Spina Bifida

Symptoms or Behaviors

Each year, about 1,500 babies are born with spina bifida. Hispanic women have the highest rate of having a child affected by spina bifida when compared to other groups. Incidence fell noticeably in the 1990s when the FDA mandated folic acid fortification in some foods.

Spina bifida develops during the first month after conception – usually before a woman knows she is pregnant. Risk factors include a variety of environmental and genetic factors, such as folate/folic acid deficiency, family history of neural tube defects, maternal diabetes and obesity, and certain medications taken by the mother.

Spina bifida can occur in different forms. The mildest form, spina bifida occulta, occurs in approximately 40% of the U.S. population, but because of minimal symptoms, most are unaware of the condition. The other two types of spina bifida, meningocele and myelomeningocele, occur in approximately one out of every thousand births, with the latter having the most significant life-long implications.

About the Disorder

Spina bifida occurs prior to birth when the neural plate, a sheet of cells along the back of the fetus, fails to fully form when it develops into the neural tube. Spina bifida can occur in different forms: Spina bifida occulta, meningocele (muh-NING-go-seel) or myelomeningocele (my-uh-lo-muh-NING-go-seel). The severity of spina bifida depends on the type, size, location of the lesion and complications.

Spina bifida occulta: "Occulta" means hidden. The mildest form, spina bifida occulta results in a small separation or gap in one or more of the bones of the spine (vertebrae). Many people who have spina bifida occulta don't even know it, unless the condition is discovered during an imaging test done for unrelated reasons.

Meningocele: In a form of spina bifida called meningocele, the protective membranes around the spinal cord (meninges) push out through the opening in the vertebrae, forming a sac filled with fluid. But this sac doesn't include the spinal cord, so nerve damage is less likely, though later complications are possible.

Myelomeningocele: Also known as open spina bifida, myelomeningocele is the most severe form. The spinal canal is open along several vertebrae in the lower or middle back. The membranes and spinal nerves push through this opening at birth, forming a sac on the baby's back, typically exposing tissues and nerves. This makes the baby prone to life-threatening infections. Neurological deficits are usually present, causing paralysis of muscles in the legs and lower trunk area. Skin sensations may be impaired or absent, and bladder and bowel incontinence may be present.

In 70-90% of infants born with myelomeningocele, a structural anomaly in the brain known as a Chiari II malformation occurs, blocking the flow of cerebral-spinal fluid and resulting in hydrocephalus. This condition is immediately treated with surgical placement of a shunt, which relieves fluid buildup in the brain. Treated hydrocephalus can impact many aspects of development related to cognition, language and learning, as well as visual-perceptual and visual-motor functioning and executive functions. Social-emotional development may also be impacted by issues related to poor self-esteem, decreased motivation, and social isolation.

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Educational Considerations

- Visual perception problems which may cause difficulty with spatial discrimination, figure ground perception, and eye tracking
- Language difficulties in reasoning and comprehension, auditory decoding, and auditory association
- Inappropriate and bizarre language usage
- Reading problems in comprehension and content
- Math difficulty, especially affecting math reasoning skills
- Distractibility and inattentiveness
- Organizational problems
- Students with spina bifida may have abstract thinking difficulties. They need concrete beginnings/endings, need to experience materials, and to be an active participant
- Allow extra time to process questions and come up with answers
- Organizational skills and auditory/visual processing should be monitored
- Poor handwriting skills; may need written work modifications/accommodations and may need handwriting alternatives
- Sensory integration problems including late or non-established dominance, hand weakness, poor motor control, problems crossing midline, poor kinesthetic and tactile feedback, tactile defensiveness, and postural insecurity
- May need support to develop independent self-care skills and a consistent bowel/bladder management plan (this may include catheterization performed by school personnel and/or student)
- Will need frequent change in positions to avoid development of pressure sores
- School staff should recognize and accommodate the need for frequent absences due to medical appointments, procedures, and surgeries
- School personnel should be aware of the necessary medications and their side effects
- School staff should be aware of the signs of shunt malfunction/infection
- Speech Language Clinician may be involved to help with language development
- Often need involvement from OT/PT/DAPE staff

Resources

Spina Bifida Association (SBA)
http://spinabifidaassociation.org/resource-directory/learning-education/

SBA National Resource Center: Educational Issues Among Children with Spina Bifida (PDF)
http://spinabifidaassociation.org/wp-content/uploads/2015/07/Educational-Issues-Among-Children-with-Spina-Bifida1.pdf

Centers for Disease Control and Prevention (CDC)

Spina Bifida Fact Sheet
https://www.cdc.gov/ncbddd/spinabifida/facts.html

National Institute of Neurological Disorders and Stroke

Chiari Malformation Fact Sheet
https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Fact-Sheets/Chiari-Malformation-Fact-Sheet

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