Sexuality in Pediatric Spinal Cord Injury

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Sexual development and sexuality in youth with pediatric spinal cord injury (SCI) are critical areas clinicians must be aware of and discuss when working with youth and their families. In addition to the general sexuality issues and challenges of adolescence and adult development, youth with SCI face unique physical and psychosocial issues. The goal of this article is to provide a developmentally based discussion of sexuality in individuals with SCI from infancy through emerging adulthood. An overview of psychosocial issues related to sexual development and sexuality are presented for each stage of sexual development along with recommendations for clinical practice, including patient and caregiver education and counseling. In order to establish expectations for youth with SCI, long-term outcomes related to sexuality and fertility of adults with pediatric-onset SCI are presented. **Key words:** pediatric spinal cord injury, sexual development, sexuality

Youth with spinal cord injury (SCI) experience significant physical and psychosocial developmental milestones as they progress from infancy to adulthood. Sexual development and its unique interaction with the SCI is a critical area clinicians must be aware of when working with youth and their families. *Sexuality* is how people experience and express themselves as sexual beings, while *sexual development* involves biological, psychological, and sociocultural processes that begin in the first years of life and continue throughout the lifespan.^{1,2} In general, all youth progress through the same stages of sexual development. In addition to the general sexuality issues and challenges of adolescence and adult development, youth with SCI face unique physical and psychosocial issues, including risks for impairment in sexual functioning and fertility and for lower self-esteem and body image.³ In contrast to adults with adult-onset SCI, those injured as children or adolescents may have had no or minimal sexuality-related experiences prior to their SCI such as romantic relationships and sexual activity.

Although it is very important that clinicians focus their attention on the youth with SCI, they must also involve the parents in providing the necessary support to facilitate their children's independence as appropriate developmentally. Because of the significant changes that occur with

development, both youth with the SCI and their parents need to be provided accurate and timely anticipatory guidance, such as timing of physical and psychosocial changes associated with puberty. In addition, it is critical that youth with SCI and their parents be encouraged with expectations that the youth are to become independent, productive, social, and sexual beings throughout their lives.

The goal of this article is to provide a developmentally based discussion of sexuality in individuals with SCI from infancy through emerging adulthood. This will include an overview of sexual development and related psychosocial issues for all youth, as well as issues specific to sexual development among youth with SCI. In addition, this article will provide recommendations for health care professionals and parents (Table 1). In order to establish expectations for youth with SCI, long-term outcomes related to sexuality and fertility of adults with pediatric-onset SCI will be presented.

Stages of Sexual Development

The following section discusses the stages of sexual development for the general youth population, followed by discussion of issues specific to youth with SCI. At each stage, health care providers are encouraged to provide anticipatory guidance to parents regarding the

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Table 1. Stages of typical sexual development, considerations for pediatric SCI, and recommendations

	Typical sexual development	Considerations for pediatric SCI	Recommendations
Early childhood (0-5 years)	<ul style="list-style-type: none"> • Curiosity and exploration of own body • Appropriate touching, showing of body parts • Gender differences • Gender identity • Toileting, potty training 	<ul style="list-style-type: none"> • May be more accustomed to less privacy • Alternative toileting procedures 	<p><u>Parents:</u></p> <ul style="list-style-type: none"> • Normalize exploration, curiosity • Educate on abuse and appropriate showing of body parts <p><u>Health care providers:</u></p> <ul style="list-style-type: none"> • Discuss expectations of sexual development, sexual functioning, and fertility to parents
Middle to late childhood (6-12 years)	<ul style="list-style-type: none"> • Growth in curiosity and knowledge about sex organs/functions, differences between women and men, puberty, intercourse, reproduction, romantic relationships • Seeking information from peers • Seeking peer approval, issues of body image and body self-esteem • Early sexual attractions, experiences (eg, kissing), dating • Formal sexual education • Pubertal onset 	<ul style="list-style-type: none"> • May have limited/reduced engagement with peers • May be at risk for body image and body self-esteem issues • May not receive education tailored to physical functioning 	<p><u>Parents:</u></p> <ul style="list-style-type: none"> • Acknowledge child's sexuality, including changes in body and thoughts/feelings • Establish communication, provide education about sexuality-related issues, including abuse <p><u>Health care providers:</u></p> <ul style="list-style-type: none"> • Discuss sexual functioning, including ability to have intercourse, orgasms, fertility with youth and parents
Adolescence (13-17 years)	<ul style="list-style-type: none"> • Increase in interest and knowledge about sexuality • Increase in seeking information from peers • Continued seeking peer approval, issues of body image and body self-esteem • Identity development, independence/autonomy • Sexual experiences (masturbation, intercourse), dating • Risk behaviors • Additional formal sexual education 	<ul style="list-style-type: none"> • May have limited/reduced engagement with peers • May be at risk for body image and body self-esteem issues • May not receive education tailored to physical functioning 	<p><u>Parents:</u></p> <ul style="list-style-type: none"> • Maintain communication, provide education about sexuality-related issues • Encourage development of identity separate from disability • Encourage independence <p><u>Health care providers:</u></p> <ul style="list-style-type: none"> • Continue discussing sexual functioning, including ability to have intercourse, erections, masturbating, orgasms, fertility • Discuss issues with and without parents present
Emerging adulthood (18-25 years)	<ul style="list-style-type: none"> • Continued development of attitudes toward sexuality, sexual identity • Increased sexual activity • Romantic and sexual relationships • Peak in risk behaviors 	<ul style="list-style-type: none"> • Ensure continued communication with health care providers during and after transition to adult health care • Focus on opportunities for positive social development 	<p><u>Parents:</u></p> <ul style="list-style-type: none"> • Support social functioning <p><u>Health care providers:</u></p> <ul style="list-style-type: none"> • Continue discussing sexual functioning and related topics to young adults

expected sexual development for their child along with expectations for the future, including sexual functioning and fertility.

Early childhood

Sexual development during early childhood (ie, ages 0-5 years) is characterized by children's curiosity with and exploration of their bodies and the bodies of others.⁴ During the first several years of life, toddlers begin exploring their bodies and the functions of their body parts. This exploration is typically associated with toileting

and potty training. Children will become aware that men and women have different body parts while beginning to develop a sense of their own gender identity. As children enter the preschool years and their language abilities develop, they will begin learning the names of body parts and may start asking their parents questions about the differences they observe between men and women. As children's curiosity grows, they may want to show their body parts to others or see the body parts of other children. Parents should be careful to not overreact or express negative or shaming

feelings about such behavior. The goal of parents should be to teach their children what body parts are appropriate to show in public versus private contexts and who should and should not be seeing or touching private body parts.⁵

Children with SCI will experience sexual development similarly to that of typically developing children during early childhood. Although children with neurogenic bladder and bowel may use alternative toileting procedures, such as clean intermittent catheterization, they should be encouraged to learn and master such procedures as they would with traditional potty training.⁶ In addition, compared to typically developing children, children with SCI may become more accustomed to having nonfamily members, such as health care providers, see their private body parts as necessary for medical examinations or interventions such as management of their neurogenic bowel and bladder. To help protect children from potential abuse, parents should teach their children who should and should not be seeing or touching their children's private parts.

Middle to late childhood

Sexual development during middle to late childhood (ie, ages 6-12 years) is characterized by a considerable growth in both curiosity and knowledge about sex organs and their functions, differences between women and men, puberty, intercourse, reproduction, romantic relationships, and more. In addition, children may begin having sexual experiences (eg, kissing) during this developmental period. During middle childhood (ie, ages 6-9 years), children may be interested in learning about and exploring the bodies of their friends of the same sex.⁴ As children progress into late childhood (ie, ages 10-12 years), they begin to seek out and share sexuality-related information with their peers. In addition, they become more concerned about their peer relationships and what their peers think of them. This may lead to increased concern about appearance and issues of body image and body self-esteem.⁶ Children may also begin developing attractions or "crushes" on children of either the opposite or the same sex

and start identifying their sexual orientation. It is not uncommon for children to "date" in late childhood or sooner, which may include behaviors ranging from sitting by one another at lunch to experimenting with hand holding or kissing. Reynolds and colleagues⁷ found that the average age of experiencing a first "crush" was 8 to 9 years old and the average age for having a boyfriend/girlfriend was 12 to 13 years old.

Puberty is a developmental milestone for all youth, and typically it begins during the late childhood or early adolescent years. The onset of puberty typically occurs between the ages of 8 and 13 for girls and 9 and 14 for boys.¹ For girls, breast development and pubic hair growth begin typically between the ages of 9 and 10 and menarche typically begins at age 12. For boys, onset of genital growth typically begins between the ages of 9 and 10. Differences are found among racial/ethnic groups, with African American children having the earliest onset of pubertal development.⁸

In addition, children are likely to receive formal sex education for the first time during the end of elementary school or the beginning of middle school. Only 24 states and the District of Columbia require that public schools teach sex education, and the content of the curriculum varies among school districts.⁹ However, most comprehensive sex education programs include discussion of puberty, intercourse, procreation, pregnancy, and sexual exploitation and abuse.² Moreover, Erin's Law, legislation that has currently passed in 26 states, requires that public schools implement a prevention-oriented child sexual abuse program for students in prekindergarten through 12th grade.¹⁰

During middle and late childhood, parents should focus on establishing open, nonjudgmental communication with their children about sexuality-related issues. Parents are encouraged to provide simple and accurate information about sexuality that becomes increasingly specific as children approach adolescence. Often parents may be nervous or reluctant to begin discussing sensitive topics with their children, because they do not want to overwhelm their children or they feel unsure of the "best" time to talk about it. It is not uncommon for parents to assume that their children are unknowledgeable about

certain sexuality topics, when in fact children have gotten information from peers, the media, or other sources.⁴ Children benefit from learning information from their parents when it is discussed in an open and honest environment. Topics to be discussed include body parts, sex differences, sexual orientation, qualities of good relationships (eg, love, respect, and trust), social responsibility, values/morals, puberty, sexual exploitation and abuse, procreation and pregnancy, abstinence and contraception, and sexually transmitted diseases. Fortunately, books and resources are available to parents to help them with these discussions.

Children with disabilities, including youth with SCI, may have limited peer engagement compared to typically developing children, which may decrease their opportunity to receive sexuality-related information from their peers.^{1,11} In addition, children with SCI may already be at risk for experiencing body image or self-esteem issues due to differences in their physical appearance or abilities.³ Thus, attention should be given to promoting healthy self-esteem and body image. In terms of school-based sexual education, the curriculum may need to be modified to apply to children who have differences in physical functioning. Unfortunately, this is not always done. For example, children in special education classrooms are sometimes not included in sexual education discussions.^{3,5} Most youth with SCI are in regular education classrooms, but the curriculum may not be modified to address issues specific to them. To provide their child with accurate information, parents should be sure to understand how their child's sexual development and functioning may be affected by the presence of SCI.

In general, sexual development including onset of puberty and associated secondary sexual characteristics and menarche are not affected by SCI. Sexual functioning is affected by neurological level and severity of the SCI, so it is important that the youth and their parents have a comprehensive conversation with their child's health care providers about their child's sexual development, including the ability to have intercourse, experience orgasms, and fertility.⁴ For male youth with an SCI and their parents, health care providers should begin

to discuss issues such as management of erectile dysfunction and use of phosphodiesterase type 5 inhibitors and the potential to father children, with a high probability for the need for assistive technology. For female youth with SCI and their parents, health care providers should begin to discuss issues such as the relative lack of effect of an SCI on fertility but the risk of complications such as autonomic dysreflexia with labor and delivery (please see "Reproductive Health of Men with Spinal Cord Injury" and "Women's Sexual Health and Reproductive Function After SCI" in this issue).

Moreover, youth with disabilities are at an increased risk of physical and sexual abuse for multiple reasons (eg, dependence on others for intimate care, increased exposure to many caregivers and settings)¹; parents need to educate their child on how to identify, avoid, and report abuse. Parents of youth with disabilities may view their children as being more vulnerable and they may be more protective of their children compared to parents of typically developing children. Because of this, it is not uncommon for parents of children with disabilities to not acknowledge their children's sexuality, which may lead the children to feel embarrassed or ashamed about sexuality.⁶

Adolescence

Adolescence (ie, ages 13-17 years) is a time when youth's interest, knowledge, and experience in sexuality-related issues grow tremendously. The development of identity is a central aspect of adolescence. This includes preoccupation with comparing one's self to peers, seeking similarity, and desiring peer approval. Along with the increased desire for independence and autonomy, youth are learning to make independent decisions. This may lead to increased experimentation and risk taking in areas of substance use and sexual activity. Masturbation is also common during adolescence.⁷ By age 16 about 1 in 4 teenagers will have had intercourse, and by age 18 the rate increases to about 1 in 2.¹² As in earlier years, youth are likely to receive additional formal education in high school on topics related to sexuality. Compared to earlier years, sex education

curriculum in high school is likely to have a greater emphasis on topics such as safe sex and pregnancy. As described previously, however, sex education programs vary from state to state and from district to district, with some schools providing abstinence-only programs or education about contraceptives only to emphasize their limitations.^{2,13}

It is important that parents continue to maintain strong channels of communication with their children during adolescence. Parents should continue to discuss issues of relationships, dating, safe sex, sexual orientation, ways to safely express one's sexuality, and how drug and alcohol use can impact one's interactions and safety. Youth should be encouraged to ask questions about sexuality to their peers, parents, and health care providers and to not feel embarrassed or ashamed to do so. Although parents may be concerned about teenagers' sexual exploitation and promiscuity, social withdrawal and isolation should be of equal concern during the adolescent years.¹⁴

It is recommended that youth with SCI be encouraged to develop a strong identity separate from their disability.¹ They may experience decreased self-esteem related to sexuality and dating, and this may be more related to social constructions about sexual functioning in people with disabilities than the injury itself. For example, Potgieter and Khan³ found that among a sample of South African adolescents, norms about dating among typically developing youth caused adolescents with SCI to feel uncertain about their ability to secure a date and to maintain a romantic relationship. As the desire for independence and autonomy increases during adolescence, youth may demand increased privacy and the opportunity to do things on their own. This may require that parents and youth work together to ensure that youth with SCI are capable of completing tasks independently (eg, transferring, toileting procedures) and that they are given opportunities for time away from home (eg, arranging transportation and assistance).⁴

Although not specific to youth with SCI, adolescents with physical disabilities are reported to have similar rates of sexual activity compared to those without disabilities.¹⁵ Therefore, health care providers should provide parents and youth with information about how SCI may impact a

teenager's sexual functioning, including ability to masturbate, have erections, have sexual intercourse, experience orgasms, and fertility. These discussions may include management of erectile dysfunction with medications (such as phosphodiesterase type 5 inhibitors) or mechanical methods (such as vacuum constriction devices); sexually transmitted diseases; latex allergy and condoms; fertility-related issues such as sperm retrieval (vibrostimulation and electroejaculation); and potential pregnancy-related issues (such as autonomic dysreflexia during labor). It is also important that health care providers interview adolescents without their parents being present so that the adolescents feel free to discuss potentially sensitive issues. Most adolescents with physical disabilities report that they have not been provided with adequate information on birth control or sexually transmitted diseases.¹⁶

Emerging adulthood

Emerging adulthood is considered a distinct developmental period that occurs between the ages of 18 and 25.¹⁷ Normative milestones of this period include education, employment, financial independence, independent living, and psychological and social functioning. Sexuality is also a central aspect of emerging adulthood, as individuals continue to develop their attitudes toward sexuality and their sexual identity, engage in sexual behaviors, and develop romantic and sexual relationships.¹⁸ Risk behaviors, such as having unprotected sex or substance use, peak in the early 20s as a result of increased independence and decreased parental monitoring. Education about topics such as safe sex, reproductive health, and sexual exploitation/abuse should begin during adolescence, but it remains important that health care providers ensure that emerging adults are well-informed on these topics.

Changes that occur during emerging adulthood that may be unique to individuals with SCI are the transition from pediatric medical care to adult care and the transition from parent-controlled health care to self-management. Even though youth with SCI may have had conversations with their pediatric health care providers about their

sexual functioning, it will be important that emerging adults reinstate these conversations once they transition to new, adult care providers. Some emerging adults with SCI are successful at navigating the more mature contexts of social interactions that occur after adolescence, whereas some are more likely to experience social isolation, which could limit their opportunity to develop romantic and sexual relationships.¹⁹ Emerging adults, family members, and health care providers should all be mindful of facilitating positive social development and creating opportunities for social relationship building.

Adult Sexuality Outcomes Among Individuals with Pediatric-Onset SCI

An understanding of long-term sexual functioning outcomes in adults with pediatric-onset SCI will help to establish a baseline for expectations for youth with SCI and their parents and health care providers.²⁰ In our longitudinal study of pediatric-onset SCI, among 479 adults, aged 19 to 50 years of age who were injured prior to 19 years of age, 59% reported sexual intimacy occurring at least monthly. Individuals with paraplegia were more likely to report sexual intimacy compared to those with tetraplegia (68% vs 52%; $X^2 = 10.26$; $p = .001$).

In addition, 21% of adults with pediatric-onset SCI reported that they were parents. Of those with children, 83% had biological children with 97% being born after sustaining their SCI, 13% had stepchildren, and 17% had adopted children. Among those with biological children after sustaining their SCI, 76% did not require any form of fertility treatment (95% of the women and 50% of men). Of the women with biological children after sustaining their SCI, 39% reported having pregnancy complications, including 22% having complications with labor and 26% with delivery complications.

Women were significantly more likely than men to be parents (ie, biological, adopted, or stepparent; 36% vs 12%; $X^2 = 39.99$; $p < .001$), and those with paraplegia were more likely to be parents compared to those with tetraplegia (26% vs 17%; $X^2 = 6.23$; $p = .013$). In addition, those who were older at follow-up were more likely to be parents: 14% of those 19 to 29 years of age compared to 26% of those who were older. Factors not associated with parenting included race, severity of SCI (complete versus incomplete), and college degree. Parenting was associated with greater life satisfaction ($p < .001$) and social ($p < .001$) and occupational ($p = .002$) participation. Parenting was not associated with health-related quality of life, depressive symptoms, or participation related to physical independence, mobility, or economic self-sufficiency.

Conclusion

Because of the tremendous growth that occurs during childhood, adolescence, and emerging adulthood, a developmentally based approach to sexuality among youth with SCI must be utilized, including patient and caregiver education and counseling. Expectations for sexuality must be established and provided as anticipatory guidance in a developmentally appropriate fashion. The long-term findings in adults with pediatric-onset SCI highlight the fact that youth with SCI will have adult sexuality experiences; therefore, a goal of caring for youth with SCI should be to help them achieve similar experiences as the general population.

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