ORIGINAL CONTRIBUTION

Recommendations for Discussing Sexuality After Spinal Cord Injury/Dysfunction in Children, Adolescents, and Adults

Marcalee Sipski Alexander, MD; Craig J. Alexander, PhD

Department of Physical Medicine and Rehabilitation, University of Alabama at Birmingham, Birmingham, Alabama

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Abstract

Background/Objective: To review the literature and provide a framework for sex education for the child, adolescent, or adult with a spinal cord injury (SCI) or disorder.

Methods: Discussion and review of the literature.

Results: There is a paucity of research available regarding the impact of SCIs and disorders on sexuality in children and adolescents; however, there is a significant body of literature on this topic in adults. Recommendations based on these findings are presented. Guidelines regarding sexuality in children and adolescents with general disabilities may be adapted for the education of children and adolescents with SCIs and disorders.

Conclusions: Parents, partners, and persons with SCIs and disorders should be provided with age-appropriate information about sexuality that includes specific information with respect to SCIs and disorders. Although there has been a significant increase in information that is available about the impact of sexuality in adults after SCI, more information is needed about the effects of SCIs and disorders on the healthy sexual development of children and adolescents.

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INTRODUCTION

Although rarely discussed, the impact of a spinal cord injury or disorder (SCI/D) on sexual function is largely dependent on the age of the individual with the injury or disorder. Often, in the midst of dealing with an acquired SCI or congenital SCD, considering a child's sexuality can be a parent's lowest priority. Parents may focus on assuring the child has the greatest possibility to walk or play sports, whereas the "adult" concern of sexuality is not even considered. For the young child with SCI/D, this is also generally the case. However, as children approach adolescence, it is normal for them to begin to develop interest in sexual concerns, abilities, and relationships. Whereas the parents of able-bodied children may fear or welcome their child's emerging sexual thoughts, it is not uncommon for the parents of a disabled child to feel more protective and thereby deny their child's sexuality. This can lead to further embarrassment and worry for a child who must already confront the challenges of living with a disability.

For the adult with SCI, the situation is different in that they have a sexual history on which to base their expectations and, potentially, a partner who must also understand and respond to the impact of their SCI on their sexual functioning.

At any stage of development, however, there are specific SCI/D-related changes in sexual response to which the individual must adapt. Furthermore, there are treatments available for sexual dysfunctions that should be considered. It is the goal of this paper to review the anticipated effects of SCI/D on sexual response and how one might respond to children and adolescents with SCI/D at different periods in time. In addition, we will discuss appropriate therapies for remediating sexual dysfunction.

Please address correspondence to Marcalee Sipski Alexander, MD, Department of Physical Medicine and Rehabilitation, University of Alabama at Birmingham, 1717 6th Avenue S., Birmingham, AL 35249; phone: 205.934.2088; fax: 205.975.4896 (e-mail: msipski@uab.edu).

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Although the issues of birth control, dating, and fertility are also important for adolescents and adults with disabilities, a review of these topics is beyond the scope of this work, and the reader is referred elsewhere for this information.

SEXUAL RESPONSE AND SCI

Predictable alterations in sexual response occur based on the location and degree of the SCI/D. These responses have been extensively studied using laboratory-based research in women (1–6) and recently in men (7–10). Based on this research, certain guidelines may be provided about the ability of persons with SCI to experience psychogenic and reflex genital arousal and orgasm.

In women, the ability to experience psychogenic genital vasocongestion (a presumed correlate of lubrication) has been shown to be related to the ability to perceive a combination of pinprick and light touch sensations in the T11–L2 dermatomes (1). This is believed to be because the sympathetic nervous system is regulatory for psychogenic arousal (1,7,11). In men, the ability to experience psychogenic erection has been correlated with the preservation of the perineal sympathetic skin response (8) and with "lower lesions" (7). In our research, we also noted that the presence of the ability to perceive T11–L2 sensation in men correlated with increased penile circumference in response to viewing erotic videos (10). Thus, when communicating with patients or parents, the ability to perceive surface sensation from T11 to L2, easily described as the part of the body between the "belly button" and where the pockets in a pair of pants are, should be assessed. The greater the patients' ability to perceive surface sensation to both light touch and pinprick in these areas, the more they should be counseled to increase the fantasy and foreplay aspects of their sexual encounters.

Laboratory-based studies have suggested (1,4), but not confirmed, that the ability to achieve reflex genital lubrication is related to the presence of an intact sacral reflex arc. The neurologic pathway thought to control reflex lubrication involves the pudendal nerve and the S2–S4 nerve roots; thus, physical evidence of the maintenance of a bulbocavernosus reflex and the presence of a spinal cord lesion above the conus medullaris indicate that women with SCI should experience reflex genital arousal. Similarly, in men with SCIs, reflexogenic stimulation was correlated with the presence of the bulbocavernosus reflex and a reflexic detrusor (8) and "higher lesions" (7). Taking this information into account, it follows that men and women with SCI/D who have evidence of sacral reflex activity should be counseled to maximize physical genital stimulation during sexual activity (11).

Regardless of whether the source of data is questionnaire (12,13) or laboratory-based research (1), orgasm has repeatedly been shown to occur in approximately 50% of women with SCI. Our group further reported that the subpopulation of women with SCI who have complete lower motor neuron injuries affecting their sacral spinal cord are relatively unable to have orgasms compared with women with any other level or degree of SCI. It was also shown that, compared with able-bodied women, it took longer for women with SCIs to achieve orgasm; however, their subjective descriptions of orgasm were indistinguishable. In men with SCI, the ability to achieve orgasm was also studied in a laboratory and noted to be less common in men without evidence of anal sensation or reflex activity. In contrast to women, however, there was not a significant difference in latency to orgasm between able-bodied men and men with SCI (9). Based on these results, it is suggested that men and women with SCI/D, with absent sensation in the rectal area, and with absent anal wink and bulbocavernosus reflexes should be counseled to focus on improving their sexual arousal rather than focusing on achieving orgasm. In contrast, women with preservation of any sensation and/or reflex activity in this area should be counseled that they should have the ability to achieve orgasm after SCI. This group of individuals, however, should be counseled that it might take a longer amount of stimulation to achieve orgasm (1).

ADDRESSING SEXUALITY AND SEXUAL RESPONSE THROUGHOUT THE LIFE SPAN

The main issue related to sexuality that must be addressed in children is education. As a result, many guidelines are available. The Washington State Department of Health summarizes that, "In the early years, the foundation for mature adult sexuality is laid with such building blocks as healthy self-esteem, positive body image, good self-care, effective communication, respect for others, caring for family and friends, and a responsibility to community. As an individual matures, other essential elements are added such as understanding body changes, sexual intimacy, and commitment; knowing and using health-enhancing measures, such as health exams, abstinence, and protection; and recognizing the joys and responsibility of parenting" (14). Unfortunately, although there are many guidelines available for addressing sexuality education in children with mental disabilities, there are few guidelines related to sexuality and SCI. Therefore, the following discussion will be based on general education for children with disabilities with suggestions for specific issues that persons with SCI must deal with at different points during the life span.

The young child who sustains a SCI or is born with SCD through spina bifida will initially be unaware of their loss. As stated by Mitchell Tepper, "Children with disabilities first learn that they are disabled before learning to see themselves as sexual people" (15). Children with disabilities undergo age-related growth and development, similar to that of non-disabled children; however, they are more at risk than able-bodied children to experience physical, emotional, and/or sexual abuse (16–18). In 1 study, disabled children were found to experience abuse at twice the frequency of the general population (17), whereas in another study, the rate of abuse in disabled children was 4 to 10 times that of the general population (18). Furthermore, the detection of abuse in children with SCI/D and other disabilities is often delayed. Consequently, when it is detected, there is generally greater psychologic and or physical damage in disabled compared with able-bodied children. Another problem that contributes to this issue is that health care workers often do not associate disabilities with the potential for abuse. In the person with SCI who does not feel pain, this could manifest itself as pressure sores, trauma to the skin, or broken bones that could occur more easily in an insensate person compared with someone with intact sensation. If sexual abuse is suspected, clinicians should refer to professionals with appropriate expertise for evaluation and treatment. This may include a regional child abuse specialist or assessment center. Excellent guidelines regarding sexual abuse are available from the American Academy of Pediatrics, and the reader is referred to this reference for further information (19).

Effective therapy to promote healthy sexual development in children with disabilities includes proactive teaching of the child's parents about the impact of SCI/D on sexuality from sexual response, treatment of sexual dysfunctions, and relationships to expected consequences on reproductive function. Even if the parent does not seek this information, it is important to make them aware of the impact of SCI/D on sexual function so that they may appropriately respond to any questions that their child may ask. Effective treatment also includes discussing the issue of abuse with the parents of the disabled child so that they may be aware of the signs of abuse, how to prevent it, and what to do if it is suspected. For those physicians who are uncomfortable discussing these issues face to face with parents or children, written information may be provided, or this information may be routinely provided by other members of office staff such as nurses, social workers, psychologists, or health educators.

The National Information Center for Children and Youth with Disabilities provides some helpful guidelines for age-related sexuality education (20). From infancy to age 3 years, they note that body exploration is normal, as are accidents of bladder and bowel. These occurrences should be treated as matter of fact with a goal of teaching students what is appropriate to do in public vs private spaces.

During the preschool years, children are often learning names of body parts. Just as with any child, the child with a disability should be taught these names with dignity and respect. The child should be taught to do their bladder and bowel procedures around the same time as they would be "potty trained"; furthermore, information provided to them should be age-appropriate and accurate. Balderian (18) recommends that parents speak directly to their disabled children about abuse and develop a communication cue for the child to let the parent know something has happened. Around this time, "show me" games are common, and the parent must take care not to overreact, because this may lead to negative feelings in the children. In fact, this may be more common in children with SCI/Ds because they "show" other children how their own body works.

From ages 5 through 8 years, the early school years, children may lose interest in the opposite sex but still explore their bodies with friends of the same sex. Although this may cause parental dismay, it is again recommended that parents not overreact because these are normal behaviors. According to the National Information Center for Children and Youth with Disabilities (19), some of the topics recommended for discussion during this time include names and functions of body parts, similarities and differences between boys and girls, the basics of procreation and pregnancy, qualities of good relationships such as friendship, love, communication, respect, decision making, and knowing there are consequences to decisions, beginnings of social responsibility, values, and morals, avoiding and reporting sexual exploitation, and that masturbation can be pleasurable but should be done privately.

Ages 8 through 11 years is a time when children become more and more concerned about their interactions with their friends. During this time, most children receive some type of sexuality education in school; however, children in special education may miss this opportunity (19). Body image often becomes an issue, and this may be even more difficult for the child with a disability than an able-bodied child. It is important when relating with a child with SCI/D to listen to the child's concerns about body image and acknowledge them so they can develop a realistic sense of self. Refocusing the child (21) to develop his/her strengths may be a beneficial technique. Assuring that the child has a healthy diet, body weight, good grooming, and exercise is also recommended. General information about procreation and sexuality should be provided as the child reaches school age, with more specific information given before the child reaches adolescence. During this time, it is important to begin to discuss more detailed aspects of sexuality with them including the nuances of sexuality and the effects of SCI/D. It remains important for parents to stress the need for good communication and avoiding and reporting sexual abuse. They should be provided with an understanding of basic anatomy and physiology so that they are not surprised when the changes of adolescence occur! Moreover, they should be educated about values and the benefits of abstinence from sexual activity, the possibility of unwanted pregnancies, and the possibility of sexually transmitted diseases. Parents must use their own discretion when communicating about issues such as contraception and abstinence-only education.

During adolescence, children become even more concerned with their body image. They develop an increased need for privacy and a need to "do things on their own." This may be more difficult for the adolescent with SCI/D, and parents should try to support this need by assuring that the child has transportation and assistance for appropriate time away from home. Masturbation generally becomes common during adolescence, and children should be told that this is an acceptable activity but that it needs to be performed privately. Adolescents with disabilities are also reported to have similar rates of sexual activity as those without disabilities (22). Topics that need to be discussed with adolescents include further discussion of the impact of SCI/D on sexuality, birth control, reproduction and pregnancy, sexually transmitted diseases, and condoms. The importance of values, communication, intimacy, and love should be addressed, as should the issues of intercourse, in addition to other ways to safely and responsibly express sexuality. The issues of alcohol and drug use should also be explored in addition to general health care and the issue of sexuality and how it fits into a person's whole self. These issues are complicated and difficult for the able-bodied adolescent to deal with. Therefore, in considering adolescents with disabilities, one must take the issues of sexual development in stride, realizing the changes of adolescence are something that all people must experience, and these issues are not limited to persons with SCI/D.

Adults who experience SCI/D also have changes in their sexuality. These issues have been extensively discussed elsewhere and will not be repeated here (23,24). Changes that have been documented to occur with respect to sexuality after SCI include decreases in satisfaction, desire, and frequency of activity in both men and women. Although these changes are known to occur after SCI, one must also realize that this is just normative information about sexual functioning in the population of people with SCIs and does not necessarily indicate the person has sexual dysfunction.

CLASSIFICATION OF SEXUAL DYSFUNCTIONS

Until this year, there has not been a routine system to classify the impact of SCI on sexual response. However, an international group has recently proposed "The International Standards to Document Remaining Autonomic Function after Spinal Cord Injury" (25). This document describes a system including a suggested primary anatomic diagnosis whereby the person's SCI is classified as supraconal, conal, or cauda equina depending on the spinal location of their injury. There is a secondary classification that first indicates whether the individual complains of sexual dysfunction and then lists the type of sexual dysfunction. A tumor, node, metastases type system, such as that used for common criteria to stage cancers, was also developed for specific aspects of autonomic function affected by SCIs. With this system, for men, the effect of the injury on psychogenic and reflex erectile potential, orgasm, and ejaculation are described, and for women, the effect of injury on psychogenic and reflex genital arousal, orgasm, and menstruation are described.

TREATMENT OF SEXUAL DYSFUNCTION

Previously, treatment of sexual dysfunctions was generally relegated to sexual therapists or urologists and largely relied on the treatment of erectile dysfunction. Therapies included penile prostheses (26,27), intracavernosal injection of vasoactive agents (28), the use of intraurethral alprostadil (29), and the use of vacuum erection devices. Largely because of the development of oral phosphodiesterase-5 inhibitors, the treatment of erectile dysfunction has become commonplace. There are now 3 Food and Drug Administration (FDA)-approved drugs to treat erectile dysfunction: sildenafil, vardenafil, and tadalafil. All of these drugs have been shown to be effective in SCI. In multiple studies, sildenafil has been shown to be beneficial for the treatment of erectile dysfunction after SCI (30,31). Moreover, it has been shown to be void of significant side effects and has been noted to result in slightly lowered blood pressure in men with SCIs above T6 (32,33). Alternatively, for some men, the longer half-life of tadalafil may make it more desirable than sildenafil (34). Vardenafil was most recently studied in a double-blind, placebo-controlled parallel-group 12-week study of 418 men with SCI (35). In this report, ability to maintain an erection, achieve penetration, and ejaculate were all significantly improved with treatment with vardenafil compared with placebo.

Therapies for the treatment of female arousal dysfunction after SCI have also recently been explored. Beneficial effects of sildenafil on subjective sexual arousal along with an acceptable safety profile were noted in a laboratory-based study (36). Increased sympathetic input to the genitals through viewing anxiety-provoking audiovisual stimulation (37) and cognitive manipulation through false-feedback have been tested in women. These 2 approaches have been shown to have promising effects in the subset of women with SCIs and partially diminished ability to appreciate sensation from T11 to L2 (38). These findings have been hypothesized to be evidence for the ability of the sympathetic nervous system's ability to regulate genital arousal. In another study (39), vibratory stimulation was tested as a method to improve reflex genital arousal. Unfortunately, although beneficial results have been shown in the laboratory, a means of improving sexual arousal in persons with SCI has yet to be documented in a home environment.

Although there have been published studies related to improving arousal responses in men and women, there have not been any published studies focused on improving orgasmic ability. Although we are still in need of objective data to prove the efficacy of orgasmic therapies in SCI, it is our clinical experience that the use of vibratory stimulation may be beneficial in men and women with SCIs to improve their orgasmic potential. Moreover, there are data to support the presence of a pattern generator that results in ejaculation and orgasm-like response in animals (40,41). Thus, in patients with SCI/D with neurologic level below the level of T6, the use of vibratory stimulation should be considered as an option to attempt to improve orgasmic function.

CONCLUSION

Achieving a healthy sexual existence is something that most people strive for. This is a complicated process that is dependent on a person's stage in life, their family background, personal make-up, and relationship status. As health care professionals, it is our responsibility to help our patients achieve a healthy sexual balance. We can do this by first showing respect for our patient's background and second by providing basic age-appropriate sexual information for patients and their families. By providing sensitive education and showing availability to answer questions for our patients, we will be able to foster the development of satisfying, safe, and healthy sexual practices throughout the lifespan, despite the presence of a SCI/D.

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