



From Challenges to Success: A Case Study of Functional Improvement in Pediatric Spina Bifida

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Introduction:

This case study examines the rehabilitation journey of Pooja, a 9-year-old girl with a significant medical history of spina bifida and hydrocephalus. Pooja underwent a VP shunt insertion at 12 days old to manage hydrocephalus and has since lived with her grandparents and younger brother. Despite her early challenges, Pooja's journey encompasses various interventions and adaptations to improve her mobility and functional independence.

Throughout her early years, Pooja received occupational therapy, physical therapy, and speech services, though not until the age of 3. She entered school three years ago, where she encountered moderate limitations in expressive and receptive language and cognition, necessitating full-time special education placement. However, her gross and fine motor skills have emerged as strengths, enabling her to maneuver her manual wheelchair independently and participate actively in school activities.

Despite her progress, challenges persisted, particularly related to her lower limb function and mobility. Pooja's past medical history includes bilateral hamstring releases and subsequent knee flexion contractures, posing obstacles to her mobility and upright posture. Additionally, her family's limited compliance with brace wear and ambulation outside of school further complicated her therapeutic goals.

This case study explores the multidisciplinary approach employed to address Pooja's challenges, including modifications to her orthotic management and increased family involvement. By analyzing the interventions implemented and their impact on Pooja's functional outcomes, this study underscores the importance of tailored rehabilitation strategies in optimizing the mobility and quality of life of children with spina bifida.

Case Description:

Pooja, 9 years old Significant History

Pooja's back was closed when she was 3 days old, and at 12 days, a VP shunt was inserted to control hydrocephalus. She was discharged to home and had no further complications. She lives with her grandparents and a younger brother and attended an early intervention program from 3 to 5 years of age where she received occupational therapy, physical therapy, and speech services. She did not receive early intervention services until age 3. Pooja entered school 3 years ago and travelled in her personal manual wheelchair, with no bracing.

Present Findings

Pooja has moderate limitations in expressive and receptive language and cognition. She is in a full-time special education classroom for children with similar learning challenges. Pooja is able to follow simple verbal directions. She is the only student in class with a physical disability. Her gross and fine motor skills are her strength, and she enjoys leaving class to push her wheelchair in the hallways, stand, and walk. She is catheterized in the school nursing suite two times daily.

Gross Motor Skills

She is able to transfer, with close supervision for safety, from her wheelchair to her classroom chair and back and to a couch in the nursing suite. She is impulsive and may forget to lock her chair or may be careless moving her legs. She also forgets to position her chair properly, as instructed, and requires cues. Pooja is able to propel her chair very well and steer it without assistance in multiple environments. In her chair, she easily keeps up with her classmates as they transition into and out of the building, to lunch and recess.

Passive Range of Motion

Last year, she had bilateral hamstring releases and was in long leg casts for 6 weeks. When the casts were removed, she remained with a 15-degree knee flexion contracture on the right, but the left knee extended to neutral. When she returned to school following the summer vacation, she had full passive ROM in both legs except for her knees, where she now lacks 40 degrees of extension (R) and 20 degrees extension (L).

Upright Mobility

After her casts were removed, she was fitted with an HKAFO and a butterfly pelvic band to maintain hip extension, and drop locks at the hip and knee joints. The ankles are solid and set at 90 degrees. She was taught to perform a hop-to pattern with all joints locked, using a posterior walker. Her grandparents were instructed in brace donning and doffing at the pediatric hospital where she receives her medical care. She has been coming to school with her walker and her braces and sneakers in a bag to be donned in school for ambulation training. Multiple calls to her family have produced no change in this routine. She and her family report that she is not wearing her braces at home either in the evenings or on the weekends. Pooja's grandmother expresses that donning the brace in the morning is difficult for her owing to lack of time. It is also not reasonable to request that the classroom staff place her in her brace. If the family sent Pooja to school wearing her braces, the school nurse was willing to remove them to perform her late morning catheterizing and put the braces back on her following the afternoon catheterization, but she is resentful that the family will not comply. It is also difficult to get a commitment from Pooja's grandparents that they will help her stand and practice walking after school and/or on weekends. Pooja receives a weekly physical therapy session in school, and her program consists of transfer training, gait training/practice walking, and a strengthening program for her trunk and upper extremities. Active and active assistive ROM is also performed, with an emphasis on knee extension. She is consistently able to ambulate with close guarding for a distance of approximately 500 yards before becoming tired. She likes to walk to the school nurse for a visit before returning to her class. Pooja's greatest challenge in upright appears to be her excessive right knee flexion contracture, which causes that leg to be relatively shorter than the left. This creates instability when she is upright because her weight bearing is predominantly on the left leg. She must overuse her arms for additional support. She also appears fearful when standing with her posterior walker unless she receives contact guarding for reassurance. Practice with an anterior-facing rollator walker provided the support she needed, and the walkers were switched.

Manual Muscle Testing

She has strong arms and trunk and the following bilateral lower extremity active muscle function: "Fair" hip flexion and adduction; "Poor" knee extension; "Poor" knee flexion; and "Trace" ankle dorsiflexion.

Action Taken

A conference call was held between the school-based PT, the PT staffing the spina bifida clinic, and Pooja's orthopedic surgeon. We decided to experiment, and the pelvic band of the brace was removed. The orthotist also added a 2-inch wedged shoe lift under the right shoe to compensate for her knee flexion and give her a flat surface for standing on her right leg. Pooja's grandmother was called and attended a clinic appointment to again receive instruction on donning and doffing Pooja's braces, and the suggestion to have Pooja wear them daily was repeated by the clinic therapist and physician. The grandmother expressed that the long leg braces (KAFO) were now much easier for her to manage. Additional information was given to alert her that Crystal is nearing adolescence, the time when she will be less likely to gain new upright skills unless her functional walking significantly improves. Pooja's grandmother left that appointment with a renewed commitment.

Results

Pooja is presently coming to school wearing her braces each day. She sits in class with both knees locked, thanks to the assistance of the classroom staff, to stretch her knee flexors on the right and to prevent further tightening on the left. Her legs are propped up on a small box as her wheelchair does not have elevating leg rests. She continues to walk with the therapist each week, and standing has been added to her daily program. She is positioned upright by the classroom staff in a standing box for up to 1 hour each day. It is much easier and quicker for them to lock her knees, and she only requires setup and supervision to pull up to stand. The staff also walks with her from her seat to the standing table and back. The standing box has a tray so she is able to participate in her class activities and desktop work. Because she has active, though weak, hip flexors, she is able to use a reciprocating pattern of leg movement, and the shoe lift has provided a better base of support and reduced her dependence on her arms for support. Her walking endurance has improved. She often switches to a hopping gait that increases her speed. She is able to maintain her trunk erect over her hips and does not flex forward. It is planned that the classroom staff will slowly increase her walking program and she will leave the classroom for longer distances, as they feel more comfortable. The goal is for her to walk twice a day to the nurse for her catheterizations rather than use her wheelchair. The nurse is now able to perform the catheterization without removing Pooja's braces, so it is faster and easier. Finally, a small picture card has been developed and is attached to her chair for easy access, to remind her of the correct sequencing of steps to set up and safely transfer out of her wheelchair. It also serves as a prompt to the staff, who help her. This adaptation has greatly improved her level of safety.

Conclusion

While the pelvic band was initially appropriate for her lesion level and lower extremity strengths, it appeared that its removal was a key to moving her forward in the standing and gait components of her therapy program. The removal of the pelvic band has not impacted her speed, endurance, or pattern of movement in a negative way. The classroom staff is more energized to be involved, and it is easier for them to assist. Her family has also increased their participation and compliance by sending her to school wearing her braces. Pooja is an exercise ambulator, and for the goals of maintaining her upright skills; weight control; leg, trunk, and arm strengthening; and cardiovascular function, this plan has been successful. If she had begun this ambulation program earlier in her life, her strength and motivation to walk might have resulted in a higher level of function. Continued effort will be made by the teacher, school nurse, school PT, and the clinic staff to encourage increased involvement at home, to have Pooja in her braces, and walking

on weekends and during extended holiday and summer vacations, at the minimum. If her walking skills improve, additional opportunities to walk longer distances and increased upright time can be added to her daily classroom routine.

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