Pediatric Care of the Child with Spina Bifida

by Adrian Sandler MD

The pediatric management of children with spina bifida (myelomeningocele) can be challenging and very rewarding. Folic acid supplementation in recent years has been highly successful in decreasing incidence of neural tube defects by 70%, but the incidence among newborns in this country is still around 2-5 per 10,000. This article highlights a few important management issues for primary care.

In utero closure

Pioneering work at Vanderbilt has led to a large NIH multi-center trial of in utero closure. Outcome data regarding motor and sensory impairments and prevention of hydrocephalus are eagerly awaited. Information about the trial can be obtained at the National Institute of Health website.

Recognizing the Chiari crisis

The Chiari II malformation (downward displacement of the cerebellar vermis, elongation of medulla and fourth ventricle) is present in almost all patients, and may present with symptoms at any age. Infants are especially vulnerable, presenting with stridor (laryngeal dysfunction), weak cry, reflux, apnea, and feeding problems. Babies with progressive or severe symptoms usually require urgent cervical decompression.

Diagnosis of the “hostile bladder”

Ninety percent of newborns with spina bifida have normal urinary tracts on ultrasound examination. The challenge is to detect and provide early treatment for those babies who have a so-called hostile bladder and who are at risk of upper-tract deterioration. Although measurement of neonatal post-void residuals is helpful, consultation with a pediatric urologist in early infancy is advised to detect and treat dyssynergia. Urodynamics (VUDS) is a valuable tool, and clean intermittent catheterization (CIC) or vesicostomy are very effective in preventing hydronephrosis and renal insufficiency.

Treating constipation

Most infants and toddlers with spina bifida develop constipation, typically passing frequent, small, hard stools. If left untreated, fissuring, rectal prolapse, poor appetite, and urinary tract infections may occur. Moreover, chronic constipation can interfere with attainment of fecal continence. The management of constipation through diet, osmotic agents and stimulant laxatives is an important pediatric responsibility.

Initiating bladder and bowel programs

Almost all children with myelomeningocele have neurogenic bladder and bowel that causes functional impairment and incontinence. These issues should be routinely and repeatedly addressed in anticipatory guidance. Incomplete emptying of the bladder predisposes children to urinary tract infections, which may place the kidneys at risk if accompanied by high bladder pressures and/or vesico-ureteric reflux.

Fortunately, CIC is a simple procedure that protects the kidneys and may also lead to
urinary continence. CIC should be done five times a day, and catheters can be safely washed and re-used. Most children with spina bifida can learn to do the procedure themselves. We typically begin a bowel regimen at around age 4 years, using digital stimulation, suppositories, or mini-enemas, and then begin CIC. It is very rewarding to help a child with spina bifida to be out of diapers by school entry!

**Avoiding antibiotics in asymptomatic bacteriuria**

Asymptomatic bacteriuria is common in children with neurogenic bladder, and in the absence of reflux, there is usually no need to treat with antibiotics. Zealous treatment of bacteriuria leads to emergence of resistant strains, which are then harder to treat if symptoms should develop. Children with vesico-ureteric reflux should be on prophylactic antibiotics and CIC. Dipsticks for nitrites and leucocyte esterase are useful screens, and annual renal ultrasound examinations provide a non-invasive means of monitoring the upper tracts.

**Learning and attention problems**

Children with spina bifida as a whole score about one standard deviation lower on IQ tests than average, but there is great individual variability. Severe hydrocephalus and shunt complications may be associated with cognitive impairments. Verbal abilities are generally higher than non-verbal abilities. Visual-perceptual learning disabilities and attentional/organizational problems are rather common. Individualized educational planning and provision of special education and related services can be very helpful. The pediatrician’s role in these areas is outlined in AAP policy statements.

**Promoting healthy sexual adaptation**

Precocious puberty occurs commonly in girls with spina bifida and hydrocephalus, and may require endocrinology consultation. Spinal level may be related to sexual function in males, and male infertility is felt to be common. Around 70% of men with spina bifida report having erections, and contemporary surveys of teens and young adults provide encouraging evidence that intimacy and sexual relationships are attainable goals. Young people with spina bifida look to their doctors and clinics for information and discussion of sexuality.

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