Tell the truth about spina bifida

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The majority of children with spina bifida experience mental retardation, paralysis, and mental deficits. Many parents fear that their child with spina bifida will be mentally retarded, never walk, and suffer bladder and bowel incontinence. Physicians who routinely tell pregnant women that their fetus with spina bifida will be mentally retarded, never walk, and suffer bladder and bowel incontinence are ignoring a wealth of recent literature that contradicts this stereotype. Most of these children are intelligent, adaptable, and able to function well in society. Mirzai et al. comment, ‘The majority [of children with myelomeningocele] can have a normal IQ and a socially acceptable degree of continence and be able to walk.’

In brief, approximately two-thirds of children with spina bifida may reasonably expect to ambulate the majority of the time, although almost all ambulators will have lesions at L4 or below. Cochrane and coworkers reported that children they studied participated in hockey, dancing, swimming, basketball, horseback riding, wheelchair sports and competitions, golf and weight lifting.

INTELLIGENCE

After walking, the most common concern of parents with a newly diagnosed fetus with spina bifida is intelligence. Bowman et al. reported that 85% of the 71 young adults followed by their group were attending or had graduated from high school and/or college, and 63% attended regular classes. Forty-five percent were actively employed, and almost 10% worked as volunteers. Most of the 71 patients lived with their parents, although 11 lived independently and two were married. Mirzai et al. noted that 60% of their young adults had normal IQ and development. However, a normal IQ was seen in 76% without hydrocephalus. In McLaurin’s series, 70% had a normal IQ. Finally, Steinbok et al. observed that 58%
of their cohort attended public school, and were in the appropriate grade for their age. Clearly, most children with spina bifida are not 'mentally retarded'.

HYDROCEPHALUS

Historically, almost all newborns with spina bifida received shunts. For example, Steinbok et al. reported a 91% shunt rate in 101 children after a minimum follow-up period of 8.6 years, a rate almost identical to that of McLaurin. Cochrane studied 85 children with spina bifida and reported that 100% of infants (20/20) with lesions at L3 received shunts, as did 97% (30/31) with lesions at L4–L5, and 91% (31/34) with sacral lesions. Finally, data obtained from the International Myelodysplasia Study Group on 147 patients born between 1980 and 1997 with 'low lumbar' or 'sacral' lesions showed that 94% required shunts. Recent data indicate that these rates may be too high. The Children's Hospital of Philadelphia published shunt rates among 189 children treated for spina bifida between 1983 and 2000. One hundred percent (35/35) of children with thoracic level lesions received shunts, compared with 88% (100/114) of children with lumbar lesions and only 68% (27/40) of children with lesions confined to the sacrum. In recently treated patients, therefore, the upper level of the spina bifida lesion appears to be a major determinant of the need for shunt placement. Fewer neurosurgeons are automatically placing shunts at the same time as the spinal lesion is closed.

CONTINENCE

Although most parents recently informed that their fetus has spina bifida do not express great concern about bladder and bowel incontinence, the issue frequently arises in initial counseling. Bowman et al. noted that 85% of their young adults (60/71) used clean intermittent catheterization (CIC), and 90% of those (54/60) performed their own catheterization. For those patients on CIC, 15% always had urinary continence, 68% were dry the majority of the time (75–100%), and 7% were dry 50% of the time. Fifty-two percent of the young adults reported bowel control the majority of the time, and 52% reported 100% social bowel continence. Steinbok et al. reported 75% social continence of urine, defined as the ability to remain dry and odor-free without the use of a diaper, and 86% social continence of bowel.

THE TRUTH

It should be obvious from this brief review that while spina bifida results in a spectrum of disabilities, with comprehensive medical care most affected children will grow into young adults with normal intelligence, walking, and with social continence of both bladder and bowel. Certainly, a small number of affected children will experience devastating sequelae, but an equal number will be apparently normal, and prenatal imaging is becoming increasingly sophisticated in identifying the extent of disease and likely long-term outcomes. As Bliton and Zaner observed, 'From our discussions with these women and their partners, we came to recognize that ultrasound diagnosis of spina bifida was a momentous event for them that evoked a potentially devastating set of experiences.

Healthcare providers should not allow their own lack of knowledge to magnify their patients' fears of delivering a crippled child. We urge all those involved in prenatal care to learn the facts, and tell the truth about spina bifida.

REFERENCES