anything you want to make sure you do before you leave high school?" Participant C: "I don't know…" Mother: "Have a date?" [laughs] Participant C: "Shut up!!"* (Participant C and his mother).

Certain participants made it very clear that they did not want their parents to know about their sexual or romantic life. One 19 year old female talked openly about her love life when alone, but stopped talking and changed the subject when her mother approached: "*At school we had work appreciation brunch and… [mother leaves the room] Okay… what else… Today I was crying… I was all upset…. My boyfriend and I had a huge fight… I don't know if after my prom I'm going to stay with him… But I haven't told my mother 'cause I'm afraid of what her reaction is going to be…" [mother comes back in and Participant A smiles silently]*.

## Sexuality

Participants revealed very different experiences with sex: *"People with spina bifida and stuff, when they are with their boyfriends or girlfriends, they have different levels of their disability"* (Participant B, male 28). While few revealed that they engaged in sexual relationships, sex was often on their mind, coming up frequently in their visual narratives: "*What's on my mind: hot girls!*" (Participant E, male 17); "*I go to strip-clubs yes… I watch porn sometimes yah… I'm a guy*!" (Participant B, male 28), or joking: "*Things are better on your hands and knees…*" (Participant H, female 24). Several gave explicit reasons for not having sex, such as not being self-confident enough, "*I'm really shy around girls sometimes…* " (Participant C, male 16), while others talked openly about engaging in sexual experiences with others: "*it's my fault to have had sex with her the very first day*" (Participant B, male 28). One participant sought medical support so that he could have a sex life: "*I used to go in there once every two weeks to get shots on my penis to get an erection, so I'm able to have sexual intercourse…*" (Participant B, male 28).

## Fertility and parenthood

The theme of having children or getting pregnant was predominant throughout all the participants' videos, in the form of wishes for the future, worries, or questions: "*With [my girlfriend], it's getting pretty serious. I don't know if she wants kids with me or anything, though*" (Participant B, male 28).

Most participants hoped to have a family in the future: "*That I get a good house, good children, and a good job.*" (Participant D, female 13); "*I hope to have a good job some day and a nice place to live, and being married and have kids…*" (Participant H, female 24). Participants who interviewed friends or family members heard hopes that the participant would have a family in the future: "*I hope that you are still with [your boyfriend], that you guys get married, have kids.*" (sister of Participant H, female 24); "*I hope that you love and experience love, love someone else besides your family who loves you… I hope you have a family, if you want.*" (mother of Participant C, male 16); "*We wish your manhood will be a healthy one*," (grandmother of Participant I, male 18); "*I hope that maybe she'll get married and have some kids…*" (sister of Participant J, female 24); "*Marry, have children, make me a grandmother so I can spoil them*," (mother of Participant E, male 17).

The question of pregnancy or having children was brought up in the context of female participants' consultations with health professionals: "*As far as getting pregnant, there is no reason you can't, unless there is any other reason, unrelated to your spina bifida.*" (Doctor of Participant F, female 18). The possibility of pregnancy came up indirectly when health professionals recommended that their female patients take folic acid: *Doctor: "Are you taking folic acid right now?"* Participant H*: "No… should I be?" Doctor: "If you are thinking about getting pregnant at all… then you should be taking… Well, anybody, any female of child-bearing age should be on folic acid. Yah, if you are sexually active at all, you should be taking it."* (Participant H, female 24 and her doctor); *Doctor: "Yah, I just like to remind people that if you have a boyfriend and think of having babies, you need to take extra folic acid.*" (Doctor of Participant F, female 18).

Yet, several female participants did not seem to understand why they had to take folic acid: because they were not informed about it, "*I actually don't know why I take the folic acid… [laughs]*" (Participant J, female 24); because they were not sexually active, *Doctor: "Do you have a boyfriend?" Participant F: "No". Doctor: "So you need 4 milligrams if you think there is any chance you can get pregnant, because—" Participant F: "Which probably won't happen!"* (Participant F, female 18 and her doctor); or because they are far from thinking of having children, "*The baby thing isn't in the cards. I mean we are not doing anything that would actually cause me to be pregnant… unless there is any secret way! [laughs]*" (Participant H, female 24, talking to her doctor).

In the case of young men, the subject of having children did not seem to be discussed with health professionals. Lack of discussion about fertility was a problem for several participants: "*I'm still trying to get a hold of doctors to figure out if I'll ever be able to have babies myself…*" (Participant B, male 28). Some recounted myths: "*I was talking to [my girlfriend] about stuff and she was telling me I'd have to have some type of surgery or whatever to give her my sperm… because that's one thing about the disability, it slows down certain people's sperm count… I've known quite a few from the hospital school who have children of their own, you know without surgery and stuff, I don't know if I can do that or not… Well, I know I can do the act, but I don't know if I can pass sperm or whatever…*" (Participant B, male 28). A female participant told her boyfriend that if they had a baby, she would need a Caesarean section because the limitations of her body would inhibit a vaginal delivery, although there was no indication in her visual narrative of where this information came from.

## Need for more talk on sexuality

Some participants expressed the need for more information regarding the sexual realities of young people with disabilities. Although they were aware of the limits of what they could show on camera, they valued the VIA project as a way to inform others about the sexuality of young people with SB: *[Participant H's sister addressing Participant H, female 24, and Participant H's boyfriend]* "*But you know what though, if you guys ever have sex in front of the camera, you can just use it to say, 'This is how disabled people have sex!!' [laughs].*" Participants explicitly requested that health professionals talk about sexuality with their patients with disabilities: "*There are some people that can't get erections and there are*

> *some people who can, and doctors will never like talk about that because it's just like a forbidden thing that a lot of people with my disability want to learn about. Like I had to go through a lot to figure out. Those are just some ideas that I'm thinking that doctors don't focus on and they don't ask a lot of questions on that because it's not… it's not important to people, but it is for us because we… some of us don't know what it's like to do that, I know I can get semi-erections, I don't know if I can ejaculate, I have no idea, I don't know if I can have kids… that might be the only way they can learn about it, because some people are not comfortable about it. The word penis is okay! Yah, you know they have to always use weird words… you know, it's called a penis, it's called a vagina, its… grow up! It's just the body, and it's just… people being ridiculous…*" (Participant B, male 28).

## Discussion

Overall, participants were concerned about dating, sexuality and romantic relationships in a developmentally typical way for adolescents and young adults (Suris, 2002). They talked about sexuality and sexual matters openly and spontaneously on camera, without being prompted, emphasizing both the importance of these issues in the lives of young people with disabilities and their lack of places and people with whom they can discuss them. However, given the specifics of their condition, participants reported difficulties in finding answers to many of their questions. They wanted information directly from their physicians, including functional ability, ability to procreate, and possible medical interventions. These results confirm previous findings showing that patients with SB request sex education, rate their knowledge on the topic of sexual health as poor or extremely poor (Sandler et al. 1994; Sawyer & Roberts, 1999), and would be interested in having provider-initiated conversations about the effects of their condition on sexual activity whether among females or males (Sawyer & Roberts, 1999; Sawyer et al. 2001). We found an important gap between the information desired by youth with SB and what physicians are providing, falling short of practice policies for adolescent health care (Alexander et al. 2014).

In participants' videos where health professionals addressed the need for folic acid with female patients and the patients stated that they did not wish to have children, providers did not address contraception, condom use, or latex allergies (Visconti et al. 2012). These discussions around folic acid could be used as opportunities for education in sexual health. When not addressed early on, gaps in sexual knowledge appear to carry into adulthood (Gatti et al. 2009), so it is essential that education about each patient's sexual and reproductive capabilities begin long before sexual activity does. Although the issue of sexual health can be more complex and patient-specific for young people living with disabilities, it is imperative that their sexuality be acknowledged and supported with information and open discussion by their health care providers.

The World Health Organization has identified that adequate sex education is a right of every individual, regardless of disability (World Health Organization, 2006), and that without it, the physical and emotional health of the adolescent is at risk (Murphy, 2005). Yet the questions and concerns being expressed by participants in this study indicate that sex education can be inaccessible to young people with special needs and they do not seem to receive adequate specific information regarding their sexual health and well-being. This might be due to the fact that they receive general sex education at school and it is not supplemented or individualized by family or physicians (Cardenas et al. 2008). Participants' uncertainty about their fertility is especially worrisome because – either because they assume infertility or want to test it – they may be more likely to engage in unprotected sex, presenting risks of unwanted pregnancies or sexually transmitted infections.

Parents often accompany patients with disabilities to health care visits at later ages than able peers, inhibiting open conversations about sexual health. Although they openly disclosed sexuality concerns on video, participants deliberately kept that information from their parents, a developmentally appropriate autonomy-seeking behavior. This should serve as a reminder that health professionals should make themselves a reliable and safe source of sexual health care by maintaining confidentiality with all patients when they address the issues of sexuality and romantic relationships (Berlan & Bravender, 2009).

Parents of participants expressed concerns for their child's current or future sexual and romantic lives, as well as hopes for future childbearing possibilities. Although conversations specific to sexuality do not often occur between patient and parent (Blum et al. 1991), caregivers have been shown to play an important role in supporting adolescents with SB in becoming independent adults (Rich, Patashnick, & Kastelic, 2005). As has been recommended for adolescents with cystic fibrosis (Frayman & Sawyer, 2014), parents of young people with SB need support in educating and empowering their children early and often on issues of condition-specific sexual health, so that they are appropriately prepared to discuss these issues as the child matures. Educating parents can allow them to serve a positive role in their adolescent's developing sexual attitudes and behaviors (Klein et al. 2005), as well as reduce parental apprehensions regarding their child's future (Akre & Suris, 2014).

Some participants engaged in online dating and chatting as a way to counter their physical isolation, confirming existing data about youth with chronic conditions who use social media as a place to socialize as "regular", rather than sick teenagers (Van Der Velden & El Emam, 2013). Parents and youth must be educated about the potential risks and benefits of internet dating. Health professionals should inquire about online dating on a routine basis and could use this as an occasion to expand the discussion about "offline" sexual health, behaviors, and well-being. As previously suggested (Suris et al. 2010), further research is needed on the use of social media by this population.

Some limitations to the study should be addressed. First, this study results from secondary analysis of qualitative data collected on the illness experiences of young people with SB. Without having specifically addressed participants' knowledge, beliefs, and fears of sexuality on camera, we had a limited amount of data to analyze. Yet, under such circumstances, the fact that these data emerged spontaneously speaks to the necessity for focused research on this topic. Second, because of the rapid evolution of Internet dating, findings of sex-related online behaviors may be somewhat outdated, even though the motivating concerns of adolescents and young adults with SB regarding their sexuality remain unchanged.

Despite these limitations, this study has several unique strengths. Using the VIA method to collect qualitative data and empower patients to express themselves, we were able to address the emic point of view of young people with SB regarding their sexuality. VIA reduces the power dynamic between patient and clinician by giving participants control of clinically relevant information; they now have the attention of clinicians viewing their visual narratives. VIA opened a window into the lives of adolescents and young adults with SB, providing unique insights on topics they may not otherwise have felt comfortable discussing with researchers or clinicians, producing data that is unattainable in a medical visit. VIA visual narratives gave a rich understanding of young people's SB knowledge, questions, concerns, and fears stemming from uncertainty regarding their sexual health.

While adolescence is often a confusing time, questions surrounding one's developing sexuality can be complicated by a chronic, function-limiting medical condition. By listening to these voices, heeding their suggestions, and answering their questions, the medical community can help empower young people with SB in regard to their sexual health. Through sexual and reproductive health education with their patients and parents starting at an early age, medical providers can further encourage healthy emotional and physical development in disabled adolescents' transitions from childhood into adulthood.

Four main practice implications stem from this study. First, providers need to address a gap in communication with their patients with SB regarding their sexuality and sexual health. Second, sexuality education of people living with SB needs to be individualized, start early, and continue into adolescence and young adulthood to support safe and healthy sexual behaviors. Third, clinicians should routinely inquire about and counsel patients with SB about online sexual behaviors and dating. Finally, parents of young people with SB need education and support in order to guide their children regarding condition-specific sexual health.

## Acknowledgments

This research would not be possible without the participants, clinicians and staff of Boston Children's Hospital for identifying and recruiting VIA participant, Julie Szymczak for field coordination, and Jennifer Patashnick for assistance with analysis. VIA-Transitions research was supported by grant #K23 HD01296 from the National Institute of Child Health and Human Development, as well as condition-specific grants from the Deborah Munroe Noonan Foundation, the William F. Milton Foundation, and the Christopher Reeve Paralysis Foundation. Christina Akre was supported by a grant from the Swiss National Science Foundation.

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### Key messages

- Youth with spina bifida have unanswered questions about sex and their capabilities
- The developing sexuality of youths with spina bifida is complicated by their condition
- Providers need to address sexual health and well-being with youths with spina bifida
- Youth with spina bifida need specialized reproductive health and sex education early on