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Six- and 12-month functional outcomes among patients with confirmed acute flaccid myelitis (AFM) with onset in 2018, United States

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Abstract

Purpose: Acute flaccid myelitis (AFM), an uncommon but serious neurologic condition, primarily affects children, and can progress quickly to paralysis and respiratory failure. Data on long-term outcomes of patients with AFM are limited. We report on functional status through 12 months for AFM patients who became ill in 2018 in the United States.

Methods: Health departments collected information on outcomes at 6 and 12 months after onset of AFM using a standardized form that asked patients or their parents/guardians about functional status. Analyses were restricted to confirmed cases.

Results: Of the 238 confirmed AFM cases reported to CDC in 2018, 90 (38%) had assessments at 6 months, 82 (34%) at 12 months, and 49 (21%) at both 6 and 12 months. Among the 49 patients with data at both time points, the proportion of patients reporting significant or severe impairment at 6 months ranged from 2% to 59% depending on the outcome. Although proportions decreased by 12 months and ranged from 2% to 51%, most patients had some impairment at 12 months. No deaths were reported.

Conclusions: Six- and 12-month outcomes in patients with onset of AFM in 2018 span a wide range of functionality, particularly of upper and lower extremities. Importantly, improvement appears to occur over time in some patients.

Keywords

acute flaccid myelitis; functional outcomes; impairment

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Conflict of Interest

The authors have no conflict of interest to report.

Disclaimer: The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention, US Department of Health and Human Services.

Ethical Considerations

This study, as part of standardized public health surveillance, is exempt from Institutional Review Board approval.

Introduction

Acute flaccid myelitis (AFM) is an uncommon but serious neurologic condition primarily affecting children [1–4]. During the acute phase of illness, patients often present with a respiratory or febrile illness followed by sudden onset of weakness in one or more limbs. AFM can progress quickly to paralysis, with ventilatory support needed in a quarter of patients [5]. Muscle weakness in AFM patients often affects the proximal muscles, such as the muscle groups in the neck, shoulder girdle, and hips. Consequently, proximal muscle weakness can significantly impact activities of daily living and self-care. Data on long-term outcomes of patients with AFM are limited by the small number of participants and only a few studies have described functional changes over time. These studies suggest that although weakness persists, patients continue to improve [6–8].

National surveillance for AFM started after the first large increase in AFM cases in the United States occurred in 2014 [1,9]. Subsequent national increases in cases occurred during 2016 and 2018, with the largest number of cases reported in 2018 [10]. To better understand outcomes through 12 months among patients with confirmed AFM, patients with illness onset in 2018 were contacted about their functional status at two time points after onset of AFM illness.

Methods

As part of AFM surveillance, health departments reported patients with acute onset of flaccid limb weakness (the clinical criterion for AFM) to the Centers for Disease Control and Prevention (CDC) using a standardized form to collect demographic and clinical data and submitted biological specimens for enterovirus testing. For surveillance purposes, confirmed cases of AFM were defined as patients who met the clinical criterion as verified by CDC and had magnetic resonance imaging showing spinal cord lesions largely restricted to gray matter in one or more vertebral segments [11]. Clinical and radiographic information from patients meeting the clinical criterion for AFM were reviewed and classified by a panel of neurologists for surveillance purposes and included in the CDC AFM surveillance data.

Beginning in 2018, surveillance processes for AFM were expanded to collect information on outcomes at 6 and 12 months after onset of limb weakness. Health departments were asked to follow-up with patients with confirmed AFM who were included in the CDC AFM surveillance data, using a standardized form that asked patients or their parents/guardians to categorize patient status on seven functional domains (overall impairment, physical condition, upper limb functions, lower limb functions, sensory components, excretory functions, and support factors). The form was adapted from a previously validated assessment tool “PULSES” that assessed impairment and disability [12] (Appendix). Each question was rated on a 4-point scale from 1 to 4 (normal or independent to severely disabled or dependent). Assessments were conducted within a range of time after onset of limb weakness; ranges were 5–9 months and 11–15 months for the 6- and 12-month assessments, respectively.

Descriptive analyses were restricted to confirmed cases with onset in 2018 who had available outcomes data at 6 months, 12 months, or both. Outcomes were examined by severity of the acute illness using the following definitions of severity: 1) need for mechanical ventilation; 2) all four limbs affected; and 3) admission to intensive care unit (ICU). Outcomes were also examined by pathogen detected; patients who were enterovirus D68 (EV-D68) positive were compared with patients who were EV-A71 positive or not positive for EV-D68 or EV-A71 because data have suggested that certain enterovirus types lead to more severe presentations of AFM [13]. For the severity and pathogen analysis, each of the outcome questions were collapsed to dichotomous categories of no/mild dependence versus moderate/severe dependence and compared using the Chi-square test. A separate descriptive analysis was conducted to examine change in each outcome measure among cases with outcomes data at both the 6- and 12-month time points.

Although the functional outcomes assessment was not included as part of AFM surveillance until 2018, an attempt was made to collect functional outcomes data at a single time point greater than 12 months after onset of illness from AFM cases with onsets before 2018 (onset of illness from 2014 to 2017) and who are part of the CDC AFM surveillance data. Patients were contacted during summer 2021 by their respective health department or by CDC through a contract research organization funded to assist with this activity. Patients who were successfully located and agreed to participate were administered the same standardized form used for the 2018 cohort; descriptive analyses were also performed for these data.

Data were analyzed using SAS (version 9.4; SAS Institute) and p-values <0.05 , calculated using the Chi-square test, were considered statistically significant. Data on outcomes for patients with confirmed AFM and onsets from 2014 through 2018 were collected as part of standardized public health surveillance and determined by the CDC not to be research involving human subjects.

Results

Of the 238 confirmed AFM cases reported to CDC in 2018, 120 patients from 26 of the 42 states with AFM cases reported, responded to at least one assessment; 90 (38%) had assessments at 6 months, 82 (34%) at 12 months, and a total of 49 (21%) had assessment data at both 6 and 12 months. Characteristics of patients during their acute illness by assessment time point are presented in Table 1. Characteristics of non-participants at either 6 or 12 months were not statistically significantly different from participants (data not shown).

Results of outcomes at the 6- and 12-month assessments are presented in Table 2. At 6 months, one patient (1/90, 1%) responded as having severe overall impairment, defined as involvement of at least 3 extremities and respiratory impairment; most patients (54%, 49/90) responded as having significant overall impairment, defined as major involvement of at least 2 extremities; 36% (32/90) responded as having minor overall impairment, defined as any minor involvement, and 8% (7/90) responded as having no overall impairment. Most patients (70%, 62/88) responded that they had upper limb impairment, including 38 (43%) that were dependent on some assistance for activities of self-care and 24 (27%) who had some impairment but had age-appropriate independence in these activities; 30% (26/88)

responded as having no upper limb impairment. Almost half of patients (42/87, 48%) responded as having lower limb impairment, including 29 (33%) who were dependent on some assistance for mobility and 13 (15%) who responded as having independent mobility with some impairment. Sensory (i.e., ability to communicate through speech, hearing, and vision) and excretory function impairments were less common: 75% (65/87) responded as having independence in communication and vision with no impairment, and 80% (69/86) had complete voluntary control of bladder/bowel sphincters. For physical condition, which describes how frequently the patient requires medical monitoring to assess functioning of cardiovascular, gastrointestinal, urologic, and endocrine, as well as neurologic systems after AFM diagnosis, 41% (36/88) responded as needing minimal medical monitoring, 35% (31/88) responded as having medical problems that required at least weekly medical attention, and 14% (12/88) responded as requiring at least daily medical attention. Overall, 32% (28/88) were able to fulfill age-appropriate roles and perform tasks without assistance, 65% (57/88) required at least some adult assistance, and 3% (3/88) reported being dependent on long-term institutional care. No deaths were reported among patients at either the 6- or 12-month assessment period among this cohort.

For most outcome measures, the proportion of patients responding with no or minimal dependence was slightly higher among participants at 12 months compared with participants at 6 months, but these differences were not statistically significantly different (Figure 1). Most patients also continued to have no sensory and excretory function impairment. For the overall impairment and physical condition categories, some patients responded as having more severe impairment or needing more monitoring at 12 months than at 6 months. The difference in severity was only statistically significant for overall impairment. A total of 49 patients had outcomes data available at both 6 and 12 months to examine whether changes in impairment occurred over time at the individual level. The proportion of patients reporting significant or severe impairment at 6 months ranged from 2% to 59% depending on the outcome. Although the proportions decreased slightly by 12 months and ranged from 2% to 51%, most patients still had some impairment at 12 months. Additionally, the number of patients reporting no impairment at 6 months for the different functional outcomes increased or remained the same for most outcomes by 12 months. Of the 29 patients reporting significant overall impairment at 6 months, 4 reported less and 3 reported greater impairment at 12 months (Figure 2).

Analysis of outcomes by severity of the acute illness differed based on the definition of severity used. For patients requiring mechanical ventilation during acute illness (severity definition 1; n=26) none of the outcome variables were statistically significantly different from patients not requiring ventilation during acute illness at 6 months. However, at 12 months, patients who required mechanical ventilation during acute illness were more likely to require support (i.e., dependence on assistance in age-appropriate roles and performance of tasks or dependence on long-term institutional care) than patients who were not ventilated during acute illness (p=0.01). Patients with all four limbs affected during acute illness (severity definition 2; n=25) were more likely to have moderate to severe lower limb involvement (p=0.002) and require more support (p=0.006) at 6 months but none of the outcome variables were statistically significantly different at 12 months. Patients requiring ICU admission during acute illness (severity definition 3; n=47), were more likely to

have moderate to severe overall impairment ($p=0.02$), upper limb ($p=0.02$) and lower limb impairment ($p=0.03$) and require support ($p=0.01$) at 6 months compared with patients not admitted to the ICU. At 12 months, these patients were more likely to require support ($p<0.001$). When comparing patients by pathogen, those with a specimen positive for EV-D68 ($n=16$) were more likely to have moderate to severe overall impairment ($p=0.001$), upper limb impairment ($p=0.03$), and require support ($p=0.01$) at 6 months compared with patients who had a specimen positive for EV-A71 ($n=4$). Results were similar when comparing patients with an EV-D68 positive specimen to those with a specimen not positive for EV-D68 or EV-A71 ($n=68$; data not shown). At 12 months, in addition to having more moderate to severe overall impairment ($p<0.001$), upper limb impairment ($p=0.05$), and requiring support ($p=0.04$), EV-D68 patients ($n=13$) were also more likely to have moderate to severe physical involvement ($p=0.04$) compared with patients who had a specimen positive for EV-A71 ($n=7$). Compared with patients not positive for EV-D68 or EV-A71 ($n=60$), EV-D68 patients ($n=13$) were more likely to have sensory impairments ($p=0.02$) and require support ($p=0.05$) at 12 months.

Of the 333 patients with confirmed AFM and onset during 2014 through 2017 that were part of the CDC AFM surveillance data, 49 (15%) were successfully located and agreed to participate. The median length of follow-up for these patients was 4.6 years (range, 3.3–6.9 years). Similar to results from patients with onset in 2018 at the 12-month assessment (Table 2), most had no sensory (81%) or excretory involvement (65%) and reported fewer severe outcomes for upper (82%) and lower limb function (68%), physical condition (60%), and support factors (81%); however, a greater proportion responded as having severe overall impairment unlike the patients with onset in 2018 (24% vs 8%, respectively). One patient (2%) had died by the time of contact for follow-up; details were not available about the timing or cause of death.

Discussion

Overall, 38% and 34% of patients with onset of AFM in 2018 provided responses at the 6- or 12-month assessments, respectively, and 21% provided responses at both time points, making this the largest and most representative study of AFM long-term functional outcomes to date. Most patients had minimal involvement of sensory and excretory components at both 6 and 12 months but were more likely to be dependent on help for upper and lower limb and support factors at 6 months; the proportion that were dependent decreased slightly by 12 months. Up to 22% and 35% of patients with assessments at both 6 and 12 months reported at least some impairment of limbs and support functions at 6 months, respectively; by 12 months, the proportion of patients responding with no dependence increased by a range of 0%–35% depending on outcome. AFM can be a devastating illness that can result in lifelong consequences, but importantly mortality associated with the acute and convalescent phases is uncommon.

Reliably measuring and summarizing AFM outcomes in a standardized way is challenging because there is no single tool currently available for this purpose. Several different tools have been used in various studies [6,7,14] and all included a clinical evaluation by a physician. The assessment tool used in our surveillance activity included a survey

that relied only on self-report via interview, the validity of which can be limited by subjectivity. Although the tool we used has been validated for functional impairments [15], the development of a standardized tool for evaluating functional outcomes among patients with AFM across institutions will provide more comparable results.

Consistent with other studies examining long-term outcomes among patients with AFM [8,16,17], our assessments found that few patients fully recover, and a majority still report having significant overall impairment at the 12-month follow-up period. However, when comparing dependence at 6 and 12 months after onset of weakness, some patients were less likely to report complete dependence at 12 months, suggesting possible improvement or adaptation over time. Children may learn to adapt when their physical strength has not improved and that could be interpreted as progress or improvement. Alternatively, because responses were based on self-report, perceptions of either improvement or challenges at the time of the 12-month assessment could have impacted the response and resulted in reporting that indicated slight improvement or worsening at 12 months compared to 6 months for some of the patients. This may also have been true for the cohort with onset of AFM from 2014–2017 who reported overall impairment as more severe after a longer follow-up period than patients from the 2018 cohort. Overall, patients with AFM followed longer than 12 months have shown continued minor improvements in motor recovery and function most often in a distal to proximal pattern [6–8,18]. Rehabilitation therapy, especially when provided early, but even when provided months to years after onset of illness, has been shown to help lessen long-term consequences of AFM [14,19] and is a critical component of the clinical management and treatment of patients with AFM.

Although we do not have data on initial impairment for comparison, we identified certain indicators of clinical severity in patients with AFM during the acute phase of illness that might be associated with worse outcomes. In our assessment, patients who were admitted to the ICU were more likely to have more severe overall, upper and lower limb impairment, and require more support factors at 6 months and continued support at 12 months. Similarly, patients who had all four limbs affected were more likely to have more severe lower limb impairment and require more support factors at 6 months. Patients who were positive for EV-D68 were more likely to have more severe overall and upper limb impairment and require more support factors at 6 and 12 months when compared with patients who were positive for EV-A71. Similar results were found when EV-D68 positive patients were compared with patients who were not positive for either EV-D68 or EV-A71 (results not shown), indicating that EV-D68 might be associated with worse outcomes than other enteroviral causes of AFM. Other studies examining outcomes of patients with EV-D68 positive AFM have shown that outcomes are severe, with disability lasting long-term, especially in the most affected muscle groups [7,8,13]. Clinical and neuroimaging data suggest that EV-D68, like poliovirus, has an affinity for motor neurons in the spinal cord. Damage, either due to direct neuronal injury or the inflammatory response related to infection, can result in long-term deficits [16,20]. Our findings support previous studies and suggest that severity during the acute illness, along with etiology, can help guide long-term prognosis.

This assessment is subject to several limitations. Only about a third of the total number of patients with confirmed AFM in 2018 participated and the same patients did not always participate in both the 6- and 12-month assessments, which limited our ability to assess longitudinal changes. The patients who did respond may not be representative of AFM patients overall, as respondents with more severe outcomes may have been more likely to participate than those with minimal involvement or full recovery. However, when comparing the baseline characteristics of acute illness in participants and non-participants, no differences were found. Additionally, to minimize the burden on families when completing these assessments, we limited the follow-up period to 12 months post onset and did not collect details on therapies or treatments received during hospitalization or the follow-up periods. Thus, we were unable to determine if improvements continue to occur after 12 months or to explore possible links between treatments and outcomes. Collecting data from an earlier cohort of patients, however, provided additional information on functional outcomes at a time point greater than 12 months after onset of illness. Furthermore, phone interviews made it difficult to assess whether improvements in outcomes were related to muscle strength or functional adaptations to compensate for weakness. The availability of better, standardized follow-up and functional outcome measures will be important for understanding long-term outcomes of AFM.

Understanding outcomes among patients with AFM is important for targeting treatment and management plans to provide optimal care. Based on data from this cohort of patients with AFM with onset during the last peak year in 2018 – the largest long-term follow-up cohort to date – patients reported continued dependence on care, particularly for function of upper and lower extremities, up to 12 months after initial onset of weakness. Importantly, improvement, which may include adaptation to allow more independence in activities in daily living, does appear to occur over time in some patients. Studies have suggested that continued rehabilitation therapy and targeted treatments could result in further improvements. Longer periods of systematic, clinic-based follow-up that includes collection of data on acute and ongoing treatments and services received will be important for examining and understanding factors that influence longer-term outcomes among these patients.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

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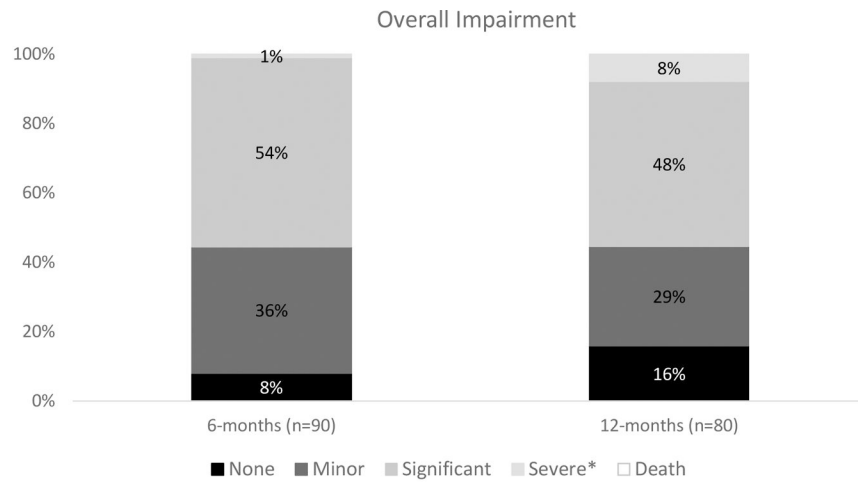
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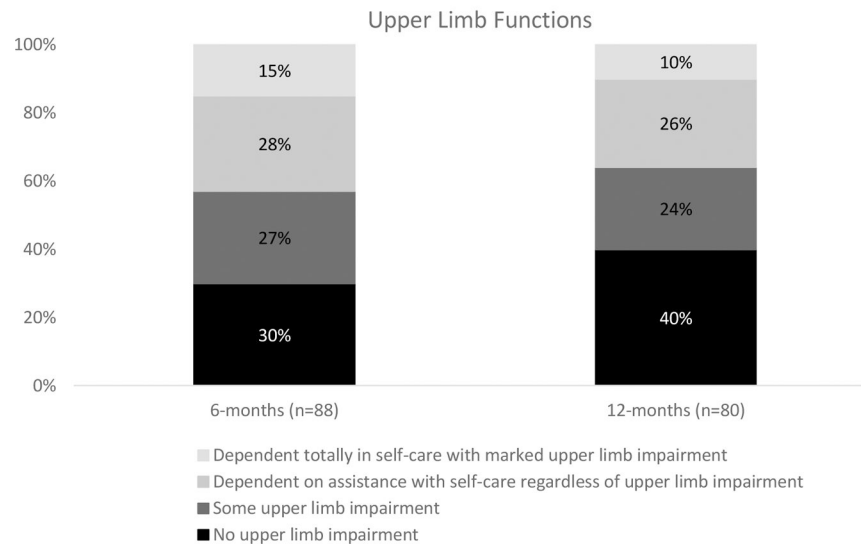
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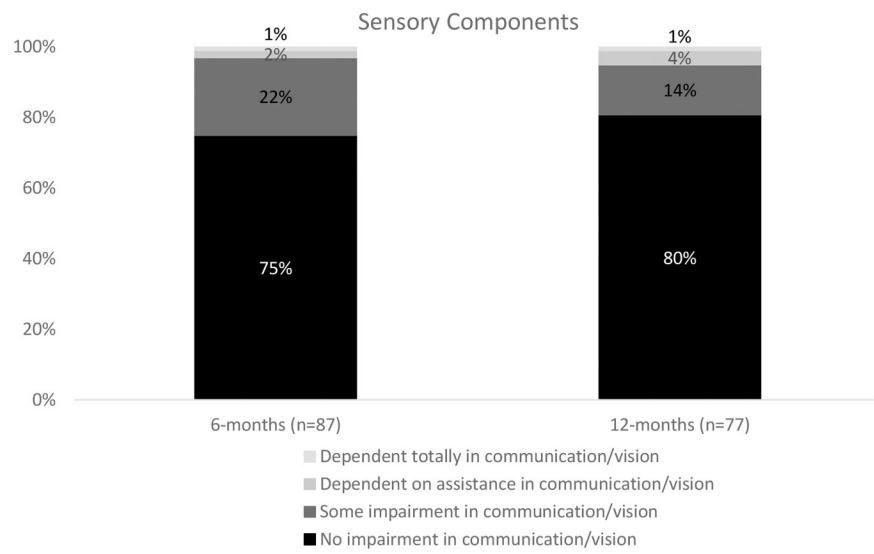
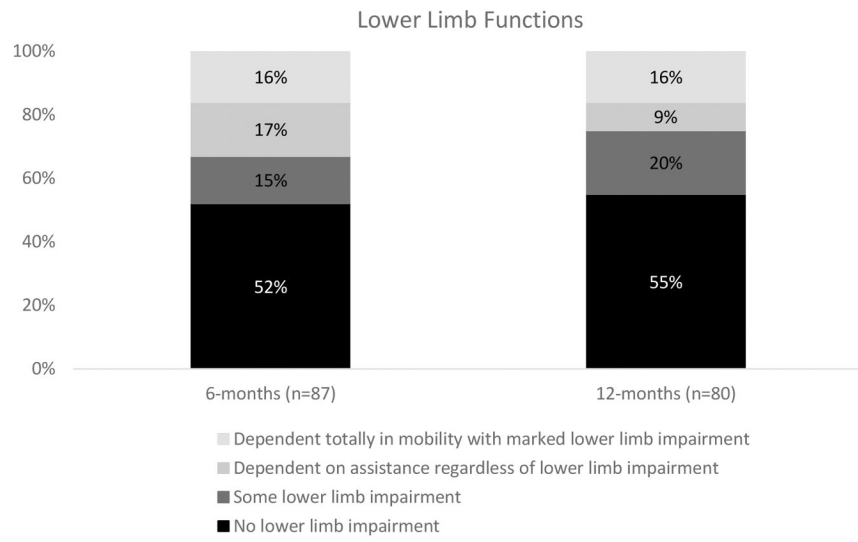
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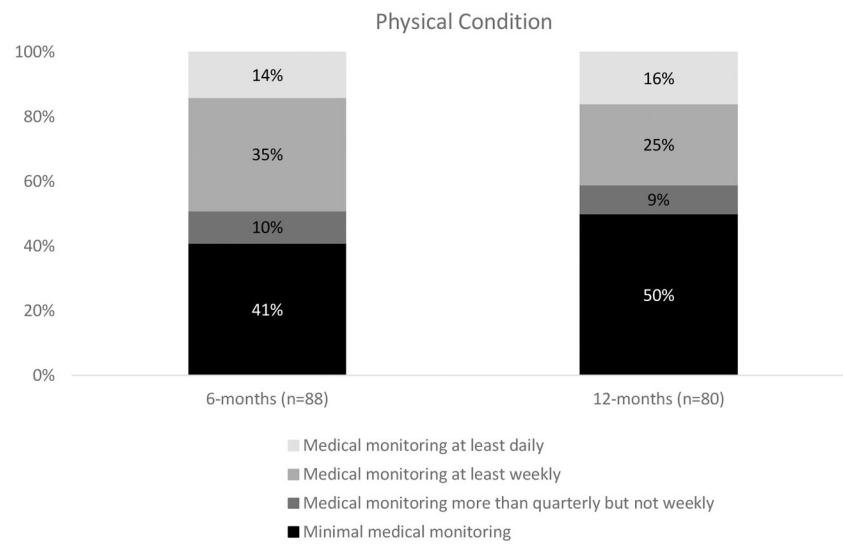
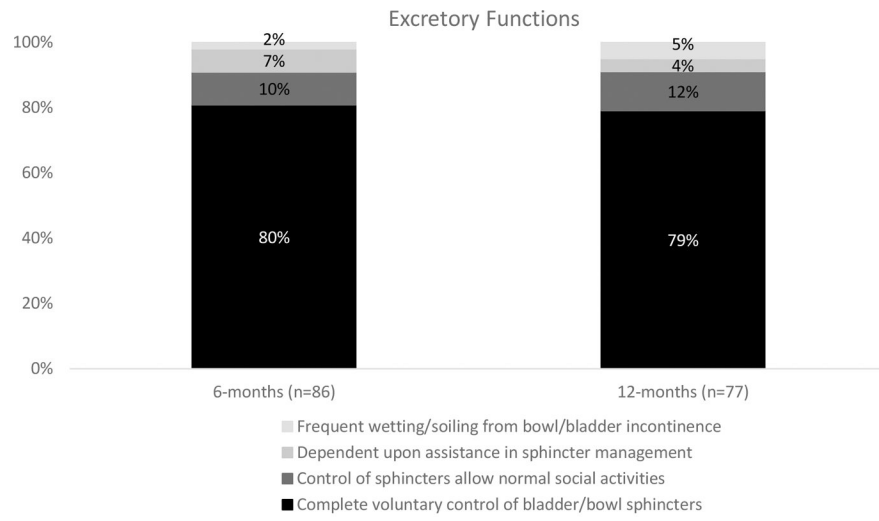
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* Difference was statistically significantly different between the 6- and 12-month follow-up.







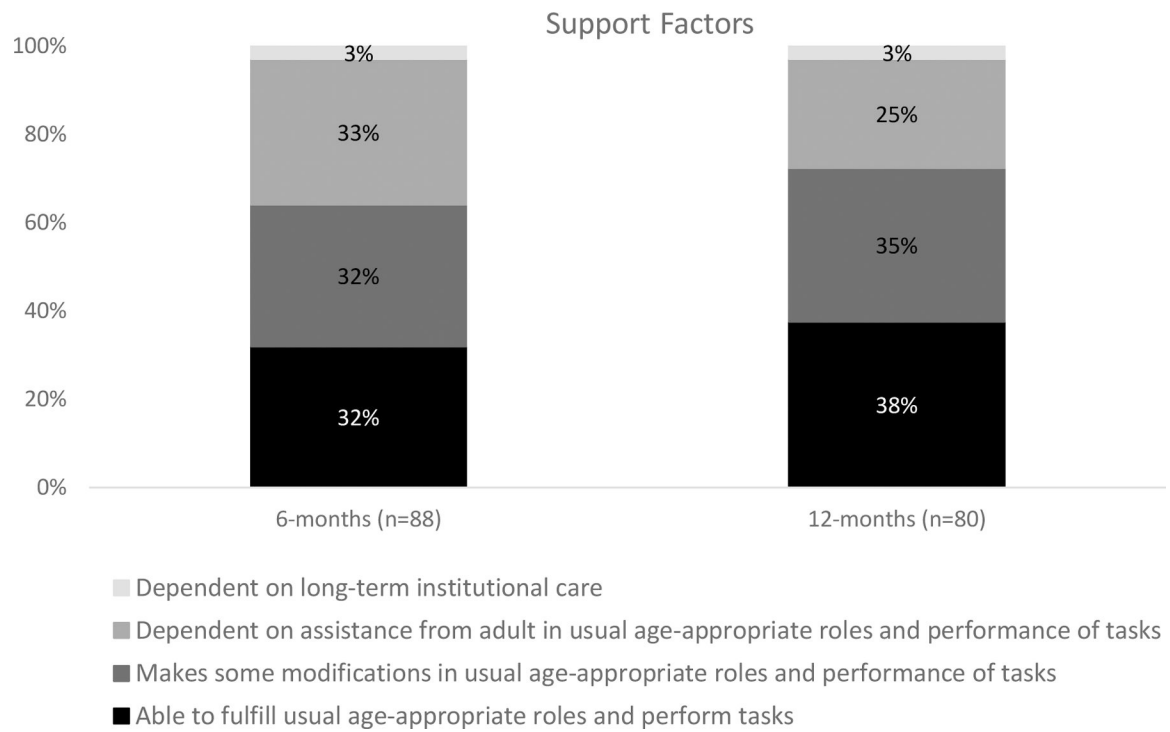


Figure 1. Comparison of functional outcome measures among confirmed AFM cases with onset in 2018 who had data for the 6- and/or 12-month assessments*, United States.

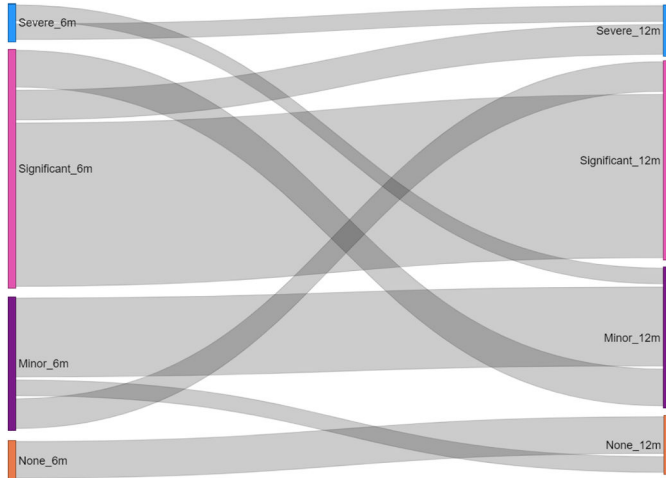
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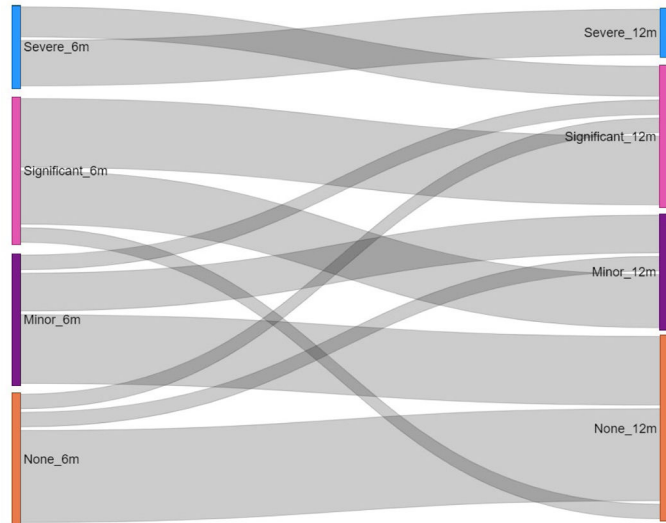
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Overall Impairment



Upper limb function



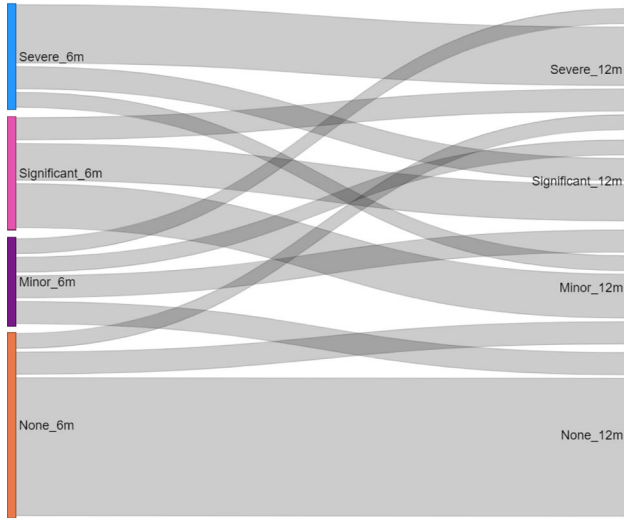
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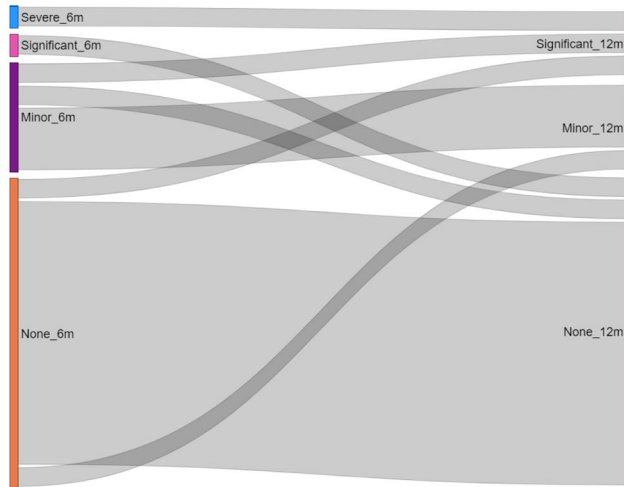
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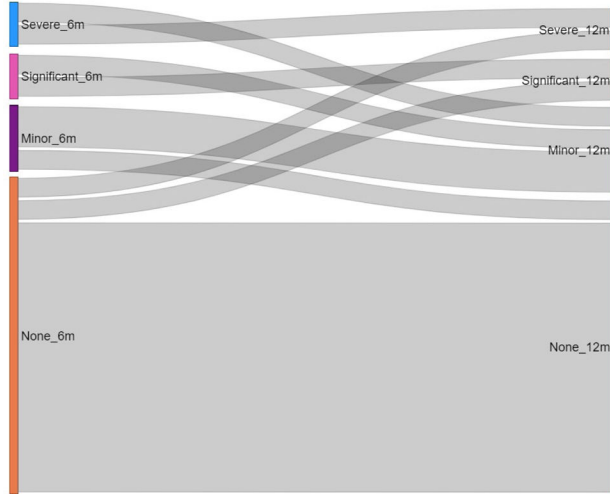
Lower limb function



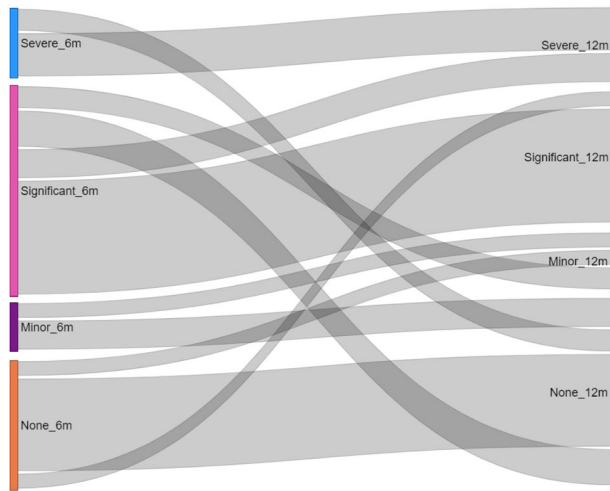
Sensory function



Excretory function



Physical condition



Support function

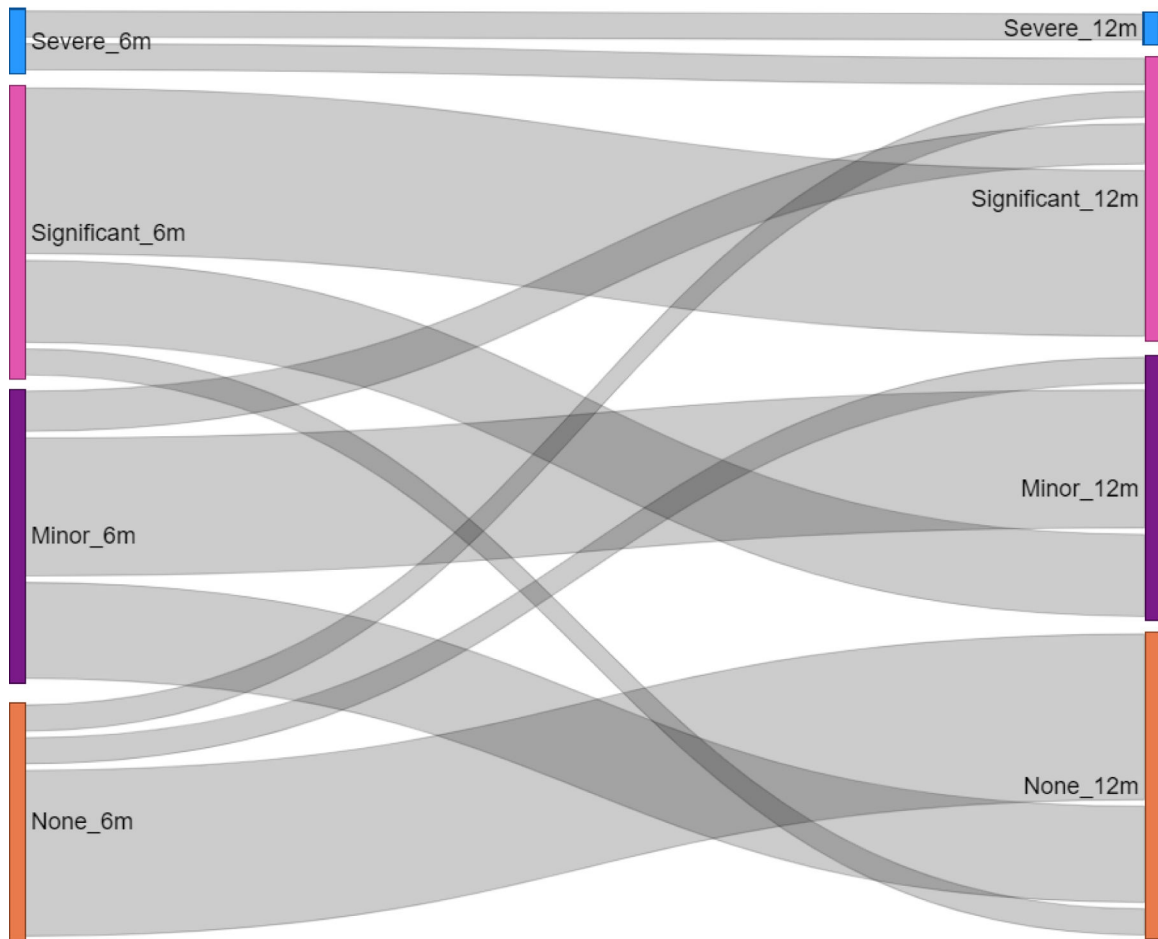


Figure 2. Outcomes of patients with confirmed AFM with onset in 2018 and follow-up data at both the 6- and 12-month assessments to show individual progression over time (N=49).

Table 1.

Demographic and clinical characteristics of confirmed AFM cases at time of acute illness (onset of illness in 2018) who participated in functional outcome assessments at 6- and/or 12-months*.

Characteristic	6-month assessment, n (%) [†]	12-month assessment, n (%) [†]
N contributing to responses	N=90	N=80
Median age, years (interquartile range)	5.5 (3.8–8.4)	5.2 (3.1–8.0)
Gender, male	52 (58)	43 (54)
Hospitalized	87/88 (99)	77/78 (99)
ICU	48/86 (56)	50/75 (67)
Respiratory support	29/61 (48)	26/50 (52)
Mechanical ventilation	26/28 (93)	20/25 (80)
Any cranial nerve abnormalities	20 (22)	16 (20)
Number of limbs affected [§]		
1	26/89 (29)	23 (29)
2	30/89 (33)	24 (30)
3	8/89(9)	9 (11)
4	25/89 (28)	24 (30)
Limbs affected		
Upper only	37/89 (41)	30 (38)
Lower only	12/89 (13)	10 (12)
Both upper and lower [¶]	15/89 (17)	16 (20)
All 4	25/89 (28)	24 (30)
Enterovirus status		
EV-D68 positive	16 (18)	13 (16)
EV-A71 positive	4 (4)	7 (9)

* Data for some characteristics may be missing; the denominator is provided when data are missing.

[†] Percentages may not add up to 100%, as they are rounded to the nearest percent.

[§] One patient who participated in the 6-month assessment did not have number of limbs affected indicated.

[¶] Both upper and lower limbs affected is defined as having 3 limbs affected.

Table 2.

Number and proportion of confirmed AFM cases with onset in 2018 with functional outcome measures on seven domains using the adapted “PULSES” assessment tool (Appendix) at the 6- and/or 12-month assessment period^{*}, United States.

Outcome measure	6-month follow-up, n (%) [†]	12-month follow-up, n (%) [‡]
Impairment	N=90	N=80
None	7 (8)	13 (16)
Minor (any minor involvement)	32 (36)	23 (29)
Significant (2 extremities, major involvement)	49 (54)	38 (48)
Severe (3 extremities and respiratory involvement)	1 (1)	6 (8)
Death	0 (0)	0 (0)
Upper limb functions	N=88	N=80
Age-appropriate independence without upper limb impairment	26 (30)	32 (40)
Age-appropriate independence with some upper limb impairment	24 (27)	19 (24)
Dependent on assistance with self-care with/without impairment of upper limbs	25 (28)	21 (26)
Dependent totally in self-care with marked upper limb impairment	13 (15)	8 (10)
Lower limb functions	N=87	N=80
Independent in mobility without lower limb impairment	45 (52)	44 (55)
Independent of mobility with some lower limb impairment	13 (15)	16 (20)
Dependent on assistance with or without lower limb impairment	15 (17)	7 (9)
Dependent totally in mobility with marked lower limb impairment	14 (16)	13 (16)
Sensory components	N=87	N=77
Age-appropriate independence in communication/vision with no impairment	65 (75)	62 (80)
Age-appropriate independence in communication/vision with some impairment	19 (22)	11 (14)
Dependent on assistance in communication/vision	2 (2)	3 (4)
Dependent totally in communication/vision	1 (1)	1 (1)
Excretory functions	N=86	N=77
Complete voluntary control of bladder/bowel sphincters	69 (80)	61 (79)
Control of sphincters allows normal social activities	9 (10)	9 (12)
Dependent upon assistance in sphincter management	6 (7)	3 (4)
Frequent wetting/soiling from bowel/bladder incontinence	2 (2)	4 (5)
Physical condition	N=88	N=80
Minimal medical monitoring	36 (41)	40 (50)
Medical monitoring more than 3-month interval but not weekly	9 (10)	7 (9)
Medical problems require medical attention at least weekly	31 (35)	20 (25)
Medical problems require intensive medical attention at least daily	12 (14)	13 (16)
Support factors	N=88	N=80
Able to fulfill usual age-appropriate roles and perform tasks	28 (32)	30 (38)

Outcome measure	6-month follow-up, n (%) [†]	12-month follow-up, n (%) [†]
Must make some modifications in usual age-appropriate roles and performance of customary tasks	28 (32)	28 (35)
Dependent on assistance from adult in usual age-appropriate roles and performance of customary tasks	29 (33)	20 (25)
Dependent on long-term institutional care	3 (3)	2 (3)

* Some patients may not have responded to all of the questions about specific functional outcomes in the assessment at the time of interview.

[†] Percentages may not add up to 100%, as they are rounded to the nearest percent.

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