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Medical care of adults with spina bifida

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Abstract. Survival into adulthood for individuals with spina bifida has significantly improved over the last 40 years. Health services research suggests the majority of patients with spina bifida are now over 18 years old. Adults with spina bifida have ongoing increased medical needs compared to the general population, including spina bifida-specific care, age-related secondary disabilities, and general adult medical needs. Unlike pediatric-aged patients, adults may not have access to multi-disciplinary spina bifida clinics and must often coordinate their own care with adult providers less familiar with spina bifida and the associated monitoring and treatment issues. This article will provide an overview of the medical issues of adults with spina bifida, highlighting areas that are different than pediatric care.

1. Introduction

With aggressive, nonselective closure at birth, rapid neonatal shunting of hydrocephalus, and proactive bladder programs, survival to adulthood for individuals living with spina bifida has significantly improved over the last 40 years. Published longitudinal data indicate a 50–94% survival rate to adulthood depending on hydrocephalus, shunt status, and decade of birth [8,9,31] with those born after the mid-1970's having the greatest survival. Analysis of medical claims data suggests that the majority of individuals with spina bifida are now over 18 years old [32].

The health of adults with spina bifida can vary widely based on age, level of lesion, number and severity of co-morbidities, degree of self-care skills, amount of family and community supports, and access to medical care. The effect of lesion level on spina bifida is well known with higher level lesions having greater impact on neuromuscular function resulting in greater risk for mobility, skin, spine, and cardiopulmonary problems [14]. Those with hydrocephalus are at risk for learning disabilities, particularly if there were multiple shunt complications [14]. Age impacts health in this population due to the changes in medical management of infants and children with spina bifida over the last generation [38]. Those born before the mid 1970's will have significantly different health than those born later because both aggressive neonatal care and preventive bladder programs were standard care only after that time period [9,11]. Before non-selective treatment, only those without significant hydrocephalus who remained unshunted tended to survive early childhood. Similarly, early renal failure was common before catheterization programs [9]. Procedures have also changed over time such that ventriculoatrial shunts, ileal conduits, colostomies, and certain orthopedic surgeries are more common in older adult patients, requiring unique screenings and interventions no longer necessary for current pediatric patients.

Access to medical care has been shown to change outcomes in spina bifida. The benefits of multidisciplinary clinics compared to uncoordinated care by individual providers are known [5,18,25] yet less than half the multi-specialty spina bifida clinics follow adults and only a handful of adult spina bifida clinics exist [40]. Therefore, individual medical providers may be responsible for overseeing much of the care for their adult patients with spina bifida.

This review will examine the medical care of adults with spina bifida, emphasizing the differences from pediatric care and the additional considerations of adult-onset medical conditions. It is not meant to be a comprehensive review of adult spina bifida management

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which has recently been published elsewhere [10]. Articles included for this review were selected for their focus on adult-aged patients and the diagnosis of spina bifida (compared to mixed populations such as all hydrocephalus or all spinal cord abnormalities).

2. General adult health care

Because so much emphasis is placed on spina bifida-specific care, the general health care needs of these adults are sometimes overlooked. As with any adult, those living with spina bifida need routine primary and preventive services. According to the US Preventative Services Task Force [47] all adults should regularly have their body mass index assessed; receive blood pressure monitoring; have cholesterol checked by age 35 for men and 45 for women, or earlier if risk factors are present, receive age-appropriate cancer screening; receive STD screening if sexually active; be screened for depression; and be screened for diabetes if they have hypertension or hyperlipidemia.

Adults should also receive regular counseling on tobacco and illicit substance use, domestic violence, healthy diet and exercise, motor vehicle safety, and safer sex practices. The intervals for each of these preventive services depend on risk factors, but most importantly, there needs to be one clinician on the spina bifida team that ensures this care is provided.

There are unique issues that need to be considered in spina bifida, including the adult patient's cognitive abilities and capacity to make informed decisions [4]. For those adult patients who depend on other caregivers, guardianship or power of attorney status needs to be addressed. For those who retain their own decision capacity, executive functioning, organizational abilities, and health literacy skills may impact health outcomes.

3. Spina bifida care

A major goal of longitudinal medical care in spina bifida is to prevent secondary conditions, defined as potentially avoidable health outcomes that are causally related to, but not part of the natural history of the primary diagnosis [19]. Examples of secondary conditions are shunt infections, kidney infections, renal failure, decubiti, osteomyelitis, and amputations. Therefore, diligent assessment of neurologic status, optimal surveillance of bowel and bladder function, frequent evaluation of mobility aides, and monitoring of skin integrity are essential medical services for this population. Compared to pediatrics, less is written about the optimal frequency of surveillance or which tests are most appropriate for adults. In addition, a broader differential diagnosis is necessary for adult patients with common presenting complaints because of the likelihood of a general adult-onset medical condition, the impact of negative health behaviors (i.e. smoking), and the longitudinal effects of spina bifida-related conditions and treatments, such as a neurogenic bladder and clean intermittent catheterization.

4. Neurosurgical issues

The three most commonly described issues for adults with spina bifida are shunt complications, tethered spinal cord, and syringomyelia.

4.1. Shunts

Approximately 80–85% of patients with spina bifida have ventricular shunting of their hydrocephalus [14, 24]. By adulthood, many have had stable hydrocephalus for several years and may be told they have arrested hydrocephalus or shunt independence. However, there are numerous reports and small case series demonstrating late-onset shunt failure requiring emergency revisions, or worse, sudden death with an obstructed shunt found on autopsy. In a retrospective review of 320 emergent shunt revisions in 110 patients aged 14–31, 7.5% and 3.5% of the emergent operations occurred in shunts 10 and 15 years old, respectively [43]. In the same study there were five deaths attributed to shunt malfunction, some in individuals under evaluation for subtle symptoms [32].

In another retrospective review of 51 headache evaluations in 23 adults with spina bifida and CSF shunts, 33% had confirmed increased intracranial pressure despite unchanged ventriculomegaly or normal ventricular size on over half of the neuroimaging [12]. In this study intracranial pressure monitoring was useful in determining whether shunt or third ventriculostomy revision was necessary. This study also found that headache characteristics often associated with shunt malfunction in pediatrics were not predictive symptoms in these adults. The positive predictive values of headache location, early morning onset, and associated vomiting were 43%, 54%, and 45% respectively.

Additionally, shunt failure can present with more insidious symptoms including gradual changes in neu-

rocognitive function. One small series of adolescent and adult patients believed to have stable ventriculomegaly and no symptoms of shunt malfunction found abnormal pressure waves on intracranial monitoring. In addition, there were significant improvements in neurocognitive function following shunt replacement, particularly in verbal and visual memory, motor coordination, attention, and cognitive flexibility [21].

Other presentations of shunt malfunction in adults include vision loss, bulbar dysfunction from Chiari compression, worsening scoliosis, symptomatic tethered cord, and syrinxes. Thus, some advocate a high index of suspicion for shunt malfunction for almost any neurologic, orthopedic, or urologic decline [8].

Shunt types have changed considerably over the years with ventriculoatrial shunts common only in the over 35 age group [15]. Because this type of shunt can lead to shunt nephritis and renal failure, annual assessment of kidney function and screening for proteinuria and hematuria is recommended. Serologic testing with C3, C-reactive protein, cryoglobulins, and ANA, as well as blood and CSF cultures can confirm the diagnosis [13]. Pre-procedure prophylactic antibiotics are also recommended for these patients [2].

Ventriculoperitoneal shunts are now most common, and patients with programmable valves need to either know their resistance level or have a written copy of the setting with them at all times. This information is important during any MRI procedure where reprogramming is necessary.

Optimally, adults with spina bifida who have shunts should be evaluated by a neurosurgeon at least once every two years to screen for complications [28]. If this is not possible, at least one neurosurgical visit to establish a baseline exam is recommended, and another clinician who understands the potential secondary neurological conditions associated with spina bifida should evaluate the adult patient annually. For those patients who have transferred care away from their pediatric providers, copies of their previous surgeries, last neurologic exam, and neuroimaging reports should be provided to the new clinicians. With the current capabilities of most radiology centers, digital copies of the most recent neuroimaging could also be provided to the new team. Patients with shunts should be counseled to keep their own digital copy of their most recent neuroimaging, particularly during travel or if they live a distance from their usual neurosurgical care.

Regular assessment of adults with ventricular shunts should include an annual ophthalmologic exam which should include an assessment of the ocular muscles, color vision, and optic disc. Some advocate periodic neuropsychological testing to uncover deterioration of memory, attention, or motor skills as an indication of shunt problems [23].

4.2. Tethered cord

Adults with repaired spina bifida aperta, especially with myelomeningocele, lipomatous change, or previous tethered cord, are at risk for retethering syndrome. Radiographic changes consistent with retethering are very common and only a percentage of patients develop symptoms attributed to the entrapped nerves. While growth spurts are the most common cause of retethering in childhood, the most common mechanisms in adults are falls, back trauma, heavy lifting, and vaginal childbirth. Similar to pediatrics, the diagnosis of symptomatic tethered cord syndrome in adults is made by clinical findings, including new-onset back pain, changes in gait, worsening lower extremity spasticity, and changes in bowel and bladder function. Changes on urodynamic profiles, such as increasing bladder contractures, decreasing bladder capacity, and decreasing urethral sphincter pressure, may help distinguish a symptomatic tethered cord from other causes of back pain. There are no published case series of outcomes for adult patients with spina bifida and retethering; however, pain may not quickly or completely resolve and frequently recurs over time [35]. Often, a conservative approach for an acute exacerbation of tethered cord symptoms is attempted first. Non-steroidal anti-inflammatory medications and even steroid bursts have been successful in alleviating a flare of back symptoms [34].

4.3. Syringomyelia

Adults with spina bifida remain at risk for developing a syrinx anywhere along the spinal cord. One case series reported a prevalence of 48% of adult patients who underwent MRI of the spinal cord [22] As with children, the development of a syrinx may be a manifestation of a shunt malfunction [35]. Because syrinxes can be asymptomatic, a baseline MRI of the total spine is recommended for all adults for comparison to future neuroimaging in case new neurological symptoms develop. A thorough annual neurological examination with emphasis on changes in muscle tone (increased or decreased), ascending loss of sensation, and loss of motor strength of the upper and/or lower extremities may uncover a clinically significant syrinx.

Syringobulbia is the most important syrinx to find and should be considered whenever there is a change in oromotor control, daytime or nighttime breathing control, or voice quality. An urgent referral for neurosurgical evaluation, with an evaluation for shunt malfunction, is warranted.

5. Musculoskeletal issues

Once linear growth is complete, there are fewer orthopedic surgical issues. In adults, the major orthopedic surgical concerns are related to previously implanted spinal rods and chronic degenerative changes or osteomyelitis of insensate limbs or pelvic bones. Surgery may be necessary to remove broken, painful, infected, or protruding rods. Chronic or recurrent decubiti leading to chronic or recurrent osteomyelitis may require amputation of the affected limb [30].

More common orthopedic complaints are nonsurgical in nature, including chronic pain resulting from abnormal posture and body mechanics of the back, hips, and legs during ambulation and in the neck, wrists, and shoulders during wheelchair propulsion. Annual reassessment of mobility equipment is essential. Adults also need to re-evaluate the most effective means of mobility and consider transition to wheelchair if pain, fatigue, or joint and skin injuries become significant. Retrospective reviews demonstrate that those with lesion levels above L5 are significantly less likely to ambulate by age 30 [17].

While back pain can be a symptom of tethered cord, other de-conditioning and degenerative adult-onset processes may be responsible [35]. The effects of chronic lower body weakness and altered gait can cause musculoskeletal pain in the lower back, particularly if the patient has a Trendelenburg gait, significant pelvic obliquity, or excessive lumbar lordosis. A re-assessment of gait, orthotics, and mobility aides may help with body mechanics and alleviate discomfort. Anecdotally, physical therapy and aquatic therapy have alleviated pain associated with deconditioning. Although there are no published studies in spina bifida, individuals with chronic neuropathic pain may benefit from a trial of medications with indications for neuropathy or fibromyalgia pain. There is some evidence in the spinal cord injury literature of improved pain using certain antiepileptic medications and these drugs have anecdotally been helpful in some patients with spina bifida [36, 44].

Aside from contractures and tightness from disuse, spasticity is an uncommon complaint in spina bifida, and when present may indicate a symptomatic tethered cord or significant syrinx. New spasticity warrants a neuroradiographic evaluation of the total spinal cord. If neither a syrinx or tethered cord amenable to surgical correction is identified, then treatment of spasticity may include physiotherapy, oral muscle relaxants, botulinum toxin injections, and intrathecal baclofen; however, there are no trials of any of these therapies in adult spina bifida.

6. Feet

Joint trauma, particularly of insensate feet in ambulatory patients with spina bifida, may lead to Charcot arthropathy. The presence and treatment of this condition has been described in the pediatric age group, but not in the adults [26]. There is little reason to assume there would be fewer cases of Charcot arthropathy in ambulatory adults and therefore, insensate feet should be examined at every visit. Feet should also be examined for calluses, condition of toenails, and skin breakdown. Orthotics should be examined for proper fit and to identify needed repairs. Similar to the insensate diabetic foot, a spina bifida foot would benefit from routine care by a podiatrist or other foot specialist.

7. Osteoporosis

Only one study in adults with spina bifida has looked at bone density [48]. Twenty-one male and females (52%/48%) adults ages 19–47 (mean 30), including all levels of ambulators, were evaluated for bone density in intact lumbar vertebrae, non-deformed hips, and/or forearms. Thirty-three percent of the subjects had osteopenia in at least one site by World Health Organization standards. There was a trend towards lower bone density in the femoral neck in non-ambulators compared to ambulators, but this did not reach statistical significance. There have been no studies in adults with spina bifida regarding treatment. Until more information is available about what factors contribute to osteopenia in adult spina bifida and studies demonstrate benefit from pharmacologic treatment, no recommendations can be made for screening or medication therapy. Patients can be encouraged to take adequate calcium (1500 mg daily) and vitamin D (800 IU daily). There is likely to be some benefit from weight-bearing exercise, including the use of standers and walkers.

8. Cardiopulmonary

Cardiac causes are listed as a common cause of death in registry-based studies of adults with spina bifida [22, 39], but the mechanisms are not elucidated. Mechanistically the most likely cause is cardiopulmonary failure from the long-term effects of significant kyphoscoliosis, particularly for those with thoracic and high lumbar lesions. Individuals who never received spinal rods, or whose rods were removed due to complications are theoretically at risk for cardiopulmonary compromise from the significant spinal curvature. Because the compression effects of severe kyphoscoliosis may lead to restrictive or obstructive lung volumes and decreased cardiac stroke volume, these patients should be periodically evaluated for hypoxia and clinical features of right heart failure.

In addition to the cardiopulmonary effects of kyphoscoliosis, individuals with spina bifida appear to have an increased risk for sleep apnea. In infancy, the risk is associated with Chiari malformations and is predominantly of the central apnea type [20]. In adults, obstructive apnea becomes a problem (personal data). The exact contributions of low muscle tone, increased neck and chest girth, hydrocephalus, and Chiari malformation is not known, but adults should be asked about snoring, breathing pauses during sleep, fitful sleeping, difficulty arising, and daytime somnolence. Sleep apnea should also be part of the differential diagnosis of headaches, especially for cephalgia present upon awakening.

9. Obesity

Risk factors such as sleep apnea, decreased cardiopulmonary capacity, low muscle mass and tone, and chronic pain may contribute to the propensity towards obesity. Because the basal metabolic rate of those with spina bifida may be decreased, greater calorie restriction is needed. In addition, some form of aerobic exercise, either individual or through an adaptive sports program, should be encouraged [42].

10. Vascular and skin issues

Adults with spina bifida and myelomenigocele have smaller blood vessels and slower lower-extremity blood flow compared to the both those without spinal cord dysfunction and those with acquired spinal cord injuries [7]. The likely explanation for this finding is a combination of underdevelopment of the vascular system due to life-long paralysis below the level of the myelomenigocele and overall smaller body size. In addition, the vascular wall shear stress is higher in spina bifida which may lead to endothelial damage [7]. This may explain the propensity for decubiti, cool and cyanotic limbs, and difficulty treating wounds and osteomyelitis in this population. Given these increased risks, patients should be counseled to avoid the additional vascular insults of smoking and hypercholesterolemia.

In addition to decreased arterial flow, there can be venous insufficiency and impaired lymphatic drainage, probably due to the combination of decreased lower extremity tone and lymphatic compression from prolonged sitting (for those in wheelchairs). For these conditions, the use of compression stockings may be helpful but could be complicated by an increased risk of pressure sores if the stocking is poorly fitting. Anecdotally, a few patients have tried lymphedema pumps with some benefit.

Decubiti remain a significant concern in adults with spina bifida with insensate areas at highest risk. In addition to the childhood risks of poorly fitting orthotics, incontinence, obesity, prolonged sitting, improper wheelchair seating, vascular and lymphatic insufficiencies, and inadequate nutrition, adults contend with weaker tissues in areas of previous decubiti.

11. Latex allergy

Adults with spina bifida, like children, are at higher than average risk for reacting to latex. The mechanism for this allergy remains unknown but the adult needs to remain vigilant about potential exposure in both medical and general community environments, including certain foods that may trigger reactions. Adults with severe reactions, including anaphylaxis and respiratory compromise, should be counseled to wear a medical alert bracelet and carry auto-injectable epinephrine with them at all times [42].

12. Urological issues

Adults with spina bifida continue to have neurogenic bladders. Depending on their age, they may or may not have been on lifelong clean intermittent catheterization (CIC) programs, which were introduced in the

1970's. Studies of adults born before aggressive bladder care document the prevalence of renal abnormalities of 41% [1].

Adults with neurogenic bladders need regular screening of the kidneys, ureters, and bladder, although they may not need as frequent or extensive of an evaluation as the rapidly growing pediatric patient. Renal ultrasounds are recommended at least every two years to assess for hydronephrosis, hydroureter, and nephrolithiasis [42]. For those patients with a large body habitus in whom ultrasound may not provide adequate visualization, assessment of the kidneys with CT or nuclear uptake scans may provide more information.

Changes in continence or an increased frequency or severity of urinary tract infections warrants a voiding cystourethrogram (VCUG) to look for vesicoureteral reflux and urodynamics to assess bladder and sphincter pressures. Changes in bladder dynamics or sphincter tone may reflect poor adherence to CIC or a symptomatic re-tethering of the spinal cord.

Surveillance cystoscopy is recommended for anyone with a bladder augmentation starting 5 to 10 years after the procedure. Transitional cell cancer, squamous cell cancer, and adenocarcinoma have been found on cystoscopy as early as 8 years after augmentation. The median age in one study was 37 years old and almost all were advanced stage at diagnosis [3]. Most concerning in this series is that only 7 of the 19 cancers were in patients who had a bladder augmentation. The remainder were in adults with non-augmented neurogenic bladders. Thus, surveillance cystoscopy probably needs be performed in all adults with neurogenic bladders. Smoking was not a major factor in this study, but patients should be counseled on the potential additive risk of bladder cancer in tobacco users.

13. Renal failure, dialysis, transplantation

The risk of renal failure in older adults with spina bifida can be eight times greater than the general population, particularly for those who have a urinary diversion procedure such as an ileal conduit [1]. Most of the renal failure prevalence is reported in European studies, in patients with older urologic procedures, and those not adhering to CIC. In populations of patients who are closely followed in their spina bifida clinics renal failure is uncommon [8]. Therefore, adults with older urinary diversions or those not using CIC need more intensive monitoring of kidney function and surveillance for urinary tract infections and renal scarring.

Survival rates for individuals with spina bifida and renal failure on dialysis are reported as 94% at one year and as good as 82% at five years. Overall, it appears that survival on dialysis, as well as survival after renal transplantation, is equal to those without spina bifida [1]. Therefore, adults with spina bifida should receive renal replacement therapy or transplantation, if necessary.

14. Bowel issues

Abnormal bowel function is present in most adults with spina bifida. Problems include constipation, urgency, incontinence, and hemorrhoids. Although there are no published reports of treatment trials exclusively in adults with spina bifida, bowel programs may include medications, fiber, enemas, cecostomy, colostomy, and anal plugs. The antegrade colonic enema (ACE) procedure, most commonly described in pediatrics, may also be available to adults. No single program has worked for all patients. In one clinic, only 38% of the patients reported having a bowel program, but the majority report bowel continence at least 75% of the time [8]. Bowel function and continence should be addressed as this is a major issue for socialization, employment, and possibly long term health. The unanswered question in the older adult population is the risk of colon cancer in patients with chronic stool retention and whether a screening colonoscopy is warranted prior to age 50. Colonoscopy should be performed for other red flag findings such as non-hemorroidal rectal bleeding, heme-positive stool, iron deficiency anemia, weight loss, obstructive symptoms, recent onset of constipation, rectal prolapse, or change in stool caliber [28].

15. Sexuality and reproductive issues

Aside from early-onset puberty and menarche in women with spina bifida and hydrocephalus, there are limited studies of gynecologic issues in these patients. The few articles published often combine women with spina bifida, spinal cord injury, and multiple sclerosis. While the neuromotor and musculoskeletal challenges are similar in these groups, the differences are significant, especially the effects of congenital hydrocephalus on neuroendocrine function and the abnormal fetal development of the neurourologic system in spina bifida.

While there are no published reports of abnormal menstrual cycles in adult women with spina bifida, the challenges of immobility and contractures on menstrual hygiene are known [16,17]. Neuromuscular abnormalities impact sexual activity, especially positioning and sensation. Sexual functions such as lubrication and orgasm depend on the level of the neurologic impairment. The neurogenic bowel and bladder also impact sexual activity and women should be counseled to evacuate both prior to intercourse. The bladder should be emptied again after intercourse to help prevent urinary tract infections.

Contraceptive and STD prevention concerns for women with spina bifida include latex allergies for condom use, immobility and the risk of thromboembolism for estrogen-based therapies, and the potentially detrimental effects of depot progesterone on bone density. Aside from the latex allergy, the other concerns are mostly theoretical, and both estrogen and progesterone-based contraception is offered.

Women with spina bifida are believed to have normal fertility and at least 70% of those who conceive have successful pregnancies [16]. The gravid uterus can adversely impact balance and ambulation, ventriculoperitoneal shunt drainage, neurogenic bowel and bladder function, urinary or colon conduit and stomal patency, skin integrity, and pulmonary function, particularly with significant co-morbid kyphoscoliosis. Therefore, the optimal obstetrical care for women with spina bifida would be in a center that specializes in high risk pregnancies in conjunction with neurosurgical and urological consultation. Careful attention in the later stages of pregnancy for shunt malfunction, obstructive uropathy, bowel obstruction, skin breakdown, symptomatic tethered cord, and respiratory compromise is warranted.

Cesarean sections are common due to the neuromuscular changes of the perineum and contractures of the hips and lower extremities; however the location and path of the ventriculoperitoneal shunt and any bowel or bladder conduit must be considered. Vaginal deliveries have been associated with exacerbating symptomatic tethered cord.

Pregnancy outcomes are generally good, with some reports of congenital abnormalities [27]. There is a known 4–7% prevalence of offspring with spina bifida and a proven risk reduction with high dose folic acid supplementation (4–5 mg daily) prior to conception and during early gestation [49]. Therefore, all women with spina bifida of reproductive age should be counseled about folic acid supplementation and all those who are planning pregnancies should be prescribed folic acid 4 mg daily.

The effect of menopause on women with spina bifida is unknown; however the known results of hypoestrogenemia on bone density, urogenital ligaments and sphincters, and epithelial tissues are especially important given the increased risk of osteoporosis, incontinence, uterine prolapse, and decubitus ulcers for this population [16].

There are no studies of breast, cervical, uterine, or ovarian cancers in women with spina bifida. However, in the general population infertility and nulliparity are risk factors for ovarian cancer; obesity and nulliparity are risk factors for uterine cancer; and obesity and early menarche are risks for breast cancer [45,46]. Women with spina bifida may be more likely to have these risk factors so annual mammograms beginning at age 40 and routine preventative gynecologic care should not be postponed or disregarded due to difficulties obtaining mammograms or pelvic exams due to kyphoscoliosis or contractures. Alternatives to mammography include breast ultrasound and CT. An alternative for the bimanual pelvic exam is a pelvic ultrasound to look at the uterine stripe and ovaries.

Men with spina bifida have issues with erectile dysfunction, anorgasmia, retrograde ejaculation, and azospermia [6,50]. As expected, the higher the neurologic lesion level, the less likely to have typical function. Psychogenic erections and ejaculation are preserved at higher lesion levels than erections by tactile stimulation or orgasms during ejaculation [37]. Sildenafil has been shown to help men with spina bifida and erectile dysfunction in a dose-related response [33]. None of the other selective phosphodiesterase-5 inhibitors have been studied.

Similar to the women, the risk of neural tube defects for offspring of men with spina bifida is increased, and higher dose folic acid (4–5 mg) is recommended for their partners. Contraception and STD prevention for men are mostly affected by potential allergies to latex condoms.

16. Conclusion

Adults with spina bifida continue to have increased medical needs compared to the general population. They require ongoing evaluation and treatment of spina bifida-related conditions as well as screening and management for both secondary disabilities and general adult-onset illnesses. Adults with spina bifida would benefit from the same type of coordinated medical care offered by multi-disciplinary spina bifida clinics

that their pediatric cohorts currently enjoy. Research that includes only adults with spina bifida, including middle-aged patients, is necessary to understand the late secondary conditions of spina bifida and the longitudinal effects of the childhood procedures, such as ventricular shunting, bladder augmentation, urinary diversion, and spinal rods.

Additional resources

Guidelines for Spina Bifida Health Care Services Throughout the Lifespan, Third Edition, M. Merkens, ed., Spina Bifida Association, 2006.

Health Guide for Adults Living With Spina Bifida, Spina Bifida Association of America, Washington, D.C., 2005.

(Available from the Spina Bifida Association, www.spinabifidaassociation.org).

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