Spina Bifida

Background

Spina bifida is a birth defect that occurs when the spinal column does not form properly, leaving a portion of the spinal cord and spinal nerves exposed through an opening along the back. This incomplete development is a neural tube defect that occurs during the first month of pregnancy. Nerve damage causing weakness and loss of sensation below the defect is determined by the location of the lesion along the developing spine.

There are different types of spina bifida ranging from mild to severe. A myelomeningocele is the most severe form that occurs when a portion of the spinal cord or nerves are exposed through an opening in the spinal cord. When people refer to spina bifida, most often they are referring to myelomeningocele.

Most children born with a myelomeningocele will have changes in their brain structure, bowel and bladder, and physical mobility. Complications may include Chiari malformation, hydrocephalus, seizures, poor eye-hand coordination, incontinence, constipation, and scoliosis. Children with spina bifida commonly experience learning disabilities, especially in attention span, memory, organization, sequencing, and problem-solving.

Exposure to latex does remain a concern as many children with spina bifida are allergic to products that contain latex. School staff should be educated on exposure risk and avoidance strategies for latex-containing products.

Treatment options for spina bifida are initially focused on the surgical repair of the lesion (in utero or shortly after birth), then management of co-occurring conditions. Some children with SB will need surgeries for problems with their feet, hip, and spine.

Management in school could also include bowel and bladder support. Students may have a daily bowel regimen that is completed each evening at home. Even in patients that are continent, it would be helpful for school to have supplies readily available for any accidents.

Top Takeaways for School

Malformation of the spinal cord and its effects on the central nervous system can cause paralysis and other extensive secondary medical conditions.

Spina bifida can affect a part of the brain causing neurobehavioral issues. Executive functioning tasks like planning, organizing, and problem-solving may be difficult. Difficulty with executive function can also affect the student's motivation for things like self-care.

Despite physical mobility needs that may require the use of assistive devices or orthotics, students may appear fidgety and restless in class due to poor impulse control.

Poor eye–hand coordination and depth perception may make tasks like reading, writing, and other fine motor skills difficult (e.g., learning to grasp urinary catheter for self-catheterization).

Reinforcing safe urinary catheterization practice can promote independence such as dictating step-by-step instructions, participating in gathering supplies, or learning to self-cath.

Latex-containing products in a school environment should be avoided. Consider items such as art supplies, erasers, rubber bands, science lab materials, rubber mats, flooring, balls and other gym equipment.

Considerations for the Individualized Healthcare Plan (IHP)

- Nursing diagnoses: Risk for disturbed sensory perception, impaired physical mobility and impaired thought process
- Allergies or food restrictions (latex, latex-containing products)
- Elimination interventions and equipment (consider catheterization brand/system, French size, frequency, and cleaning techniques; location of procedure; level of assistance)
- Assessment of implanted medical device (consider location, date of surgical placement, and device-specific information)
- Use of specialized equipment, adaptive equipment, and orthotics
- Activity, positioning, transferring (consider precautions and/or restrictions)
- Skin check, pressure relief techniques
- Temperature regulation considerations in school setting and transportation
- Consider emergency action plans (EAPs) and emergency evacuation plans (EEPs) related to special health care needs, including staff education/training

Discussion Starters for the Educational Team

1. Would the student benefit from evaluations or assessments in any of the following areas: physical therapy, occupational therapy, speech and language therapy, assistive technology, adapted physical education, functional behavior, psychology, hearing and vision?
2. Would the student benefit from additional academic support and/or modified education (e.g., copies of notes, extra time, reduced workload, simplified instructions, alternative formats for presentation of material, 504/IEP)?
3. Can strategies be implemented to assist the student with executive function (e.g., plan, prompts, organizers, agendas)?
4. Does the student need support with gross or fine motor skills in the classroom?
5. Is the physical school environment safely accessible for the student's mobility needs (e.g., entry and exit, ramps, location of classes, access to elevator, doorways)?
6. Does the classroom environment support the student's needs and/or equipment (e.g., desk/seating options, maneuverability space, electrical outlets, flash pass for bathroom or nurse)?
7. Will staff receive education/training to implement the student-specific emergency plan?

Resources

Kennedy Krieger Institute: Center for Spina Bifida and Related Conditions
kennedykrieger.org/patient-care/centers-and-programs/center-for-spina-bifida-and-related-conditions

Spina Bifida Association
spinabifidaassociation.org/

For more information, please scan the QR code or visit: KennedyKrieger.org/SHNIC

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