

Spina Bifida Guideline

Mobility guidelines for the care of people with spina bifida

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Abstract. The Spina Bifida Association (SBA) is the organization that represents the needs of the population with spina bifida (SB). They are tasked with advocacy, education, optimizing care, and providing a social voice for those with spina bifida. In response to the tenet of optimizing care they were tasked with developing up to date clinical care guidelines which address health care needs for those impacted by spina bifida throughout their lifespan. This article will discuss the SB Mobility Healthcare Guidelines from the 2018 Spina Bifida Association's Fourth Edition of the Guidelines for the Care of People with Spina Bifida.

Keywords: Myelomeningocele, spina bifida, neural tube defects, mobility

1. Introduction

The Spina Bifida Association (SBA) is the national organization in the United States representing individuals of all ages with spina bifida. One of the tenets of the SBA is to be the driving force behind providing the best care possible for this population. High quality best practice guidelines are a method to achieve this goal. Guidelines not only improve quality of care but provide a framework of standardized practice [1]. The Guidelines for the Care of People with Spina Bifida, as discussed here, followed a well-defined formalized process of development [2]. These guidelines are multifaceted; however this discussion is focused on aspects of mobility and how this impacts the health and well-being of those with spina bifida.

Mobility is defined as the ability to move within a person's environment including the home and community. Methods of mobility will be different for each individual based on multiple factors. Different approaches will need to be used based on functioning neurologic levels [3,4]. Some children will be ambulatory without assistive interventions while others will need bracing, assistive devices or wheelchairs to navigate the home and community. Mobility is a fundamental learning experience for young children. It is well known that the childhood experience of exploring their environment leads to enhanced cognitive and psychosocial development [5]. Children with spina bifida may have significant physical limitations that can impede this natural exploration and impact developmental progress. Health care providers recognize the importance of ensuring that young people with spina bifida have opportunities to engage in meaningful activities. In addition, mobility needs may change as an individual ages; therefore it is important for health care providers to factor in the aging process. Having clear mobility guidelines, based on clinical experience and evidence-based information,

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can provide practitioners across the country with the best tools to care for their patients.

2. Guidelines goals and outcomes

The goals of the mobility guidelines were both practical and aspirational and divided into the three areas listed below.

2.1. Primary

- Develop expectations for mobility based on age and neurologic level.
- Understand and utilize appropriate mobility devices and therapy interventions to optimize mobility across the age spectrum.

2.2. Secondary

- Reduce the threats and effects of pain, aging, neurologic deterioration, and obesity on mobility.
- Reduce risk of pressure injuries. (Integument (Skin) Guidelines)
- Maximize safe functional mobility and acquisition of developmental milestones for social and environmental exploration.
- Maximize safe and functional mobility for Activities of Daily Living (ADL), as well as, social, recreational, and pre-vocational/vocational goals.

2.3. Tertiary

- Understand how primary and secondary outcomes affect quality of life.

3. Methods

The mobility group was tasked with researching and developing guidelines of care for individuals with SB related to mobility across the age spectrum. This topic was in the previous set of guidelines and was identified by the SBA as needing an update [6]. The initial phase of this process included searching current and historical evidence-based research and recruiting clinicians/scientists with expertise in the identified topic area. The guideline development process for each topic group was well defined by SBA with timelines and working phases [7]. The mobility working group included physicians and physical therapists with a long track record

of clinical and research expertise. The first task for this group was to review the previous guidelines and the International Classification of Functioning, Disability and Health (ICF) model and then develop the mobility guideline goals and objectives (noted above). Since the team was geographically separated the majority of work was done via electronic media conferencing. The team was then tasked with developing clinical questions that would direct best care for the SB population. In addition to relying on clinical expertise, questions were developed and reviewed by a panel of consumers either with SB or family members of a child/adult with SB. They were then asked to rank the clinical questions based on importance to the population. It was extremely important during this phase of guideline development to get feedback from families and individuals so as to identify what is really important in their day to day life and to understand the long-term needs of the SB population from their perspective. The group could comment on the existing questions and were also able to propose new ones.

The next phase was to do a review of scientific literature that had been identified by the SBA executive committee as being relevant to mobility issues for individuals impacted by SB. It was necessary for the mobility group to use historical articles as they provided a framework for relating neurologic level to impairment and ultimately the mobility of an individual. They also had to use data on normal development related to social and cognitive outcomes in young children.

Phase 3 methodology is well described in the article by Dicianno et al. which reviewed the group consensus process and eventually led to the guidelines being submitted to the SB oversight panel [7].

4. Results

The literature review resulted in the team identifying 19 journal articles that were specific to mobility. There was limited research available for many of the topics, so the group had to expand the literature search to articles related to development.

In areas where there was limited information for guidance the team had to develop an expert consensus. When members could not reach consensus, the Expert Consensus Decision Pathway was used to achieve resolution [8].

5. Discussion

Movement is a basic human need for both survival

Table 1
The clinical questions developed by the mobility group

Age group from guideline	Clinical questions
0–11 months	<ol style="list-style-type: none"> 1. What are expected developmental milestones based on the early neurological exam related to motor skills? 2. If early mobility is delayed, do mobility devices improve developmental outcomes such as cognitive performance, social skills, and visual attention? Types of early mobility devices would include caster carts, pediatric cars, and age-appropriate manual wheelchairs. 3. Do such mobility devices help with contracture prevention?
1 year–5 years 11 months	<ol style="list-style-type: none"> 1. Does being overweight or obese impede the development of mobility? 2. Does a positioning/stretching program prevent contractures and how long does it need to be implemented? 3. What is the usual trajectory of gait development by neurologic level, including specific gait parameters such as cadence and efficiency? 4. What is the role of treadmill training on gait development and fitness? 5. What are the long-term consequences of walking with or without orthoses/crutches on the joints in the lower extremities and the spine?
6–12 years + 11 months	<ol style="list-style-type: none"> 1. What is the usual trajectory of mobility-based acquisition of skills on neurologic function? 2. What are the factors that influence the transition from ambulation to wheelchair mobility for different neurologic levels? 3. What are typical gait parameters and patterns for different neurologic levels? 4. What is the role of gait analysis to monitor gait and make recommendations to optimize function? 5. Is there a benefit of early use of forearm crutches or KAFOs to protect the knee joint from abnormal forces? 6. What is the impact of scoliosis on gait, transfers and wheeled mobility? Does spine surgery impact any of these variables? 7. In wheelchair users, are there signs of early shoulder or wrist wear and tear? Does early wheeling adversely or protectively affect upper extremity and trunk development? 8. What factors positively encourage independent mobility?
13–17 years + 11 months	<ol style="list-style-type: none"> 1. What is the role of gait analysis to monitor gait and recommend interventions? 2. Should forearm crutches or KAFOs be used to protect the knee when torque has been identified? When should they be instituted? Does early use prevent damage to the knee joint and prevent pain from developing? 3. What is the impact of scoliosis on gait, transfers, and wheeled mobility? Does spine surgery impact any of these variables? 4. What is the impact of linear growth on walking ability? 5. What factors influence the child's preference of wheelchair mobility over walking (for instance, energy efficiency, balance, and speed)? 6. What is the rate and pattern of loss of ambulation for community and household ambulators by neurologic level? Are there other main causes for loss of mobility besides pain, progressive weakness, growth, and obesity? 7. Are there benefits to using standing devices on ROM, bone health, and quality of life?
18+ years	<ol style="list-style-type: none"> 1. What is the rate and pattern of loss of ambulation, ability to effect transfers and wheeled mobility? What causes loss of mobility function (for instance, pain, obesity, aging, and fitness)? 2. Is there a role for gait analysis to monitor gait and optimize function (for instance, to assess joint torque and shear forces)? 3. What is the role of forearm crutches or KAFOs to protect the knee when valgus forces at the knee may cause long term knee pain? 4. Are there benefits to standing devices and walking therapy as an adult? 5. What is the role of physical therapy and fitness programs in maintaining mobility? 6. What factors impact mobility long-term (i.e., improving technique, shoulder strengthening, engaging in fitness programs, and other activities)?

and development. We no longer have to “run from the lions” but we still retain that need to move. Mobility, the quality or state of being physically mobile, characterizes a person's ability to move within their environment. The quality of mobility can be compromised to varying degrees in individuals with SB. We know that movement and mobility follow a predictable pattern of development and that impaired neurologic function will impact this process. Children with spina bifida have neurologic lesions that affect both motor and sensory function and can impact mobility [9]. Using this in-

formation clinicians can predict the level of mobility a person will ultimately be able to achieve. Therefore, understanding how neurologic lesions can impact mobility provides the context for an honest and directed discussion with families regarding that common first question of “will my baby walk?”

Early research in children shows that mobility impacts not only physical parameters but cognitive and psychosocial factors. Children need to move to develop. Typically, motor development is a head to toe process [10]. The baby must overcome gravity and learn

Table 2
Current clinical guidelines for mobility

Age group	Guidelines	Evidence
0–11 months	1. Assess neurologic and motor level using standardized assessment tools so there is a baseline to monitor for neurologic changes.	Clinical consensus
	2. Assess multi-domain developmental milestone progress using standardized tools.	Clinical consensus
	3. Refer to early intervention programs and implement physical and occupational therapy programs to optimize skill attainment in fine motor and gross motor domains.	Clinical consensus
	4. Maximize motor development using good body alignment with an emphasis on trunk control as a first key goal.	Clinical consensus [15,16]
	5. Use the “Back to Sleep, Prone to Play” model that emphasizes postural control acquisition as the foundation of movement. Focus on antigravity muscle activity that engages the trunk extensors before the trunk flexors. Lack of prone positioning is linked to developmental delays in typical infants and therefore has an impact on children with disabilities.	Clinical consensus [17]
	6. Provide a family-centered approach and, in conjunction with the family, develop strategies to incorporate mobility within the home environment and daily routine.	Clinical consensus
	7. Use casting, splinting, and orthoses to support and maintain alignment and movement. Monitor skin according to recommended guidelines.	Clinical consensus, See guidelines for Skin and integument
	8. Collaborate with orthopedic specialists to monitor for age specific musculoskeletal problems.	Clinical consensus and the Orthopedics guidelines
	9. Encourage weight-bearing activities daily to promote bone health.	Clinical consensus
1–5 years + 11 months	1. Assess neurologic level and strength changes using standardized assessment tools at each clinic visit. Monitor for changes in gait, sensation, bowel and bladder function, and musculoskeletal changes.	Clinical consensus [18]
	2. If the child is not pulling to stand, consider using a standing frame or mobility device to get him or her upright and weight bearing.	Clinical consensus
	3. Emphasize mobility options for all children including ambulation and wheelchairs. Make sure parents are aware that all children who have the potential to walk may have some delay in achieving this milestone.	Clinical consensus [19]
	4. Use appropriate bracing to assist weak muscles and protect the lower limbs from torque and shear forces.	Clinical consensus [20]
	5. Ensure proper wheelchair fit, posture, and technique in children who use wheelchairs, in order to reduce energy expenditure and promote long-term function.	Clinical consensus
	6. Have an understanding of options for durable medical equipment (DME) and consider current and future DME needs.	Clinical consensus
	7. Encourage weight-bearing activities daily to promote bone health.	Clinical consensus
	8. Collaborate with orthopedic specialists to monitor for age specific musculoskeletal problems.	Clinical consensus and the Orthopedic guidelines
6–12 years + 11 months	1. Assess neurologic level and strength changes using standardized assessment tools at each clinic visit. Monitor for changes in gait, sensation, bowel and bladder function, and musculoskeletal changes.	Clinical consensus [18]
	2. Discuss with families the benefits of the different types of mobility devices including ambulation aides and wheelchairs based on predicted mobility potential.	Clinical consensus [21]
	3. Monitor walking or wheeling ability with standardized outcome measures. Consider gait studies if ambulation is changing or information is needed on optimizing bracing.	Clinical consensus [22]
	4. Continue flexibility, range of motion (ROM) and strengthening exercises to maintain mobility goals, whether using ambulation devices or a wheelchair.	Clinical consensus [23]
	5. Teach independence in putting on and taking off orthoses.	Clinical consensus
	6. Educate child about the importance of physical activity to maintain flexibility, strength and health, especially during growth years and explore adapted physical education opportunities or recreational sports options with the family.	Physical Activity Guidelines [24]
	7. Start teaching children to be involved in their own care by educating them to watch for signs and symptoms of pressure injuries, fracture, and neurologic changes.	Clinical consensus, Self-Management and Independence Guidelines
	8. Ensure proper wheelchair fit, posture, and technique in children who use wheelchairs, in order to reduce energy expenditure and promote long-term function.	Clinical consensus [25]
	9. Encourage weight-bearing activities daily to promote bone health.	Clinical consensus
	Collaborate with orthopedic specialists to monitor for age-specific musculoskeletal problems.	Orthopedic Guidelines

Table 2, continued

Age group	Guidelines	Evidence
13–17 years + 11 months	1. Assess neurologic level and strength changes using standardized assessment tools at each clinic visit. Monitor for changes in gait, sensation, bowel and bladder function, and musculoskeletal changes.	Clinical consensus [18]
	2. Monitor ambulation or wheelchair mobility. If ambulation is declining, suggest alternate mobility options.	Clinical consensus
	3. Continue therapy or home programs to maintain mobility goals, emphasizing flexibility, ROM, and overall strengthening.	Clinical consensus
	4. Verify that the teenager knows how to check insensate skin, especially after activity, and how to ameliorate friction and pressure.	Clinical consensus, Skin and Integument Guideline
	5. Optimize gait with supportive orthoses or devices for balance. Monitor for torque forces on the joints or excessive forces in the upper body.	Clinical consensus [20]
	6. Explore the best mobility option with the teenager and have a frank discussion about the risks and benefits of all systems.	Clinical consensus
	7. Monitor for a secondary injury and, if identified, implement a prevention program. Areas at risk of secondary injuries for children who walk are the knees and ankles and the shoulders and wrists in those who use a wheelchair.	Clinical consensus
	8. Recommend therapy interventions to maintain mobility if there is a change in functional status.	Clinical consensus [26]
	9. Collaborate with orthopedic specialists to monitor for age specific musculoskeletal problems.	Orthopedic Guidelines
18+ years	1. Assess neurologic level and strength changes using standardized assessment tools at each clinic visit. Monitor for changes in gait, sensation, bowel and bladder function, and musculoskeletal changes.	Clinical consensus [18]
	2. Monitor walking or wheeling ability and check for factors that may negatively impact mobility.	Clinical consensus [26,27]
	3. Continue to discuss the benefits of being involved in physical activities.	Clinical consensus
	4. Continue with home programs to maintain flexibility, ROM, and strengthening as this will impact mobility.	Clinical consensus
	5. Optimize gait with supportive orthoses or devices for balance. Monitor for torque forces at the knee or excessive forces in the upper body.	Clinical consensus
	6. Teach adults with Spina Bifida about the systems of care related to mobility equipment and orthoses. Adults need to know how to identify who to call when they experience problems with their mobility devices, and the extent of their health insurance coverage and benefits.	Clinical consensus
	7. Educate adults on the importance of preventing loss of mobility (both ambulation and wheelchair) through the use of appropriate technique and maintaining a healthy weight and level of strength.	Clinical consensus
	8. Collaborate with orthopedic specialists to monitor for age specific musculoskeletal problems.	Orthopedic Guidelines

postural control. This may be impaired in children with spina bifida – therefore the guidelines around “back to sleep” and “prone to play” should be encouraged [11]. These early programs are essential for motor control and psychosocial development in all children, but may be even more critical for children with disabilities.

Functional postural strategies used in therapy are critical for early foundational elements of mobility. Developmental milestones in children with SB may be delayed or need adaptive strategies. At an age when a child should normally be sitting or standing the use of adaptive equipment is perfectly acceptable in getting them upright. Having an understanding of an individual’s potential will help guide therapists in defining strategies to facilitate movement.

Mobility can take on many faces including the use of a wheelchair as a way to navigate the environment. Based on the individual’s neurologic and functional level, early adoption of a wheelchair]may allow a child a capacity to explore their environment that might otherwise be compromised. The timing of when a person

may choose to transition to using a wheelchair for primary mobility is a very personal decision. However, individuals should be made aware that this option may enhance mobility and quality of life.

These guidelines were developed to help care providers and families optimize mobility across the age spectrum. Needs will change over time, but the benefits of mobility remain the same. Changes in mobility due to secondary complications or conditions, and the effects of aging and overuse are not well understood. Best practices that seek to understand and ameliorate threats to maintaining healthy mobility need to be developed through future research.

Below is a list of some known benefits of mobility:

- Contracture management
- Exercise: cardiovascular-respiratory effects
- Strength effects and endurance
- Community engagement/household mobility
- Bone density
- Bowel and bladder evacuation
- Facilitates ability to perform self-care activities

- Pressure reduction/redistribution
- Improve underlying pain
- Reduce stress

The guidelines related to physical activity and wellness are additional resources related to benefits from movement [12].

There are a number of validated measures that a clinician can use to assess mobility Scales such as the Hoffer scale, Dias Functional Mobility Score, Pediatric Neuromuscular Recovery Scale (Peds NRS), and spatiotemporal gait parameters in children with myelomeningocele (MMC) are just a few employed today. With the advent of actigraphy monitoring, movement and mobility are able to be quantified and correlated with these scales. The authors feel that measures to follow neurologic changes and track improvements should be used in clinical practice. Recent data has shown that orthotics and gait aides positively impact stride and oxygen consumption [13,14]. As we begin to understand these concepts, we can use this information to keep our patients with spina bifida moving longer and more efficiently.

6. Conclusion

Movement and mobility are often impaired in the SB population. The SBA has developed the current guidelines to help families and health care professionals optimize care by providing direction in approaching this population [2]. We celebrate victories and embrace challenges to advance the care and science of those with spina bifida. Further research will need to be done to improve our understanding of mobility and its physical and psychosocial benefits. Research gaps in secondary complications and medical conditions that impact mobility may provide insight on how to best manage mobility over time. Movement is fundamental to the human experience and we are entrusted to maximize a person's potential using the above guidelines.

Acknowledgments

This edition of the *Journal of Pediatric Rehabilitation Medicine* includes manuscripts based on the most recent "Guidelines For the Care of People with Spina Bifida," developed by the Spina Bifida Association. Thank you to the Spina Bifida Association for allowing the guidelines to be published in this forum and making them Open Access.

The Spina Bifida Association has already embarked

on a systematic process for reviewing and updating the guidelines. Future guidelines updates will be made available as they are completed.

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- Lisa Raman, RN, MScANP, MEd, former Spina Bifida Association Director, Patient and Clinical Services
- Jerome B. Chelliah, MD, MPH, Johns Hopkins Bloomberg School of Public Health

Additional acknowledgments

- Julie Bolen, PhD, MPH, Lead Health Scientist, Rare Disorders Health Outcomes Team, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention
- Adrienne Herron, PhD Behavioral Scientist, Intervention Research Team, National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention, Centers for Disease Control and Prevention
- Judy Thibadeau, RN, MN, Spina Bifida Association Director, Research and Services; former Health Scientist, National Spina Bifida Program, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention

Funding

The development of these Guidelines was supported in part by Cooperative Agreement UO1DD001077, funded by the Centers for Disease Control and Prevention. Its contents are solely the responsibility of the authors and do not necessarily represent the official view of the Centers for Disease Control and Prevention or the Department of Health and Human Services.

Conflict of interest

The authors hereby declare no conflicts of interest.

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