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ABSTRACT

Children with Rett Syndrome (RS) have neuromotor impairments that impact their mobility. Poor hand function among children with RS limits the selection of an assistive device for ambulation. **Purpose:** The purpose of this case report is to describe the process of selecting an assistive device for a child with RS to promote ambulation. **Method:** This single subject case reports on a 5-year-old girl with RS at a suburban mid-western early childhood special education setting. **Results:** The child in this case was able to walk the farthest distances with a metal toy shopping cart and then with an anterior facing four-wheeled walker. **Conclusion:** The outcome suggests that physical therapists and health professionals caring for young children with RS consider using a metal toy shopping cart to establish and practice ambulation prior to selection of a longer term, adjustable anterior facing walker like the one in this case report.

KEYWORDS

Ambulation, assistive device, physical therapy, preschool, Rett Syndrome

Rett Syndrome (RS) is a rare neurodevelopmental genetic disorder affecting 1:10,000 to 23,000 female births (International Rett Syndrome Foundation, 2013; Kozinetz et al., 1993). Children with RS may initially be diagnosed with hypotonic cerebral palsy (CP) or autism spectrum disorder (ASD) (Pizzamiglio et al., 2008), but the distinguishing clinical features of RS include typical development during the first 6–18 months of life followed by loss of hand skills, regression of motor and communication skills, and stereotypic hand movements (Downs et al., 2013; Fehr et al., 2011; Lotan & Ben-Zeev, 2006).

There is variability in RS presentation and genetics. In 95% of cases, RS is associated with a mutation on the MECP2 gene (Foley et al., 2011). The location of the mutation may determine the level of severity (Christodoulou & Weaving, 2003). Additional characteristics of RS include irregular breathing patterns (breath-holding, hyperventilation) when awake, abnormal muscle tone, growth retardation, and deceleration in head growth (Cass et al., 2003).

Children with RS have difficulty with transitional movements (i.e. moving from sitting to crawling, crawling, pulling to standing), independent standing and walking, and dyspraxia (initiation and coordination of movement, and establishment of a motor plan) (Lotan & Ben-Zeev, 2006; Lotan & Hanks, 2006; Pizzamiglio et al., 2008). As a result of these difficulties, children are referred to physical therapists (PT) and occupational therapists (OT) for gross and fine motor coordination, strengthening, facilitation of mobility skills, sensorimotor functioning, and adaptive equipment recommendations. When ambulation is a goal, PTs and OTs may work together on the selection of an appropriate assistive device for ambulation (e.g. canes, walkers, gait trainers). The purpose of this case report is to describe the process of selecting an assistive device to promote ambulation for a 5-year-old girl with RS at a suburban mid-western early childhood special education setting. This case adds to the evidence base and presents the complexity of RS in a firsthand clinical experience.

A literature search did not identify any published case reports on the selection of assistive devices for children with RS (or other disabilities) in a school setting. For children with RS, skills generally regress and stabilize within a range of time in four stages. Stage one is the onset of symptoms (0 to 18 months). Stage two is described as the rapid destructive phase (12 months to 4 years). Stage three is a period of stability (a plateau) along with the possible reacquisition of motor skills and ambulation (3 years of age to adulthood) (Foley et al., 2011; Lotan & Hanks, 2006). Finally, stage four is described as late motor deterioration (with limited mobility) (Lotan & Ben-Zeev, 2006). Encouragement of independent mobility is important at all stages as mobility is associated with advances in social, language and cognitive development in all children (Uchiyama et al., 2008).

Loss of walking skills in the second stage of RS can lead to an evaluation for use of an assistive device. The device selection depends on the physical environment of the school, student needs [e.g. the child's balance, body coordination, and hand use (grasp, strength, dexterity)], all of which are impaired in children with RS (Fehr et al., 2011; Lotan & Ben-Zeev, 2006). A prescribed device should also be age appropriate, so that it does not place children with RS at risk for teasing (Frankel et al., 2010; Heerey et al., 2005). Devices to consider include anterior (forward facing) walkers or posterior (reverse) walkers, canes, or gait trainers (Campbell, 1999). Gait trainers support the child at the trunk and do not

require as much hand function as walkers. The appropriate device for the child with RS will be one that is supportive enough to be safe, while maneuverable enough to encourage reacquisition of gait.

CASE DESCRIPTION

The child for this case is a 5-year-old non-verbal girl diagnosed with RS at age 28 months, who came to the attention of the first author at the age of 3.5 years. The child's parents provided informed consent for this University Institutional Review Board approved case report. Early intervention and outpatient physical therapy records indicate that the birth and early development history for the child was unremarkable until she was referred to PT at age 17 months due to gross motor concerns. According to testing using the Peabody Developmental Motor Scales, 2nd Edition (PDMS-2), gross motor functioning was at the 8–10 month level. She was creeping on hands and knees, but not pulling to standing at furniture. She could cruise if placed in a standing position, but was not able to walk independently. At 34 months of age, an initial school-based physical therapy evaluation reported her skills to have advanced to approximately the 15-month level (this was not validated with a standardized test). She was independently creeping, pulling to stand, and walking with a wide base of support on even surfaces. An outpatient physical therapy report stated that by 37–38 months of age she lost previously acquired skills for example, the ability to walk independently. At this stage she required 1–2 hand held assistance to walk on flat surfaces. She also lost the ability to creep or climb up steps and could no longer independently pull to standing or transition from sitting in a child sized chair to standing.

School based physical and occupational therapy services in her community preschool began at age 3 years. Based on this review of records this child's regressive period (stage 2) lasted from approximately 36 to 40 months of age. She was no longer losing skills when she entered the special education early childhood classroom setting at 4.5 years of age. Classroom functioning was described in the child's Individualized Education Plan (IEP) as needing “adult monitoring and physical assistance” throughout the school day for completion of classroom transitions, routines, and activities of daily living. She was transported to and from the classroom using a wagon, as she did not have a wheelchair. While in the classroom, she walked short distances with hand held assistance. When placed on hands and knees, she could crawl 5 to 10 feet. She sat in a chair unless an adult was helping her to walk or transition. This limited mobility affected her engagement with developmentally appropriate classroom materials, and impacted her ability to interact with her peers and participate in educational tasks and routines. Standardized test scores of her gross motor skills were not available, as none have been developed for children with RS.

The child also demonstrated decreased hand function in the classroom. When seated in a supportive chair or when standing with assistance, she demonstrated stereotypic hand movements including frequent hands to mouth or hands to hair. These movements would briefly subside during self-feeding, or upper extremity weight-bearing activities (crawling, standing at a support surface, pushing a cart). Functional hand use included self-feeding using a gross raking grasp to secure small snack items and bring them to her mouth. She was unable to sustain a grasp on an object for longer than 3–5 s before she resumed the stereotypic movements. Prior to her regressive period, she was reported as able to demonstrate a pincer grasp and had begun using a fork to feed herself.

In regard to the child's orthopedic status, she did not have scoliosis, although children with RS are prone to developing scoliosis in preadolescence (Ager et al., 2006). Using a universal goniometer, lower extremity passive range of motion measures included: bilateral hip external rotation of 90 degrees (45 degrees is typical), thigh-foot angle measurements of 25° on the right-hand side and 32° on the left (10° is typical for a child 5–7 years old) (Berryman Reese & Bandy, 2010; Staheli, Corbett, Wyss, & King, 1985), and ankle dorsiflexion of 0° bilaterally (20° is typical) (Sass & Hassan, 2003). Bilateral ankle valgus was also present. She demonstrated elbow and knee hyperextension in weight-bearing positions, indicating weakness in core muscle strength and extremities. Functional weakness was also observed during standing or assisted walking, as the child would become shaky when fatigued. Formal balance testing was not attempted, as she was unable to stand without support. Breath holding and hyperventilation were often demonstrated during ambulation or changes in position. When the child experienced breath holding during ambulation, she would stop walking until she could regulate her breathing again. If she experienced hyperventilation, she was able to continue walking, but her movements were recorded as labored.

The child received private physical therapy in addition to the school-based therapies. Outpatient PT was provided 45 min, one time per week. School-based PT was provided 30 min, 2 times per week. She also received OT, speech therapy, and special education services in the school setting.

During special education in the early childhood classroom setting, ambulation success was noted when she pushed a metal toy shopping cart with assistance for steering (Figure 1). Over a period of 2 months she progressed from walking 5 feet to distances up to 55 feet while pushing the sturdy (13 pound) cart with the same amount of adult assistance. She pushed the cart by either grasping the handle of the cart with both hands or resting the heels of her closed hands on the handle. Her hands would grasp the handle together for 2–3 s before one hand was brought to her mouth or hair while she continued moving forward. After several steps, she would switch hands, often while continuing to walk. She would frequently stop, adjust her posture and hands, and resume walking. She required close supervision due to her decreased balance and her inability to maintain her grasp.

Figure 1. Metal Toy Shopping Cart.

Due to the child's success pushing the metal toy shopping cart, a decision was made to select an assistive device (walker or gait trainer) for use at school. A gait trainer or walker could be adjusted for growth, provide more support if needed, and appear more socially appropriate as she entered

elementary school (Figure 2). Use of an assistive device had previously been considered, but rejected by parents and staff with the hope the child would regain independent walking.

Figure 2. Anterior Facing Four-Wheeled Walker with a Horizontal Bar and Lateral Hand Holds.

Intervention

The intervention was a series of assistive device trials. The trials were performed while the child was enrolled in the special education early childhood program housed within an elementary school. She attended the program four afternoons per week for 2.5 hr for the duration of the school year.

For this retrospective case report, school-based PT and special education records related to mobility were reviewed for data explaining the assistive device selection process over a 6-month period. At the time of the record review, the child had a school-based goal for walking school distances with an unnamed assistive device. The records described the type of device trialed, distance walked, level of assistance needed, and the therapeutic adjuncts used (orthotics, wraps). The device to be selected would need to allow the child to meet the school mobility demands, i.e. moving a distance of approximately 100 feet from the exterior door to the classroom 1 to 2 times per day, as well as classroom distances of 1 foot to 25 feet several times per day. Anecdotal comments from staff (teacher, speech and OT, paraprofessional) were collected during the writing of this case report capturing their opinions on suitability of the devices.

The assistive devices used during the trials were either property of the school district, loaned from a medical equipment vendor, or borrowed from a used equipment lending facility. The following toys, pediatric walkers or gait trainers were trialed for various lengths of time during the intervention: (1) a metal toy shopping cart, (2) an anterior/posterior gait trainer with chest support, (3) a posterior gait trainer with upper body supports and rotational handles, (4) an anterior/posterior gait trainer with a seat, hip and chest supports, (5) an anterior front-wheeled walker with lateral stationary handles, and (6) an anterior four-wheeled walker with a horizontal bar and lateral handholds. The anterior/posterior gait trainer with chest support, and the posterior gait trainer with upper body supports and rotational handles were selected based on clinical reasoning, taking into account the child's strengths, impairments, and previous successes. The anterior/posterior gait trainer with a seat, hip, and chest supports was recommended by the child's private PT and an equipment vendor who was familiar with the child. The two anterior facing walkers were selected based on their similarity to the structure and/or weight of the shopping cart.

Throughout the trials, the child's base of support limited her balance and forward progression while walking. In standing, her hips were abducted and externally rotated with marked external rotation of her tibias. She wore bilateral ankle-foot orthotics during all of the assistive device trials. Additionally, in all PT initiated trials she wore Theratogs™ TogRite strapping, based on recommendations from her private PT and parents. This wrapping method with Theratogs™ TogRite strapping was used to promote neutral lower extremity alignment during physical therapy sessions in order to meet the IEP goal of walking “school distances” with an assistive device. With the wrapping, the child was able to walk with forward facing hips, knees, and ankles while using the assistive device. Wrapping was not used during trials with the special education teacher as it was considered a skilled physical therapy service that only a PT could perform.

Steering of all the devices was challenging for the child. She needed supervision for safety and assistance with steering for all of the devices trialed. To assist with steering, a small loop of exercise tubing was tied to the front or side of the assistive device and gently tugged by the PT or special education teacher to help the child walk without bumping into objects. The loop was not tugged to initiate walking, only to assist with steering when the child was already moving.

For each trial in the intervention, a special education teacher or a PT measured the distance the child walked in a school hallway 1–2 times per day, during 10–15 min trials with each assistive device. Prior to use, each device (except for the toy shopping cart) was adjusted to the child's height by the PT or equipment vendor. The child was placed in standing at the device with assistance to place one or both hands on the device if needed. The pelvic or trunk straps were secured around the child when the child trialed each of the three gait trainers.

For the anterior facing four-wheeled walker with a horizontal bar and lateral handholds, the child grasped the walker at the front bar, rather than the hand holds. She was unable to maintain a grasp on the handholds of the walker at her sides due to her limited hand function associated with RS. However, she was able to hold/rest her fists on the front bar of the device. When the child was perceived to be secure and balanced in the walker or gait trainer, physical support by the PT was removed and she was encouraged to walk with the particular device and adult assistance for steering only when needed. The anterior four-wheeled walker with a horizontal bar and lateral handholds has a braking feature, which stops forward motion when pressure is applied to the handholds. This feature was not fully utilized since the child held onto the front bar and used it to maintain her balance, rather than the lateral handholds.

TABLE 1. Results for Assistive Ambulation Devices Trialed in Intervention

Device	Initiated walking	Number of trials	Longest distance walked (feet)	Reason for discontinuing use	Staff comments
Toy Shopping Cart	Yes	49	134	Continued using while trialing other assistive devices.	"Light weight and is easily maneuverable around the classroom and hallway"
Anterior/Posterior Gait Trainer with chest support	Yes, 1 out of 4 trials	4	8	Inconsistent ability to initiate gait and continue school distances.	"It seems that there is a lot of gait trainer around her preventing her from being close to her peers as well as tables for instruction and work time."
Posterior Gait Trainer with upper body supports and rotational handholds	Yes	15	10	Student had difficulty consistently initiating walking and was unable to maintain for longer distances.	"More light weight than mustang." "More approachable in this than mustang; kids could get next to her."
Anterior/Posterior Gait Trainer with seat, hip and chest supports	No	3	0	Unable to initiate walking.	"Prevents her from getting close to her peers and tables, as there is so much stuff around her."
Anterior front-wheeled walker with lateral stationary handholds	Yes	2	5	Discontinued as too light-weight for safe use.	"Not enough space for hands. Current handles do not work for her."
Anterior 4-wheeled walker with a horizontal bar and lateral handholds	Yes*	11	110	Purchased walker for permanent use.	"Light enough that an adult can pick it up to move it, but sturdy enough for her to use." "This walker has been utilized with ease within the classroom. She understands how to approach the walker and where to put her hands." "It is easy for any adult staff member to get her set up"

*Able to maintain open palm grasp for up to 17 s with one hand.

Measures

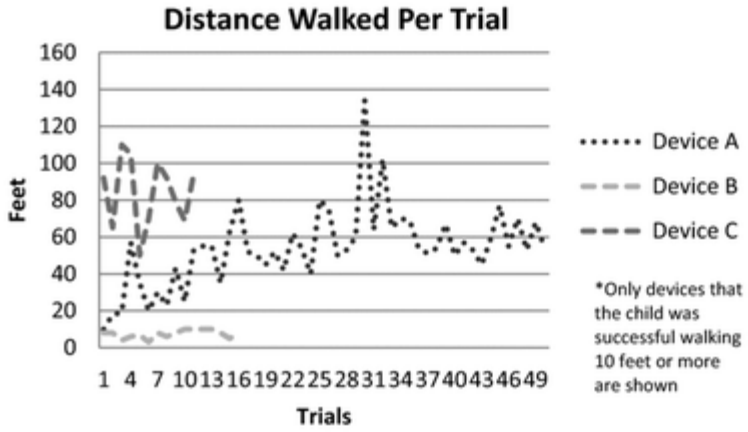
Measures included initiation of walking, the distance walked (number of 12 inch floor tiles covered) and a qualitative component that captured staff input on their reaction to the devices. The length of each trial of each device included practice time and was approximately 10–15 min. The trials occurred primarily in a straight school hallway on a tile floor to eliminate the need for sharp turns around classroom furniture and ambulation over carpeting. As the child became more successful with a particular device, additional practice occurred over classroom distances of 1 foot to 25 feet several times per day. If the child did not immediately begin walking at the beginning of a trial, she was verbally encouraged to walk and given 30 s of wait time for motor planning. If walking was not initiated at that time, PT facilitated initiation and continuation of ambulation for 10 to 20 feet, and then offered another opportunity for her to initiate mobility independently. If and when the child initiated walking, the longest distance of continuous walking was recorded as well per assistive device, the adjuncts used (wraps and/or ankle foot orthotics), and additional comments regarding the student's performance. Walking distance was measured by counting the number of 12 inch × 12 inch tiles walked over. The trial was discontinued if no walking occurred during the 10–15 min period.

Outcomes

Over the 6 month time period that records were reviewed for this case report, the child trialed six different devices. The initiation of walking, number of trials, longest distance walked, reason for discontinuing use and staff comments were recorded (see Table 1).

The number of trials varied from 3 to 49 times. The variability in the number of trials was determined based on availability of the assistive device and the child's success with it. The anterior/posterior gait trainer with a seat, hip, and chest supports was only trialed 3 times (unsuccessfully), as she was successful with more readily available devices. The distance walked per trial across devices was recorded and compared across devices. It ranged from 0 to 134 feet (see Figure 3).

Figure 3. Distance Walked Per Trial.



Device A = Metal toy shopping cart

Device B= Posterior gait trainer with upper body supports and rotational handles

Device C= Anterior four-wheeled walker with a horizontal bar and lateral handholds

The child continued to use the toy shopping cart while alternative devices were trialed. The child received 11 trials with the anterior four-wheeled walker with a horizontal bar and lateral handholds. Trials were discontinued once she was able to walk 100 feet. Due to the child's quick success with this assistive device, the school district purchased the anterior four-wheeled walker with a horizontal bar and lateral handholds for the student's permanent use in the school setting.

DISCUSSION

The purpose of this case report is to describe the process of selecting an assistive device to promote walking for a 5-year-old girl with RS. Physical Therapy records were reviewed and showed that a metal child-sized shopping cart and the anterior facing four-wheeled walker with a horizontal bar and lateral handles best fostered the child's mobility. The shopping cart allowed the child to practice ambulation and utilize her limited hand function prior to transitioning to the more permanent device.

The anterior four-wheeled walker with horizontal bar and lateral handholds was deemed the appropriate device for the child for several reasons. First, it capitalized on her available hand function by allowing her to grasp or rest her hand(s) on the horizontal bar while standing or walking. The bar on the front of the device had a square shape compared to other walkers with a round bar. Even with her limited hand function, the child was able to maintain a grasp on this square bar, while she had trouble holding onto round bars. Of note, records reveal that the child's ability to grasp the bar of the shopping cart or the anterior four-wheeled walker with a horizontal bar and lateral handholds improved from 3–5 s to 15–17 s over the 6-month time period assessed in this case report. This increase in grasp could be important for carry-over into other life skills such as static standing while holding onto a support, or grasping writing or feeding utensils.

Second, the walker provided the stability the child needed to compensate for her decreased balance, and adapted for her increasing growth as she progressed through elementary school. It was similar in weight and height to the toy shopping cart she had used successfully.

Third, the walker was small enough to be used successfully in the classroom, while the anterior/posterior gait trainer with chest support, the posterior gait trainer with upper body supports and rotational handles, and the anterior/posterior gait trainer with a seat, hip and chest supports were used mainly in the hallway. These larger assistive devices provided the needed support, but limited the child's movement due to their size and weight. In the event that the child had not been successful with a smaller device, a larger device could have been utilized with adult assistance for the purpose of exercise and its health benefits.

Fourth, the comments by the child's teacher, paraprofessional, occupational and speech therapist were positive for the selected assistive device. During the writing of the case report staff recalled that it was easy to use.

Although selected, the anterior four-wheeled walker with a horizontal bar and lateral handholds had limitations. The first limitation was that the child needed direct supervision at all times during the intervention trials. Supervision was needed for safety reasons as her trunk was not secured to the walker as it would have been in a gait trainer or walking aid. The walker also lacked a brake that could be applied for standing activities, such as donning and removing her coat and backpack during daily

school routines. A second limitation was that the walker required a posture of trunk flexion during ambulation. Trunk flexion may exacerbate scoliosis, which may develop in children with RS during preadolescence (Ager et al., 2006). Thus scoliosis monitoring is indicated. Thirdly, therapy records indicated she had previously trialed a posterior walker, but was unable to maintain a grasp on the lateral handholds at that time. Given her quick adaptation to an anterior walker and the improved grasp noted during this case report, a posterior walker may be a future option.

In terms of limitations of the case report, the single subject description limits the generalization of the results. Because the report was a record review, it limited the type and amount of data that could be described. The child did not receive an equal number of trials for each device and she did not wear the Theratogs™ TogRite strapping for every trial. Distance walked with and without the strapping was similar, although the quality of her gait was improved (neutral hip and tibia alignment) with the strapping. It may also be beneficial to know the measurements of other spatial and temporal gait characteristics during the trials, and if there were quantifiable improvements in transitional movements and hand function.

While walking distance measured in feet improved with time, patience, and practice for the child in this case, the frequency of intervention trials clearly contributed to success with the walker. The walker was used by the school staff in addition to the PT sessions, allowing for more opportunity for practice. This additional practice facilitated the establishment of a motor pattern, which is important for children with dyspraxia associated with RS (Lotan & Ben-Zeev, 2006). Foley et al. (2011) found that teenagers and women who maintained their ability to walk over a 3–4-year period were less likely to lose complex gross motor skills (e.g. transitioning to standing, bending to touch the floor, stepping over an obstacle, walking up a ramp) than younger girls with RS. Children with RS need to continue to attempt ambulation in order to retain the strength, coordination, and endurance for an active adulthood.

Although the findings in this retrospective case report cannot be generalized to other children with RS, they do add to the evidence base and help present the complexity of RS in a firsthand clinical experience. PTs, OTs, and other health professionals caring for young children with RS can consider using a metal toy shopping cart or similar device to practice ambulation prior to selection of a longer term, adjustable forward facing walker. Further research is warranted in the area of assistive devices and gait training for children with RS in the school and community setting. Given the benefits of mobility on cognition, socialization, and communication for all children (Uchiyama et al., 2008), future studies could explore the barriers and opportunities for children with RS using assistive devices in the school environment.

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