Improvements in Function Following Inpatient Activity-Based Therapy for Children With Acute Flaccid Myelitis

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Background: Acute flaccid myelitis (AFM) is an illness defined by rapid onset of flaccid paralysis in one or more limbs or bulbar muscles, with MRI findings of predominantly spinal cord gray matter abnormalities spanning one or more spinal segments following a viral illness. Individuals with AFM may require rehabilitation to promote recovery. Activity-based restorative therapy (ABRT) has previously been shown to result in positive outcomes in children with neurologic deficits related to AFM. **Objectives:** This study examined functional changes in a group of children with AFM who participated in ABRT in an inpatient setting. **Methods:** Retrospective chart review of children with AFM admitted to a single inpatient rehabilitation unit from 2014 to 2018. Children were assessed using the Functional Independence Measure for Children (WeeFIM), Manual Muscle Testing (MMT), Spinal Cord Independence Measure (SCIM), and the Physical Abilities and Mobility Scale (PAMS) as part of routine clinical care; the Modified Rankin Scale for Neurologic Disability was completed retrospectively. **Results:** Children showed significant improvements across all outcome measures, with effect sizes ranging from moderate to large. Significant change was also seen across all muscle groups on MMT, with effect sizes ranging from small to large. Consistent with previous reports, children demonstrated better function in distal than proximal muscle groups at both admission and discharge. **Conclusion:** Children with AFM who participated in ABRT increased muscle strength and made functional gains across all outcome measures. These results support the utility of rehabilitation in the long-term care of children with AFM and residual neurologic deficit. **Key words:** activity-based therapy, acute flaccid myelitis, functional outcomes

Introduction

Acute flaccid myelitis (AFM) is an illness clinically defined by rapid onset following a viral illness of flaccid paralysis in one or more limbs (and sometimes bulbar muscles), with magnetic resonance imaging (MRI) findings of predominantly spinal cord gray matter abnormalities spanning one or more spinal segments.¹ The Centers for Disease Control and Prevention (CDC) standardized case definition utilizes both clinical (acute onset of flaccid limb weakness) and laboratory criteria (MRI and cerebrospinal fluid characterized by pleocytosis). AFM affects mostly children, with biennial peaks of occurrence since 2014.^{2,3} The etiology of AFM is presumed to be viral (enteroviruses: EV-D68, EV-A71; flaviviruses: West Nile, Japanese encephalitis, adenoviruses, herpesviruses, etc.). Although a definitive causal link has not yet been established, accumulating clinical and epidemiological evidence points to EV-D68 as the agent causing the recent

seasonal childhood AFM outbreaks in the United States.⁴

Up to 41% of affected children are reported to have full recovery or minimal residual focal neurological deficits at 1 year, and continued recovery has been documented for up to 77 months from onset.⁵⁻⁹ In 2019, Bove and colleagues¹⁰ published descriptive outcomes of 167 children affected by AFM at a mean of 2.4 years post neurologic injury onset (69% of children were over 6 months from onset); only 2.44% ($n = 2$) were reported to have returned to preinjury status, 14.63% ($n = 12$) reported “some deficits, hardly perceptible unless you look,” 45.12% ($n = 37$) reported that the deficits continue to limit their child’s ability to do what they would like, and 37.80% ($n = 31$) reported their child’s ability to participate in daily activities has changed dramatically. The study also indicated that 75% of the children had residual arm paralysis, 60% had residual leg paralysis, 58% reported deficits in

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Top Spinal Cord Inj Rehabil 2020;26(4):275-282
© 2020 American Spinal Injury Association
www.asia-spinalinjury.org
doi: 10.46292/sci20-00010

walking, 12.4% had residual facial paralysis, 15.5% had dysphagia, 29.5% had continued neck weakness, 58% had pain, 21.7% had respiratory deficits, 52.7% reported significant persistent fatigue, 24% were diagnosed with osteoporosis, and 29% had residual bladder and bowel issues. Between 25% and 40% required support from a ventilator during the most severe illness, and 10% to 20% were estimated to have persistent ventilator requirement at the time of follow-up.

Individuals who do not make a full recovery may require rehabilitation, often consisting of physical, occupational, and speech therapy to optimize their recovery. Activity-based restorative therapy (ABRT), a therapeutic approach using repeated, near normal levels of both patterned and nonpatterned movement to recover function lost to neurological injury, has been previously shown to result in positive outcomes in children with neurologic deficits related to AFM.^{5,11} This study examined functional changes in a group of children with AFM who participated in ABRT in an inpatient setting.

Methods

Retrospective chart review was completed for all children diagnosed with AFM admitted to a single inpatient rehabilitation unit. Inclusion criteria for the purpose of this review consisted of children under the age of 18 who met CDC criteria for AFM diagnosis, who completed their bout of care between 2014 and 2018, and who had a length of stay longer than 2 weeks. Of the 32 children diagnosed with AFM admitted to the inpatient rehabilitation unit during that period, 29 met the criteria (three had shorter lengths of stay). Clinical information was gathered by retrospective chart reviews to obtain demographics and scores from standardized testing. The institutional review board approved this study.

Rehabilitative interventions

All children received 1 to 2 hours of occupational therapy (OT) and 2 to 3 hours of physical therapy (PT) 5 days a week and 2 hours of therapy on the weekend for the duration of their admission. Other inpatient rehabilitation interventions included the following additional disciplines as needed:

speech therapy, behavior psychology, child life play, recreational therapy, and neuropsychology. PT and OT treatment sessions were structured to include interventions in each of the five key components of ABRT^{11,12}: functional electrical stimulation (FES),^{13,14} locomotor gait training (LT),^{15,16} massed and task specific practice,^{17,18} and weight loading.

Twenty out of 29 children in this study utilized lower limbs FES cycle ergometry for 30 to 60 minutes per session, and 15 utilized upper limbs FES cycle ergometry for 25- to 35-minute sessions, two to three times per week. One child was unable to perform standardized cycling of lower limbs due to small size but received reciprocal patterning FES from the cycle without legs attached to pedals while participating in lower limbs play and kicking. Electrical stimulation using handheld devices paired with functional tasks was provided a minimum of 2 hours a day; the intervention focused on providing input to limbs and trunk muscles typically firing during therapeutic tasks. FES interventions in children with AFM are more challenging given the lower motor neuron injury and intact sensation limiting response and tolerance to stimulation. Typically, the most successful applications of FES in the presence of lower motor neuron injury is utilization of a low frequency, long pulse width stimulation, which overcomes the greater refractory periods of the injured nerve.¹⁹ Upper and lower limb weight loading was performed daily during the structured rehabilitation interventions for 30 to 60 minutes per session. Because children with AFM typically present with decreased strength proximally as compared to distally, caution was taken to provide optimal joint alignment and avoid pathologic torque on joints during the weight-loading activities. Of the 29 individuals, 15 were appropriate for and participated in LT; children were considered appropriate for LT if they demonstrated tolerance to upright standing (i.e., no signs of autonomic instability such as dizziness, sweating, change in heart rate or blood pressure if being monitored), had no joint contractures limiting range of motion required for stepping, and were able to tolerate and participate in facilitated stepping. LT included 30 to 60 minutes of treadmill training with body weight support and facilitation at the hips and lower limbs for reciprocal stepping and

standing activities. Treadmill speed was dependent on child's step length and age, typically between 1 and 1.4 miles per hour for children 3 years old and younger and between 1.4 and 1.8 miles per hour for older child. Body weight support was chosen to optimize weight bearing through the lower limbs. Treadmill sessions were followed by an additional 30 to 60 minutes of mobility activities, adjusted for each child's developmental age and physical ability, including standing in or out of supported standing frames or body weight support, ambulation with or without body weight support, crawling, sitting, or standing balance activities. Nineteen of the 29 children also participated in aquatic therapy; eight were unable to use the pool due to requiring ventilator support, one due to scheduling conflicts, and one due to age-appropriate inconsistent bowel continence.

Outcome measures

All outcome measures were administered at admission and discharge by trained therapists as part of routine clinical care. Children were assessed using the Functional Independence Measure for Children (WeeFIM), Manual Muscle Testing (MMT), the Spinal Cord Independence Measure (SCIM), and the Physical Abilities and Mobility Scale (PAMS). Additionally, the Modified Rankin Scale for Neurologic Disability (mRS) was completed retrospectively. Some outcome measures were not utilized with every child due to age or ability to participate in testing.

The *Functional Independence Measure for Children (WeeFIM)* is an 18-item scale evaluating functional independence; it yields a total score and subscale scores for mobility, self-care, and cognition.²⁰ WeeFIM Developmental Functional Quotients (DFQs) were used to account for the effect of age on WeeFIM scores for children younger than 7 years; DFQs reflect a percent of age-appropriate functioning. Individual WeeFIM items are rated on a scale from 1 (*complete dependence*) to 7 (*complete independence*), and total DFQs can range from 14 to greater than 100.^{21,22} DFQs under 30 represent complete dependence or maximal assistance, DFQs between 30 and 85 represent partial independence, and DFQs above 85 reflect modified or complete independence.²³ The WeeFIM is commonly used in

inpatient rehabilitation settings and has been well validated across patient groups, including spinal cord injury (SCI).^{24,25}

Manual Muscle Testing (MMT) scores were obtained for the following muscle groups: shoulder flexion and extension, elbow flexion and extension, digit flexion and extension, hip flexion and extension, knee flexion and extension, and ankle dorsiflexion and plantarflexion. The traditional 5-point scale was used for clinical care.²⁶ For the purpose of analysis, scores were transformed by adding 0.25 for a plus score and subtracting 0.25 for a minus score. For example, scores of 3+ and 4- were converted to 3.25 and 3.75, respectively. Scores for left and right side were combined for each muscle group, given that AFM does not systematically progress in a lateralized manner.²⁷

The *Spinal Cord Independence Measure (SCIM)* consists of 19 questions that review self-care (six questions; score range, 0-20), respiration and sphincter management (four questions; score range, 0-40), and mobility (nine questions; score range, 0-40), with a total potential score of 0 to 100.²⁸ It is validated in traumatic and nontraumatic SCI as well as acute and chronic conditions. It has shown to be reliable and have good validity in the pediatric population, 6 years of age and older, who have SCI.²⁹

The *Physical Abilities and Mobility Scale (PAMS)* is a 20-question scale, developed at Kennedy Krieger Institute, to measure 20 functional skills that include head control, developmental positions and transitions, positioning (in seating systems), splint/orthotic tolerance, sitting, standing, and higher level ambulation skills.³⁰ The possible scores range from 20 to 100. This measure has shown good reliability and validity in the pediatric inpatient brain injury population from 2 to 18 years old.

The *Modified Rankin Scale for Neurologic Disability (mRS)* is a 6-point scale assessing degree of disability or dependence on a caregiver for daily activities following neurologic disability. Potential scores range from 0 (*no deficits*) to 5 (*severe disability*).³¹ Modified Rankin Scale scores in this cohort were determined retrospectively.

Data analyses

SPSS Statistics 25 was used to perform all analyses. Descriptive statistics were used to examine

sample characteristics. Sensitivity to recovery was examined using paired *t* tests examining differences between admission and discharge scores for each measure. For each *t* test, effect sizes were calculated as [(mean at admission – mean at discharge)/standard deviation at admission].³² Strength of effects (Cohen's *d*) was assigned as follows: 0.20-0.50 (small), 0.50-0.80 (moderate), and >0.80 (large).³³ Significance was set at $p < .05$.

Results

Sample description

Sample demographics are presented in **Table 1**. All children had decreased muscle tone and absent reflexes in the affected limb(s). Most of the children (90%) had tetraplegia, with 10% having paraplegia. Ventilator support was required acutely in 52%, and 21% still used ventilator support at discharge. Sensation was preserved in all 22 children who were able to age appropriately participate in a sensory examination. Bowel and bladder function was preserved or deemed age appropriate in all patients. Neuropathic pain was recorded in 10 of the 29 children in the cohort. Cognitive function was deemed intact or consistent with age/status post AFM in all 29 children. MRI showed specific spinal grey matter involvement in all 29 patients; eight children also showed some white matter MRI changes consistent with inflammation. Cerebrospinal fluid studies were documented in 21 of 29 children, with pleocytosis reported in

20 patients and increased protein reported in 14 patients.

Most children demonstrated weakness in their neck or trunk leading to some degree of flexible curvature, and six of the eight children who were more than a year from onset had significant and fixed scoliosis of the neck or spine. On admission, all 15 children with acute AFM and upper limb weakness demonstrated shoulder subluxation.

Regarding complications in the children who were more than a year since onset, five of the seven children with upper limb weakness demonstrated ongoing shoulder subluxation. Three patients presented with lower limb flexion contractures severe enough to limit standing, as well as lower extremity limb length differences. Two children reported pathologic fractures, one reporting two humeral fractures and a distal femur fracture and the other a distal femur fracture.

Functional change during rehabilitation

As a group, the children demonstrated statistically significant gains from admission to discharge across all clinical measures administered. On the WeeFIM, significant change was seen from admission to discharge across all subdomains, including self-care, mobility, and cognition, with effect sizes ranging from small (cognition) to large (self-care, mobility, and total score). Children also showed significant improvement on the SCIM and PAMS testing, with large effect sizes seen for both measures (see **Table 2**).

Table 1. Demographics of the sample

	All patients (<i>n</i> = 29)		<1 year post onset (<i>n</i> = 21)		> 1 year post onset (<i>n</i> = 8)	
	M (SD)	Range	M (SD)	Range	M (SD)	Range
Age at onset, years	5.77 (4.10)	0.40-15.87	5.89 (3.84)	1.12-15.87	5.47 (5.01)	0.40-13.33
Age at admission, years	6.47 (4.14)	1.29-16.06	6.09 (3.83)	1.29-16.06	7.46 (5.00)	2.21-15.48
Onset to admission, days	253.59 (338.22)	5-1370	73.81 (89.32)	5-357	725.50 (288.62)	377-1370
Length of stay, days	49.69 (37.11)	16-196	50.67 (40.69)	16-196	47.12 (27.67)	17-94
Ethnicity, %						
Caucasian	86		80		100	
African American	7		10		0	
Other	7		10		0	
Gender, male, %	76		86		50	

Table 2. Change from inpatient admission to discharge on outcome measures

	Admission		Discharge		<i>t</i> test	<i>d</i>
	M	SD	M	SD		
SCIM (<i>n</i> = 18)	31.1	26.4	51.3	29.0	-3.91***	-0.92
PAMS (<i>n</i> = 27)	49.7	22.4	67.3	20.5	-7.21***	-1.39
WeeFIM Self-Care DFQ (<i>n</i> = 29)	46.3	24.1	62.7	24.7	-5.54***	-1.03
WeeFIM Mobility DFQ (<i>n</i> = 29)	39.7	26.9	57.0	23.6	-5.71***	-1.06
WeeFIM Cognitive DFQ (<i>n</i> = 26)	85.3	36.5	97.6	54.0	-2.18*	-0.43
WeeFIM Total DFQ (<i>n</i> = 26)	54.0	24.3	70.1	25.8	-11.87***	-1.54

Note: DFQ = Developmental Functional Quotient; PAMS = Physical Abilities and Mobility Scale; SCIM = Spinal Cord Independence Measure; WeeFIM = Functional Independence Measure for Children.

p* < .05. *p* < .01. ****p* < .001.

Table 3. Change from inpatient admission to discharge on Manual Muscle Testing (MMT) by muscle group

	Admission		Discharge		<i>t</i> test	<i>d</i>
	M	SD	M	SD		
Ankle dorsiflexion (<i>n</i> = 27)	2.37	1.50	2.66	1.65	-2.46*	-0.47
Ankle plantarflexion (<i>n</i> = 27)	2.28	1.53	2.68	1.74	-2.90**	-0.56
Knee flexion (<i>n</i> = 29)	1.95	1.60	2.30	1.64	-4.10***	-0.76
Knee extension (<i>n</i> = 29)	1.90	1.60	2.30	1.60	-2.63*	-0.49
Hip flexion (<i>n</i> = 28)	1.90	1.60	2.30	1.50	-3.14**	-0.59
Hip extension (<i>n</i> = 28)	1.80	1.53	2.13	1.46	-3.17**	-0.60
Finger flexion (<i>n</i> = 28)	3.09	1.70	3.41	1.50	-3.17**	-0.60
Finger extension (<i>n</i> = 27)	3.06	1.69	3.42	1.40	-3.35**	-0.64
Elbow flexion (<i>n</i> = 28)	2.52	1.69	2.81	1.70	-4.53***	-0.86
Elbow extension (<i>n</i> = 28)	2.50	1.72	2.85	1.75	-3.76***	-0.71
Shoulder flexion (<i>n</i> = 29)	2.01	1.56	2.40	1.73	-3.24**	-0.60
Shoulder extension (<i>n</i> = 28)	2.10	1.66	2.45	1.65	-3.55***	-0.67

p* < .05. *p* < .01. ****p* < .001.

Significant change from admission to discharge was seen across all muscle groups on the MMT, with effect sizes ranging from small (ankle dorsiflexion, knee extension) to large (elbow flexion); most muscle groups tested showed a moderate effect size. All children either maintained or improved strength across muscle groups, with no children showing reduced strength over time. Of note, consistent with previous descriptive reports, children demonstrated better function in distal than proximal muscle

groups in both upper and lower limbs at both admission and discharge (see **Table 3**).

Overall functional ability levels improved over the course of admission, resulting in increased independence and decreased level of caregiver burden. While the median modified Rankin score for the whole group was “4” at both admission and discharge, indicating moderate severe disability, more than a third (39%) of the group improved in rating over the course of admission, with

eight individuals improving by 1 point and three individuals improving by 2 points. At admission, 14 of the children were at a level of complete dependence for mobility (WeeFIM DFQ <30) and nine were at a level of complete dependence for self-care. By discharge, more than half improved to partial independence in both categories (9/14 for mobility and 5/9 for self-care), translating to a decrease in overall caregiver burden.

Discussion

These findings demonstrate functional improvements despite moderate-to-severe residual AFM-related neurologic deficit at admission (tetraplegia in 90%) in a group of children with AFM who participated in ABRT in an inpatient setting. All children demonstrated significant changes in muscle strength and functional progress during the course of their inpatient rehabilitation stay; statistically significant improvements were noted in all domains of SCIM, PAMS, and WeeFIM, and the mRS improved in 39% of the individuals.

These results support the role of ABRT inpatient rehabilitation, even beyond the acute phase of recovery. The children in this cohort were admitted to the inpatient rehabilitation unit an average of 8 months post neurologic deficit onset, and eight out of the 29 children were more than a year post injury onset. To date, few studies have looked at functional outcomes in the context of rehabilitative intervention in children with AFM.^{34,35} We retrospectively calculated the mRS so the change in our cohort could be interpreted in the context of previously reported outcomes; change on this measure was similar to that previously reported, even if the effect of the specific rehabilitative interventions cannot be compared directly.

Muscle strength improved in a distal to proximal pattern in both upper and lower limbs, which has been described qualitatively in prior studies. This has significant implications for rehabilitation, as weakness in the proximal upper and lower limbs leads to musculoskeletal consequences that are difficult to address, including shoulder and hip subluxation. Shoulder subluxation is particularly difficult to manage, as current bracing is often ineffective and poorly tolerated in patients. Proximal weakness in the upper limbs resulting in shoulder

subluxation can be difficult to address as available bracing to stabilize the shoulder often limits use of the distal arm and hand and is poorly tolerated. The asymmetry and flaccid nature of the neurological deficits can lead to pelvic obliquities, which further impair hip stability. Asymmetry in residual strength also leads to soft tissue contractures and scoliosis, as children functionally compensate with muscles that have retained against gravity capabilities. Scoliosis is noted to have a very rapid onset, and a balance between bracing for stability and brace-free time for trunk muscle activation and strengthening is needed. Loss of bone mass related to decreased mobility is rapid and can lead to low impact and sometimes occult fractures. Children with AFM will need ongoing monitoring for potential longer term neuromuscular consequences of AFM.

There are limitations related to the methodology of this study. The article presents retrospectively collected data obtained during regular clinical care. Although ABRT has standardized components, there is no other quantification of delivery other than the time the participants underwent supervised rehabilitative interventions. Discerning the role of natural recovery versus ABRT in the changes recorded in this cohort is difficult; the fact that strength and functional improvements occurred 12 months or later after paralysis onset does suggest that ABRT played a role. Of course, there is no control group undergoing traditional, compensatory type rehabilitative interventions that could speak to the specific ABRT efficacy. Finally, some of the outcome measures utilized in this study are designed and/or validated for individuals with SCI but not necessarily for the pediatric SCI population and, specifically, children with AFM.

Overall, children with AFM who participated in intensive inpatient ABRT made functional gains and improved strength in a distal to proximal pattern. Early intensive rehabilitation, the provision of a home and community rehabilitation program, and ongoing bouts of therapy may help to mitigate the long-term consequences of AFM. For children in the chronic state, admission to an inpatient program with care provided by professionals with expertise in treating children with AFM can provide recommendations for managing and slowing the progression of already present

secondary complications. Future research is needed to determine the best models of service delivery and factors that influence trajectory of recovery after AFM, including prospective assessment of each specific therapeutic intervention individually, ideally in a randomized manner, to determine which interventions are most effective in improving function in this patient population. In addition, evaluating change in functioning between bouts of care will help distinguish natural recovery from improvement with therapy.

Conclusion

Children with AFM who participated in ABRT experienced increased muscle strength and made

functional changes across all outcome measures. These results support the utility of this intervention even in children with significant neurological impact who are months to years from onset.

Acknowledgments

We would like to thank Shannon Inches, Anna Schneider, Jessica White, and Angelica Allen for assistance with database design, data entry, and formatting of the article.

Conflicts of Interest

The authors report no conflicts of interest.

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