Transition to Adult Care for Patients with Spina Bifida

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KEYWORDS

• Spina bifida • Myelomeningocele • Adult • Transition

KEY POINTS

- Individuals with spina bifida have multisystem involvement, leading to complex physically impairing conditions.
- Individuals with spina bifida are living into adulthood.
- There is a tremendous need for adult-centered care for those with spina bifida.
- There are successful outcomes in transitional adult programs for individuals with spina bifida.

INTRODUCTION

Spina bifida (SB), Latin for "split spine," is a congenital disorder that results from the incomplete closure of the neural tube caudally. Individuals affected with SB may have multisystem involvement, leading to complex physical and psychosocial conditions.

EPIDEMIOLOGY

Closure of the neural tube is typically complete by day 28 of embryologic age; at this time, some women may not be aware of their pregnancy. Incomplete closure of the neural tube caudally results in SB. SB occurs worldwide and across all ethnic backgrounds, although certain geographic and ethnic groups may be predisposed.[1] There is an increased risk in certain populations, including Irish and other northern Europeans; although the genetic link is unclear, it seems to be related to altered folate metabolism.[2] In the United States, approximately 1500 babies are born with SB

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each year.[3] In the United States, Latina women have the highest prevalence of having a child born with SB in comparison with other ethnic groups.[4] The cause is unclear as to why Latina women have the highest prevalence, but it has been hypothesized that differences in dietary habits, supplement use, or social structure may play a role.[5]

The etiology of SB is multifactorial; however, some factors that may increase a woman's risk of having a child with SB include[6–9]:

- Family history of previous neural tube defect
- Folic acid deficiency
- Altered folate metabolism
- Exposures to certain medications (including valproic acid, carbamazepine, methotrexate and other folic acid antagonists, excess vitamin A, retinoic acid)
- Alcohol consumption
- Obesity
- Fever
- Maternal diabetes mellitus

Folic acid supplementation has been shown to lower the risk of having a child with SB.[10–12] In 1992, the United States Public Health Service recommended consumption of 0.4 mg of folic acid daily to women of child-bearing age to decrease the risk of neural tube defects.[13] In 1998, the US Food and Drug Administration mandated that folic acid be added to enriched grain products, such as cereals. Since the fortification of folic acid into grain products, the United States has had a 31% decrease in the prevalence of SB, from 5.04 babies affected per 10,000 births to 3.49 per 10,000 births.[3]

INTEREST IN ADULTS WITH SPINA BIFIDA

Medical and surgical advancements, such as antibiotics, ventriculoperitoneal shunts, and intermittent catheterization for the management of back closure, hydrocephalus, and neurogenic bladder respectively, have increased the survival into adulthood for patients with SB. From 75%[14] to more than 85%[15] of children born with SB survive into adulthood. With the increased longevity of children with SB new challenges arise, one of which is transitioning to adult-centered care. US Surgeon General C. Everett Koop, MD, was a strong voice for the rights of children with disabilities. In 1984, he cohosted a national conference focusing on the need for transitional care for older adolescents living with chronic childhood conditions. This conference brought the issue of health care transition onto the national radar.

Organizations such as the American Academy of Pediatrics (AAP) have published guidelines on transition of adolescent and adult care, and provision of a medical home for those affected with chronic childhood conditions, including SB.[16,17] This challenge has been recognized not only in North America but around the world, including Europe and Australia.[18,19] The First (2009) and Second (2012) World Congresses on Spina Bifida Research and Care brought together leaders in SB from more than 30 nations to share their experiences in different specialties and countries, and promote the development of new collaborative research ideas.

The Rehabilitation Act of 1973, the Individuals with Disability Education Act in 1975, and the Americans with Disability Act in 1990 improved integration and access for those with disabilities. In addition to the enhanced integration and access for those with disabilities, role models with disabilities and mentors have played a role in providing the sense of possibility and success.[20] Such an exemplar is Tatyana McFadden, 11-time medal winner in Summer and Winter Paralympics and the person

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