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Editorial

The Next Step in Optimizing Sexual Health in Men Living with Spina Bifida: How Does Our Measurement Tool Measure Up?

Caring for adults with spina bifida presents a multitude of unique challenges.

Prior to the advances in neurosurgery in the midtwentieth century, survival beyond infancy was rare; living into adulthood was the exception. Today, the Spina Bifida Association (SBA) estimates that approximately half of Americans living with spina bifida are adults. This remarkable achievement of making survival into adulthood the rule, instead of the exception, has created cohorts of pioneers. Our adult patients are truly doing something that has never been done before—living for decades with varying congenital neurological deficits that can profoundly affect multiple organ systems. The doctors and nurses caring for these individuals, likewise, are venturing into uncharted territory with limited collective experience, research, and clinical tools to optimize the quality of life of these individuals. The American health care system is not particularly well-suited to deliver optimal care to a population as they progress from childhood where many received care at specialized children's hospitals and clinics to young adults with limited options for care of congenital disorders in the realm of adult medicine. Financial coverage for health care, likewise, rarely remains consistent in this country as one moves from childhood to adulthood.

For urologists, the triad of goals of protecting renal function, minimizing urinary tract infections, and creating urinary continence in the spina bifida population are well-known. Urologists begin to address these goals soon after birth and doggedly pursue them throughout the lifespan. But what about sexual health? The spinal cord and peripheral nerve pathology caused by spina bifida can negatively affect the innervation and function of reproductive organs. This can result in decreased genital sensation and altered erectile, orgasmic, ejaculatory, and reproduction function in affected males.[1,2] Furthermore, it is well documented that adolescents and adults with spina bifida are underinformed about sexual health compared to their able-bodied peers and specific to their disability.[3,4] Yet when the SBA developed a community-centered research agenda, "Having an Active Sex Life" was one of the research priorities expressed by the spina bifida community.[5]

Spina bifida is often referred to as a "snowflake" disorder because, like snowflakes, no 2 individuals with spina bifida are alike in their abilities and disabilities. That means that 2 men both born with similar low lumbar myelomeningocele forms of spina bifida may have differing capabilities for ambulation, penile sensation, erectile function, sexual satisfaction, etc. To provide optimal care for these individuals, effective tools are needed to assess their sexual function and dysfunction. Urologists routinely use the International Index of Erectile Function (IIEF) to query men regarding their sexual health.[6] The article by Rague et al (page 000) in this issue of The Journal highlights the pitfalls of the IIEF assessment tool in the spina bifida population.[7] The IIEF instrument was validated in able-bodied men who had or previously had normal sexual function and presumedly were trying to maintain their sexual activity. Young men with spina bifida, on the other hand, may have never had normal erections, orgasms, or ejaculation; may not be completely familiar with those terms; and may never have been sexually active alone or with a partner. Many of these young men may still live with their parents, and it is not surprising that Gamé et al found that erectile function in men with spina bifida measured by IIEF was better in those who were not living with their parents.[8] It is no wonder that the title of the article by Rague et al starts with "I just haven't done any of that." Unlike most able-bodied men seeking urological care, half of their study group was never previously in a relationship and, though not documented, were likely still living with their parents—a situation that does not create optimal opportunities for sexual exploration!

Towards the aim of furthering community-based research initiatives, Rague et al undertook their study to better understand from young men living with spina bifida what their attitudes were towards the IIEF tool, what gaps existed in using IIEF in men like them, and what sexual experiences specific to them are not captured by the IIEF. Structured interviews with 20 men found that several felt that

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the IIEF was not applicable to them at all because they had never been sexually active. Although others felt that the tool was applicable to them, they noted that the IIEF did not accurately address their challenges of the unpredictable variation in their sexual function and dysfunction, urinary and fecal incontinence before and during sexual encounters, reduced genital sensation, positioning for sexual activity in the presence of lower extremity dysfunction, and psychosocial barriers.

This work is a highly meaningful step along the road to improving the sexual health of men living with spina bifida. Scoping reviews of the pertinent literature have defined the current knowledge of sexual function and dysfunction in this population.[1,2] Consensus panels convened by the SBA have identified the research gaps in the field.[3,4] This work by Rague et al, in addition to adding to the litany of knowledge gaps, gave voice to the population impacted by the disorder to inform researchers how to improve the assessment tool measuring how they experience their often unique disabilities.[7] This will allow researchers in the future to refine the item bank and develop a measure to accurately define the sexual experience and health of men living with spina bifida. Once validated, health care professionals working with men with spina bifida can better assess and address their challenges in achieving satisfactory sexual health.

John S. Wiener[1]
[1]*Section of Pediatric Urology, Duke University Medical Center, Durham, North Carolina*

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