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**Pediatric Lumbosacral Myelomeningocele Assessment Toolbox**

While there is very little research or clinical guidelines on particular outcome measures for those with spina bifida, or more specifically lumbosacral myelomeningocele, there are many appropriate pediatric outcome measures that can be utilized by a physical therapist on this patient population. Using multiple outcome measures that cover various aspects of the ICF model will help provide a more comprehensive assessment and facilitate more appropriate intervention strategies.

1. **Peabody Developmental Motor Scales, 2nd edition (PDMS-2):** The PDMS-2 assesses the motor skills of children from birth to 71 months old.1 The gross motor section includes examination of reflexes, stationary activities, locomotion and object manipulation, and the fine motor section assesses grasping and visual-motor integration.1 The results can be compared to normative data of the current U.S. population by means of standard score, percentile ranks and age equivalents.2 The PDMS-2 has shown excellent test-retest and inter-rater reliability, as well as high concurrent validity with the Bayley Scales of Infant Development.2-3 This outcome measure assesses body functions and structures, as well as the activity domain of the ICF model, and would be appropriate in an outpatient setting.
2. **Functional Independence Measure for Children (WeeFIM)**: The WeeFIM consists of 18 items that measure functional performance in the areas of self-care, mobility, and cognition. Studies show the WeeFIM has excellent test-retest and inter-rater reliability, as well as good content and criterion validity.4 It is appropriate for children ages 6 months to 12 years old with developmental disabilities and has been utilized in children with spina bifida.1 The test has 18 items and is scored using a 7-point ordinal scale to indicate level of assist with each task, ranging from total assistance (score=1) to completely independent (score=7).4 This measure can be utilized in the inpatient setting, but would also be appropriate for spina bifida patients in an outpatient setting. The WeeFIM includes items on sphincter control,1 making it particularly relevant to children with spina bifida who often require intermittent catheterization and need to learn independence with self-care.
3. **Assessment of Motor and Process Skills (AMPS)**: AMPS considers the underlying motor and process performance skills required for ADL tasks. It is appropriate for individuals 3 years and older and has shown to be valid when used with individuals with developmental disabilities, including spina bifida.5 The AMPS is a standardized, highly sensitive measure of ADL performance.5 The AMPS has 82 ADL tasks with varying difficulty to choose from, and the PT observes the patient performing two of those ADL tasks.5 During the ADL tasks, the PT scores the patient’s performance on 16 ADL motor skill items and 20 ADL process skill items.5 AMPS skill items are scored based on independence, safety, efficiency, and ease of the ADL motor and process skill items that reflect the smallest observable components of ADL task performance.6 This outcome measure addresses body structure and function when examining components of motor and processing skills, but also falls under the activity and participation domains of the ICF model because it looks at overall ADL performance as well. The AMPS is a very specific outcome measure, but may be particularly helpful in spina bifida patients since evidence shows that these children not only have some motor deficits, but issues with processing as well.7
4. **Pediatric balance scale (PBS)**: Also known as the Pediatric Berg Balance Test, the PBS is a modified version of the well-known Berg Balance scale that can be used in school-aged children with mild to moderate motor impairment.8 The 14-item criterion-referenced measure assesses many of the functional activities a child with spina bifida must perform to safely and independently function within his or her home, school, or community, and include sitting balance, standing balance, sit to stand and stand to sit, transfers, stepping, reaching forward, reaching to the floor, turning, and stepping on and off of an elevated surface.8 Items are scored using a 0-4 scale, with 56 points being a perfect score.8 Minimal detectable change (MDC) and minimally clinically important difference (MCID) of the PBS have only been tested in children with CP, however, the PBS has shown excellent test-retest and inter-rater reliability in school-aged children with mild to moderate motor impairments.8-9 In those with lumbosacral myelomeningocele, the PBS would be most appropriate for those with lower-level lesions, such as L3 or lower, since hip flexor and quadriceps strength is needed to complete many of the items on the PBS. If the child is unable to complete or needs maximal assistance on a few items, it will not affect the validity of the results since there is an option to give a score of 0 for an item.
5. **Modified Six Minute Walk Test (6MWT)**: The original guidelines for the 6MWT were published by the American Thoracic Society in 2002, but in 2007 Geiger et al.10 published guidelines in the Journal of Pediatrics for administering a modified 6MWT for children aged 3 to 18 years old. The modified 6MWT assesses the child’s ability to ambulate at a self-selected speed and can help determine the child’s level of physical fitness and endurance.10 The child is instructed to cover as much distance as possible in six minutes by walking back and forth between two cones placed 15 to 20 meters apart.10 In the adult version of the 6MWT, the cones are placed 30 meters apart.10 The child’s heart rate should be taken at rest as well as immediately after the modified 6MWT, and the child’s score is recorded as the total distance covered in meters.10 In children with spina bifida, the smallest minimal detectable difference has shown to be 36 meters.11 The modified 6MWT can be very helpful for children with spina bifida as it can help determine if they will have the endurance for important daily activities, such as ambulating between classes during transition times at school, or if a manual wheelchair may be more appropriate. It can also help track progress being made in terms of fitness and cardiovascular endurance in children participating in exercise programs.
6. **Spina Bifida Health-Related Quality of Life (HRQOL-SB)**: Assessing quality of life in individuals with spina bifida is very important, since we know that children and adolescents with spina bifida have a reduced HRQOL compared to their peers.12 The Pediatric Quality of Life Inventory (PedsQL) is a very popular measure for assessing health-related quality of life, however, the HRQOL-SB was chosen because of it’s specific application and relevance to children with lumbosacral myelomeningocele. The HRQOL-SB addresses multiple domains: social, emotional, intellectual, financial, medical, independence, physical functioning, vocational and recreation.13 These domains show the questionnaire’s focus on activity and participation. The HRQOL-SB has good criterion validity, as well as test-retest reliability and internal consistency.13 There are two sets of questions, the first with 44 questions appropriate for children ages 5 to 13 years, and the second set includes 47 items appropriate for adolescents and adults ages 13 years and older.13 The HRQOL-SB can be filled out by the child with SB, the parent, or both.13 An outcome measure addressing quality of life in these individuals with spina bifida can help identify areas where the child or family is struggling and can provide insight into important things to address during physical therapy, certain community resources that may be helpful, and even may help facilitate a referral to another health discipline, such as a psychiatrist or counselor.
7. **Utrecht Pediatric Wheelchair Mobility Skills Test (UP-WMST)**: The UP-WMST is a newly developed 15-item validated outcome measure used to assess wheelchair mobility skills in children using a manual wheelchair.14 Most children with lumbosacral myelomeningocele will be able to ambulate with leg braces, but many will still need to use a manual wheelchair for longer distances and most will gradually rely more on wheelchairs for mobility as they get older.15 The UP-WMST has been studied in children with spina bifida and tests skills including forward and backward propulsion, turning, rolling on various surfaces, ascending and descending slopes, platforms and a doorstep, coming to a stop, opening and closing a door, and holding a wheelie.14 Each item is scored for the ability to complete it and each item is timed.14 This can be a great way to assess activity and participation domains of the ICF model, since activities like successful door opening and ascension of ramps are necessary for community integration.

Secondary Measures:

1. **School function Assessment (SFA):** The SFA is a good tool for the child’s school-based PT and is usually completed with the child’s teacher and other staff who regularly spend time with the child at school.1 The SFA measures the performance of functional tasks that affect academic and social aspects of school, including task supports in the form of assistance and adaptations needed, participation, and activity performance.1 This measure is criterion-referenced and can be used in children from kindergarten to sixth grade.1
2. **Spina Bifida Hips Questionnaire (SBHQ)**: The SBHQ is for those with spina bifida who have had a hip dislocation. This questionnaire evaluates the ADLs that are important to children with spina bifida and their families.16 The SBHQ has demonstrated excellent test-retest reliability as well as construct validity.16
3. **Spina Bifida Spine Questionnaire (SBSQ)**: The SBSQ is a valid and reliable questionnaire used to assess self-perception and overall physical function in children with spina bifida who have scoliosis.17 It has been shown to be particularly beneficial when used before and after scoliosis correction to assess treatment outcomes.17
4. **Timed Up and Go in Children (TUG-IC)**: The TUG-IC, also referred to as the modified TUG, is used to assess functional ambulatory mobility, including balance and difficulty turning during gait, in children with or without physical disabilities.18 Modifications from the standard TUG implemented to increase validity in the pediatric population include a smaller chair to accommodate hip and knee flexion at 90 degrees and a star on the wall 3 meters from the chair that is shoulder height for the child to touch before turning around.18
5. **Pediatric Symptom Checklist (PSC)**: The PSC is a quick 35-item screening questionnaire that is used to improve the recognition and treatment of psychosocial issues in children, specifically around cognitive, emotional, and behavioral problems. Adolescents with spina bifida are at a higher risk for anxiety and depression than their healthy peers,19 so this screen would be a great way to monitor the patient’s mental health.
6. **Tardieu Scale**: Some individuals with lumbosacral myelomeningocele will present with spasticity.20 The Tardieu scale differentiates contracture from spasticity and is preferred over the Ashworth scale for detecting discriminatory changes in tone due to interventions.20
7. **Wong Baker FACES Pain Rating Scale (WBS)**: WBS is a pain assessment scale validated in pediatric patients.21 Drawings of facial expressions represent severity of pain, starting with 0 “no hurt” and ending with 10 “hurts worst.”21 The child is supposed to choose the face that best depicts the pain they are experiencing.21

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