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Underappreciated challenges to pediatric powered mobility – Ways to address them as illustrated by a case report

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ABSTRACT

Rehabilitation Engineering and Assistive Technology Society of North America (RESNA) has published a position paper strongly advocating powered mobility (PM) for children with severe physical limitations (Rosen et al., 2009). Many studies have established that there are gains in social skills and functional mobility. While PM can aid independence, there has been more emphasis on the improvements in socialization rather than the positive changes PM can make in a child's daily living. For example, Bottos and colleagues stated the quality of life did not change for the children in their study (2001). This could be an explanation for why insurance companies deny coverage for PM. However, without coverage for PM, these children face major barriers to mobility and accessibility, even if they are able to use PM at physical therapy. If they obtain PM at home through other funding, transportation still remains an issue. These barriers have not been addressed or only briefly mentioned. We present a case of a 2 years 10 months old boy with rachischisis (cervical level spina bifida) who had impressive gains in both functional communication and social skills through achieving PM.

ARTICLE HISTORY

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KEYWORDS

developmental disability; mobility; neuromuscular impairment; pediatrics; wheeled mobility aids

Introduction

It is now well established that children as young as 14 months can be trained to use powered mobility (PM). It has positive effects on their cognitive, social, and perceptual skills (Bottos, Bolcati, Sciuto, Ruggeri, & Feliciangeli, 2001; Jones, McEwen, & Neas, 2012). Most reports are nonspecific on the cognitive and language gains that were made by the children. Given how important mobility is for typical preschool children, it would seem obvious that it is also crucial for severely physically limited children (Adolph, Vereijken, & Shrout, 2003; Guerette, Furumasu, & Tefft, 2013). Nonetheless, insurers have been resistant to fund them, agreeing with Bray, Noyes, Edwards, and Harris that “provision of wheelchairs based on cost-effectiveness evidence is not currently possible” (Bray, Noyes, Edwards, & Harris, 2014, p. 309).

The changes PM made in expressive language, cognitive skills, autonomy, and physical gains (such as improved head and trunk control) for the child in this case report are a compelling case for why PM is cost effective for achieving global developmental skills. It illustrates clearly why preschool children should receive funding. Giving a child a functional life is the ultimate reason for medical support—including PM.

Case summary

We present a case of a 2 years 10 months old male with rachischisis, complete spina bifida without acrania, and Chiari II malformation with severe hydrocephalus. The condition, which carries a high risk factor for mortality, was diagnosed in

utero. He was a term infant. Intraventricular shunt placement, closure of the spinal defect, and skin grafting were completed in the first few days of life. He was Gross Motor Functional Measure (GMFM) Level V: characterized by severe limitations in head and trunk control, and all areas of motor function, causing dependence on a manual wheelchair (Palisano et al., 1997). His physical therapy evaluation noted weakness of his neck and trunk muscles (3–5 seconds of control) and inability to sit independently. He had severe kyphoscoliosis and hip flexion contractures of –40 degrees.

His upper extremities had limited shoulder abduction, limited elbow flexion, and wrist flexion contractures with tenodesis contractures of his hands. His thumbs were flexed and adducted into his palms. The tenodesis contractures allowed dependent placement of flat items, such as a cracker, in them. However, his hands had no ability to use an adapted joy stick.

A formal speech therapy assessment was done at 17 months using the Pre-School Language Scale-4 (PLS-4): an assessment designed to identify syntactic and semantic skills of preschool children (Zimmerman & Castilleja, 2005). It found an expressive language age equivalency of 14 months. He was attempting to approximate signs for *Mama*, *Daddy*, *please*, and *bye*. At 32 months, because he had not made any progress with spoken language, his expressive language was re-evaluated using the Communication Matrix. This is a parent questionnaire administered by a speech therapist designed to determine the levels of communicative behaviors used by children with severe and multiple disabilities (Rowland, 2011). He was assessed as functioning at

12 to 14 months for expressive communication. He was using screams and whines, turning his head away, saying *uh huh*, shaking his head *no*, and signing *more*. There had been no significant change in age level for expressive language over the 15 months between the two assessments.

Within a few weeks of the second assessment, the clinical determination was made that he had sufficient cognitive skills to learn powered wheelchair mobility (PWM). The clinical goal was to give him the perception of control. It was projected that this would stimulate language development and cognitive function, improve hand function to use switches, improve head control, and increase social skills. When the training started, he was very withdrawn and passive. The skilled physical therapist (PT) structured PM activities so that they would be positive for him—encouraging a sense of control. Therapy occurred once a week for an hour. The first goal was to motivate him because he was so passive. Mobility was first introduced by allowing him to sit with his mother in the wheelchair. She used the switches to take him for a ride, and he decided where they would go. As training progressed, the PT allowed him to make choices between activities. Successive sessions built upon and sparked interest for preferred activities. He started talking after previously only using vocalizations and gestures, he began progressing with expressive language almost immediately, and also began showing more independence. About 2 months after beginning training, he was discharged from speech therapy. His discharge summary stated he was “communicating his wants and needs using single words and some phrases with >75% intelligibility.” Post discharge, he continued to make rapid gains in his expressive language.

A Permobil K450 powered wheelchair (PW), with alternative drive controls beside his head for the right and left directions and a switch at his right hand to move forward, was ordered when he was 3 years old. The assessment was completed by the PT, who is a seating and mobility specialist. Due to his severe kyphoscoliosis, hip flexion contractures, and difficulty with breathing, custom molded seating was ordered. This gave him appropriate orthopedic support and facilitated breathing. It had recline and high–low tilt seating options. Custom thumb post splints were fabricated by the occupational therapist to allow him to use the switches.

The PT and the boy’s family, under the therapist’s guidance, let him learn-by-doing with the emphasis on keeping feedback positive but accurate. The therapist did not give specific directionality commands to the child such as “press the left button,” as children do not know right from left until school age. The child was able to control these seat functions with his left hand by pressing buttons, in addition to using two switches for wheelchair control with his right. The PT trained him to go right or left and to achieve veer. This allowed more effective driving. Although he had custom splints, the child preferred the switches to using a custom joystick.

Even though he was making excellent progress, obtaining a PW for this child was challenging. The PW was ordered by the Psychiatrist (MD) and the vendor. The PT wrote a detailed letter of medical necessity, which was signed by her, the MD, and the vendor. This was submitted with the prescription. Insurance coverage for the wheelchair was denied even

though he had documented developmental progress. Appeals in writing by the PT, formal doctor-to-doctor appeal, and an external review hearing (which the PT attended to advocate for him) were all denied. Thus, the family was only able to obtain funding for the PW through community support. This family sought funds through media (both television and print), social networking, sought online giving, and applied for grant funding. Since obtaining the PW, the child has become more articulate, has increased use of both hands, and has improved upper extremity movement.

Discussion

Training in PM gives a child who has been virtually immobile the chance to experience cause and effect. This is a key part of the everyday learning of typical children because it fosters problem solving abilities that are crucial to developing a sense of autonomy, among other important cognitive skills. Its absence is an under-appreciated deficit. A study conducted by Charlene Butler on children with severe disabilities gives additional support for the influence that PWM can have on various developmental skills. Four of the six children in Butler’s study had increased frequencies in communicative behaviors and physical interaction with objects after attaining a wheelchair. Moreover, spatial exploration increased for all six children (Butler, 1986).

For children with severe motor impairments, the development of spatial awareness is greatly hindered by not having the opportunity to use PM. As in the Butler study, increased verbal expression was also associated with experiencing PM by the child in this case study.

Another factor that should be considered is the effect of severely limited mobility on a child’s behavior. Prior to achieving PM, this child needed everything to be done for him. He was withdrawn and passive. Butler noted that not being able to master movement leads to a child “with a sense of helplessness and incompetence” (Butler, 1986, p. 325). Nolen-Hoeksema, Gergus, and Seligman found that “Helpless behaviors ... [and] depressive symptoms were significantly correlated with one another” (1986, p. 440). It is difficult to determine depression in a child who has physical reasons for passivity and withdrawal.

There is very little in the literature specifically regarding the effect of passivity on children. A study of nursing home patients assigned patients to two groups and controls. One group, given extensive assistance to complete a simple psychomotor task, did much worse than both the group given only encouragement (who exhibited the best performance) and the controls (Avorn & Langer, 1982). The patient’s rapid change from withdrawn and nonverbal to engagingly talkative after gaining PM strongly suggests that depression caused by passivity had a role in his previous lack of expressive language. Further study is needed into the role of the lack of a sense of control in the functional development of severely disabled children.

Another factor not considered is learned non-use (Deitz, Swinth, & White, 2002; Taub, Uswatte, Mark, & Morris, 2006). He is now able to use a joy stick due to limited but definite improvement in hand function. This progress

probably reflects improved opportunities to use his hands—giving him the neural feedback to start to learn how to use them.

Cost remains a compelling reason that more studies need to be done on training physically limited children in PWM—including the need for longitudinal studies. Until there is enough irrefutable evidence, cost will remain a major impediment to a child's attainment of PWM. A PW can cost between \$7,000 and \$25,000 (Carr Rehab Inc., personal communication, 28 January 2016) depending on specifications. Also, custom seating needs add to the cost of the PW for children with severe disabilities. For example, since the patient received his PW, his custom-molded back rest has been changed three times, and his switches have been replaced eight times, for a total of approximately \$8,100 in 2 years, in addition to the original cost of the wheelchair. Furthermore, the cost of maintaining the PW is estimated to be about \$3,500 per year as the patient grows. These costs hinder a child's ability to obtain PWM, and they merit the attention of insurance companies in providing funding (Carr Rehab Inc., personal communication, 30 September 2016).

Transportation and home accessibility modifications are also seldom discussed issues. PWM may be limited to the child's school—secondary to transportation limitations and poor home accessibility. A wheelchair ramp has an average cost of \$1,500 to \$2,500 (The Real Cost of a Wheelchair Ramp, 2016). The price of home adaptations is difficult to assess since it depends on so many variables. These are beyond the finances of most families with special needs children—leaving them few options.

New ways need to be found to address these other issues, but even use of a PW at school or during therapy can be effective. The child's functional gains in communication and social skills started shortly after he began PWM training, which was months before acquisition of his own wheelchair. Fortunately for this patient, the community provided a ramp, house modifications, and a modified van in addition to the wheelchair. It is unreasonable, as well as impractical, for parents to have to utilize this approach to funding. At the very least, PWM training and availability through school should be more commonly available.

Conclusion

It is important that children experience the developmental stimulation of achieving PM as early as possible. This case strongly suggests that PWM is effective for enabling preschool children's achievement of functional gains in communication and social skills. Attaining communication skills is imperative for children, as it “plays a vital role in children's sociobehavioral...development” (Spilt, Koomen, & Harrison, 2015, p. 193). Gains in social skills and mobility through PWM should be put in the context of gaining overall functional life skills. This patient improved greatly on many functional levels. His cognitive abilities to make decisions, interaction with peers, problem solving skills, talking, and motor gains (progressing from momentary head control to being able to sit independently) all made significant progress. He is independent in PWM and is achieving typical cognitive development for expressive and receptive language. He will be entering kindergarten with appropriate readiness skills and social interaction with peers. This has allowed him to engage and make efforts,

which then gave positive feedback that encouraged more efforts (Stott & Moyes, 1985). Development is a longitudinal process. Much longer term studies are needed than have been done so far to further demonstrate the importance of PWM to preschool children.

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