



Society of Pediatric Nurses Department

Guidelines for Care of People with Spina Bifida☆☆☆

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Editor's Note

From time to time, SPN Department pages will provide readers with references or updates detailing best care practices or specific guidelines published by organizations or work groups focusing on various aspects of care to promote improved quality of life for the child and family. As more and more has been learned about the trajectory and potential long-term effects of the numerous congenital conditions the focus of care has gradually shifted from treatment of symptoms to prevention of untoward outcomes and providing resources directed to improving quality of life.

The concept that increasingly is being recognized as pivotal for enhancing quality of life for patient and family is coordination of care. The reality is that it truly does 'take a village' to support the multitude of needs these families present. No one organization or care provider can facilitate the various aspects of care required by the patient and family, rather there needs to be a partnership and open lines of communication among all involved. Embedded in this concept is the fact that guidelines are broad statements of desired outcomes but the implementation of these statements must be individualized to the situation. Each situation requires a different combination of resources based on presentation of the condition, age and developmental level of the child, caregiving skills and assets of family members, available community services, and communication and coordination skills of primary and sub-specialty care providers.

The following information shared by Patricia Beierwaltes provides an update based on the fourth edition of *Guidelines for the Care of People with Spina Bifida (2018)*. Multi-professional care with emphasis on patient/family centered care establishes the foundation for prevention of untoward effects and quality of life. The pediatric nurse, both inpatient and outpatient, is central to this process.

Spina Bifida is the most common, permanent, disabling birth defect. If you are a pediatric nurse, it is likely you have provided care for a child with spina bifida. Spina Bifida is a neural tube defect with an improperly formed spine and spinal cord. This birth defect may occur anywhere along the spine with resultant variability in the clinical picture. For

this reason, it is often called a "snowflake condition" as each patient is affected in a different way. The resultant impact affects neurologic structures and function, orthopedic structures and mobility, bladder function, bowel function, skin integrity, and many more healthcare issues. Because care of these patients and self-care become complicated with overlapping diagnoses, specific guidelines for care are essential but must also be individualized.

Driven by the need for improving quality of care and patient outcomes, Spina Bifida Association and the Centers for Disease Control (CDC) convened a steering committee to develop a plan for updating and expanding guidelines. Spina Bifida experts from around the world spent nearly three years developing the guidelines for care of individuals with spina bifida. Why did we invest so much time and energy into writing guidelines? The most important benefit of clinical practice

Table 1

Guideline topic areas.

System of care
Care coordination
Health promotion and preventive health care services
Prenatal counseling
Transition
Psychosocial context for self-management
Family functioning
Mental health
Self-management and Independence
Quality of life
Neuropsychology and neurosurgery
Neuropsychology
Neurosurgery
Mobility, orthopedics, and physical activity
Mobility
Orthopedics
Physical activity
Urology and sexual health
Men's health
Sexual health and education
Urology and sexual health
Women's health
Specific health issues
Bowel function and care
Endocrine "puberty and precocious puberty"
Endocrine and the use of human growth hormone
Integument (skin)
Latex and latex allergy in spina bifida
Nutrition, metabolic syndrome, and obesity
Sleep-related breathing disorders

☆ The mission of the Society of Pediatric Nurses is to support its members in their practice. One means of accomplishing this mission is to keep membership informed of innovative initiatives involving the board, committees, and members that promote research, clinical practice, education, and advocacy within the larger pediatric healthcare community. This department serves that purpose.

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Table 2
Age categories.

0–11 months
1–2 years 11 months
3–5 years 11 months
6–12 years 11 months
13–17 years 11 months
18+ years (adults)

guidelines is their potential to improve both the quality or process of care and patient outcomes (Grimshaw et al., 1995). Practice guidelines are “systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances (Lohr & Field, 1992).” Guidelines have the potential to provide concise instructions on how to manage a specific health problem (Woolf, Grol, Hutchinson, Eccles, & Grimshaw, 1999).

As there are so many overlapping conditions in spina bifida, the guidelines are divided into 25 topic areas. The topics are listed in Table 1. This format allows for focus on specific healthcare issues. Each topic is further organized into specific age categories as listed in Table 2. The guidelines offer concise instructions based on how to provide healthcare services for individuals with spina bifida. They are based on

the best evidenced-based and expert treatment available from birth into adulthood. Throughout the guidelines, there are cross-references to enhance the recommendations in the overlapping areas of concern.

The current guidelines are written for healthcare providers but may be viewed by individuals or caregivers of individuals with spina bifida. They offer a preventive approach to care that will guide those familiar and unfamiliar with spina bifida healthcare needs. These guidelines will build a more robust research agenda for spina bifida and impact outcomes. The Spina Bifida Association has a link to the guidelines: <http://spinabifidaassociation.org/guidelines>. Specific guidelines topics may be published at a later date in a White paper format by the authors of each area.

References

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