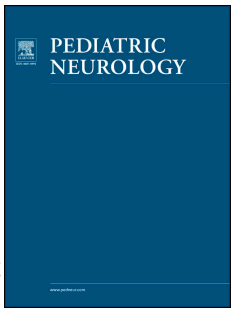

Unmet needs in the evaluation, treatment, and recovery for 167 children affected by acute flaccid myelitis reported by parents through social media

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Unmet needs in the evaluation, treatment, and recovery for 167 children affected by acute flaccid myelitis reported by parents through social media.

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Abstract

Objective. We aimed to characterize outcomes of 167 children affected by acute flaccid myelitis (AFM) by leveraging the power of social media.

Methods. Members of a closed social media (Facebook) group were invited to participate in an anonymous online survey. Descriptive statistics were applied to quantitative responses, and free-text responses were grouped into themes using a grounded theory approach.

Results. Caregivers provided information about 167 affected children; 77% were at least 6 months since onset. Clinical features matched those of larger published case series (e.g. walking impairment in 76.7%, IVIg treatment in 80.8%; 28.2% tested positive for EV-D68); 17 % children had asthma prior to AFM onset. Mean duration of initial hospitalization was 49.1 (SD = 74.0) days, and of initial inpatient rehabilitation was 42.3 (SD = 67.6) days.

Among challenges, parents frequently reported delays in diagnosis, including lack of neurological examination at initial medical evaluation for weakness. Other challenges included familial and professional impact of protracted hospitalizations, uncertainty about AFM's cause or prognosis, and the dynamic nature of care needs in growing children. The social media group played a critical role not only for social support, but also for dissemination of rehabilitation approaches and of networks of expert clinicians.

Discussion. Children with AFM have persistent and dynamic deficits, but many continue to show ongoing functional improvements beyond the initial expected window of recovery. In an emerging disease paralyzing young children, social media can strengthen knowledge networks and focus on rehabilitation.

Keywords: Acute Flaccid Myelitis, AFM, Social Media, Polio Like Syndrome, Facebook

Introduction

In 2018, the Center for Disease Control (CDC) formed a task force to tackle rising cases of acute flaccid myelitis (AFM) across the United States. Concerns had been voiced by clinicians and affected communities since at least June of 2012, when child neurologists reported 23 confirmed cases of AFM in children in California.[1] At the time, the CDC's position was that this did not represent a significant uptick in the background rate of AFM, a rare but known injury to the motor neurons of the spinal cord caused occasionally by a number of viruses,[2] including enteroviruses[3] (such as poliovirus). The best-known of these viruses is poliovirus, which was almost eradicated due to the efficacy of widespread vaccinations (22 reported cases worldwide in 2017).[4] However, larger biennial AFM clusters reported in 2014 and 2016 (326 cases were confirmed between August 2014 and June 2018), as well as 2018 (additional 158 cases confirmed for 2018 (of 311 reports under investigation), highlighted the fact that AFM rates were indeed rising.[5] A number of case reports and series have been published describing mainly the 2014 and 2016 experiences with non-polio-related AFM regionally (among others, in Arizona,[6] Colorado,[7-9] Florida,[10] Missouri,[11] Utah,[12] Washington,[13] nationally[14,15] and internationally (including Argentina,[16] Spain,[17] Germany,[18] Japan,[19] China,[20] and Australia/New Zealand[21]). These clusters of AFM coincided temporally with the first documented national outbreak of Enterovirus D68 (EV-D68),[22] a respiratory virus first identified in California in 1962 but which until 2014 had remained rare.[23] Since then, testing of nasal[14] and spinal fluid samples of children, as well as EV-D68 effects in animal models, lent support to EV-D68 as the cause of these excess cases of AFM.

With near eradication of poliomyelitis contributing to lack of training in younger medical professionals, parents whose young children were affected by this acute and sometimes devastating paralysis faced large vacuums in care with uncertain etiology and prognosis. In fact, recently, there has been an acceleration in efforts to collect prospective longitudinal data from these children and to describe the neuroimaging,[8,24,25] electrodiagnostic,[26] and infectious,[14] aspects of the condition and possible experimental therapies (e.g. fluoxetine[27]). However, as of June 1 2019, there was only 1 published case report pertaining to rehabilitation needs in AFM patients in the post-polio era.[28]

A parent of an affected child created a private social media group, "Parents of Children with Polio Like Syndrome / Acute Flaccid Myelitis", on Facebook, in 2013. The group currently includes 704 members. As with other patient support and advocacy groups, this group was founded to also help fill in voids in the scientific literature and in trained health care provider availability.[29]

In this study, we aimed to describe the gaps in the acute and chronic care of an emerging diseases, as perceived by 167 AFM caregiver members of an online social media group. First, we evaluated the representativeness of the clinical characteristics of the involved children with AFM by comparing them to published data. Then, we described the recovery and rehabilitation experiences of these children. Finally, we described parent responses regarding clinical and social needs unmet by the current healthcare system.

Methods

Survey: After obtaining permission from the closed group moderators, a link to an anonymous electronic survey was posted in the closed support group, "Parents of Children with Polio Like Syndrome / Acute Flaccid Myelitis". Survey 1 was deployed in August 2017, and parents were invited to participate via Qualtrics (www.qualtrics.com). Parents were asked to complete just one survey per child. One reminder was sent during the month period, and the survey was closed in September 2017. Survey 2 was expanded to capture additional information, including questions generated by parents on the site. To exclude duplicate responses, Survey 2 respondents who reported having previously completed Survey 1 had their Survey 1 responses excluded from analyses; and a second manual search for possible duplicate entries was performed (comparing age, state and year of onset, ethnicity). By parental request, parents had the option to skip individual questions, and so response rates varied per question.

Analyses: Descriptive statistics were used to analyze quantitative data from Surveys 1 and 2. An "S2" is included for all descriptive statistics when data were only available from Survey 2. We analyzed the free form text responses to generate a set of hypotheses relating to long-term challenges faced by children with AFM, that could be tested in future quantitative studies. To achieve this, we employed a grounded theory approach[30], which is widely used in qualitative research.[31] Specifically, steps of our methodology that are central to the grounded theory approach included: close line-by-line reading by two authors (RB, MC) of the qualitative data, identification of "open codes" (concepts anchoring the data), and iterative grouping of these open codes into more "selective" codes. Emerging themes could then be grouped into larger concepts, or categories of experiences. These larger categories were then ranked by frequency mentioned by individual respondents. Finally, quotes illustrating these individual categories were selected.

Ethical approval: This project was deemed 'exempt' by the UCSF Institutional Review Board. Before parents could access the survey, they read through a form describing implied consent and clicked to indicate their agreement.

Results

Survey Respondents.

Of 364 members of the support group in July 2017 (approximately 20% of whom were co-parents of a child with AFM but exact numbers not available), 103 parents completed Survey 1. Of about 500 members in September 2018, 116 completed Survey 2. 20 duplicates and 32 incomplete entries were excluded from analyses, for a total of 167 cases. At the time of the survey, mean duration since AFM onset was 2.37 years (median: 1.34, SD: 3.41); 68.6% of all affected children were at least 6 months since onset. Respondents' relationship to the affected patient (N=104, S2) were the mother (86, 82.7%), father (10, 9.7%), spouse (1, 1.0%), and other caregiver (grandmother or stepmother (5, 4.8%); other (2, 1.9%)).

Antecedent events.

Prior to AFM onset (S2 only), 71.1% (54/76) parents agreed with "My child was healthy with no prior medical concerns", 17.1% (13/76) reported "My child had a history of asthma", and 13.2% (10/76) reported seasonal/environmental allergies (3 reported both asthma and allergies). With respect to vaccinations (S2 only), prior to AFM onset, 89.3% were vaccinated according to schedule (67/75, S2), 6.7% were vaccinated but not up to date (5/75, S2), and 4.0% had never

been vaccinated (3/75, S2). Specifically, 94.5% (69/73, S2) were likely vaccinated against the poliovirus; just 15.6% (12/77, S2) had received any vaccine in the 3 months prior to AFM onset. Among children with siblings (141/163, S1+S2), 46.8% of siblings (65/139) also exhibited viral symptoms; no siblings or parents developed AFM. Two children (2.0%, S2) were socially connected to another affected child in their community prior to onset of AFM.

Demographic features at presentation.
We first determined whether the patients described in the surveys were similar to case series published by clinicians. As shown in **Figure 1**, the reported year of AFM onset reflected the biennial peaks confirmed by the CDC, in 2014, 2016 and 2018. At presentation, median (standard deviation, SD) age of affected children was 5 years (4.9) (N=166, S1+S2); 44.9% were in preschool or kindergarten (53/118), 80.2% were Caucasian (134/167), and 60.6% were boys (63/104, S2). For comparison, results from a review of 120 children affected in the 2012-2015 cohorts are tabulated in Table 1. In these reported cohorts, median age was higher, at 7.1 years.[15]

The majority of children were living in the United States (most prominently California, Massachusetts, Minnesota, Pennsylvania, Ohio and Texas). Of note, very few respondents were parents of the children affected in Colorado. The 23 children affected outside the United States lived in Canada (6), Australia (3), Thailand (1), and European countries (incl. England (2), Finland (1), France (2), Germany (1), Italy (1), Netherlands (1), Scotland (4), and Spain (1)).

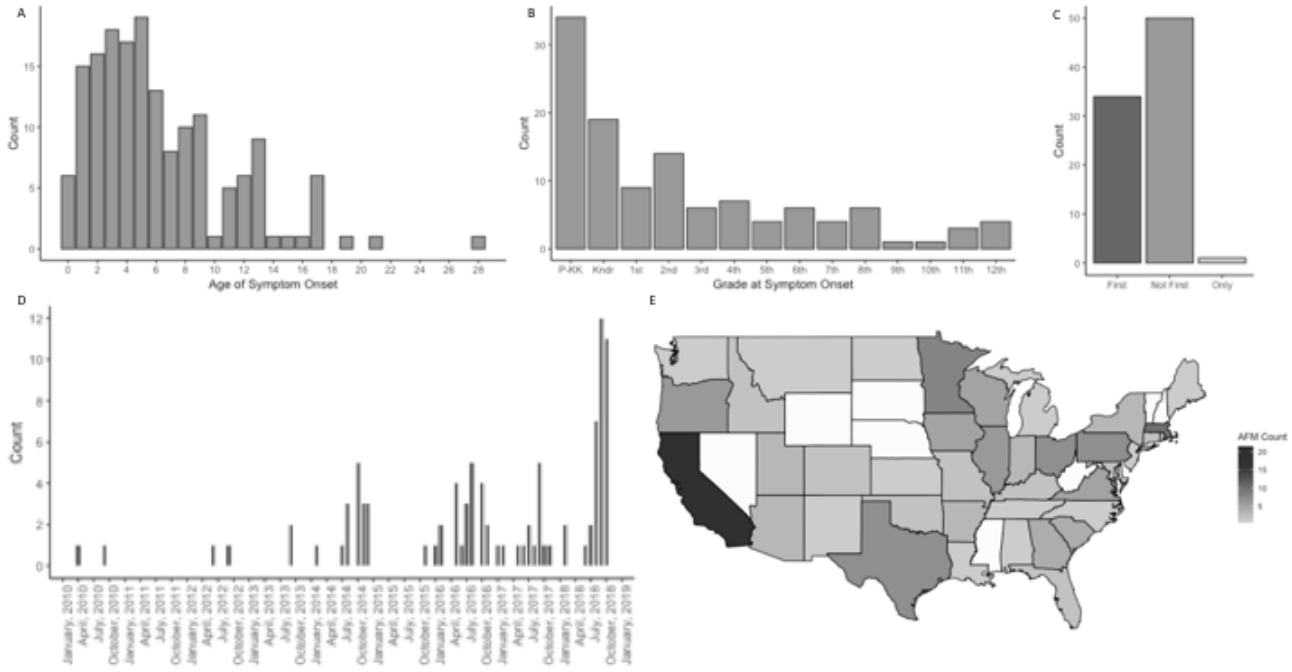

Figure 1. Demographic characteristics of 167 individuals affected by AFM in our online cohort. Age (A) and grade (B) at onset of neurological symptoms; (C) birth order; (D) month and year of symptom onset; (E) US residence at time of symptom onset, colored by count. No caregiver-reported cases from Alaska, Delaware, Hawaii, Mississippi, Nebraska, Nevada, New Hampshire, South Dakota, Vermont, West Virginia, or Wyoming.

Challenges on the Path to AFM diagnosis

Parents reported that their child did receive a formal diagnosis of AFM in 90% of cases (91/101, S2; 2% (N=2) were 'unsure'). Other diagnoses include transverse myelitis (N=4), 'post-viral paralysis' (N=1), Bickerstaff encephalitis and cervical anterior myelitis (N=1), 'acute motor axonal neuropathy' (N=1), and 'enterovirus-71' (N=1). Over one quarter of children tested positive for EV-D68 (37/131, 28.2%, S1+S2), and 3.8% tested positive for EV-A71 (3/78, S2).

When asked about challenges to diagnosis, over half (61.5%, 96/156, S1+S2) of respondents reported that their child experienced difficulty receiving a prompt diagnosis, with uncertain impact of delayed diagnosis or treatment on their child's prognosis. This seems to decrease between S1 (72.2%, 39/54) and S2 (55.9%, 57/102), possibly as a result of greater awareness about AFM in subsequent years. These challenges (S2 only), detailed in **Supplementary Table 1**, included wrong diagnosis (N=30), repeated visits to doctor or acute care facility required before the gravity of their child's condition was recognized (N=27), and receiving a diagnosis of conversion disorder/psychosomatic/'all in their head' (N=8, e.g. 'not walking due to stubbornness with potty training').

Many of these mis-diagnoses and delays may be partially attributed to a lack of a neurological evaluation by the initial clinician (e.g. 'pediatrician neglected to do a neuro exam on my son even though we told him his arm didn't work'), resulting in a variety of initial diagnoses that did not recognize a neurological syndrome (e.g. 'nothing wrong', 'dehydration', 'pulled muscle from coughing', 'rare tonsil issue', 'trauma from abuse, ingested chemicals'). In at least some of these children, specifically the younger children with less verbal ability, guarding from the acute pain that children experienced in the region of onset (e.g. neck pain with cervical spine/roots affected) could have made it more difficult to identify the paralysis (leading to interpretations such as 'toxic hip and neuropathy', 'nursemaid's elbow' (N=2), or 'neck pain from sinusitis').

Repeated visits to doctor or acute care facility arose even when a child's weakness was observed but not adequately evaluated ('discharged after overnight intravenous fluids despite being unable to sit or stand'; 'discharged while paralyzed, with a diagnosis 'fever with illness', discharged with meningitis diagnosis with weakness attributed to 'inactivity'). Even when a neurological syndrome was recognized, unfamiliarity with AFM and overlap of AFM manifestations with other neurological syndromes did result in mis-diagnoses (e.g. 'spinal stroke', 'Guillain-Barre syndrome', 'infectious facial paralysis', 'brachial neuritis') and treatment dilemmas.

Clinical presentations were overall similar to those reported in the medical literature.

Mean (SD) inpatient stay duration was 49.1 (74.0) days (median: 22, range: 0-671, N=151, S1+S2) (**Table 1**). At their nadir, the most common clinical manifestations of AFM, reported for over two thirds of children, were walking impairment (76.7%), leg weakness (79.9%), arm weakness (81.8%), sitting impairment (71.7%), and pain (66.7%). Quadriplegia occurred in 65 (40.8%, 65/159, S1+S2) of the children. Parents in the qualitative responses emphasized the burden of non-motor symptoms, such as pain, sensory changes and hypertension. Interestingly, almost one third (28.9%, 46/159, S1+S2) of these young children developed hypertension in the acute setting, a condition not reported in the AFM literature until 2019, where one mention was made of autonomic deficits.[32] There was a significant correlation between hypertension and

steroid treatment (OR 3.77, r =0.20, Fisher's p=0.017), although timing of hypertension relative to steroid treatment was not ascertained in this survey. In the 99.0% of children reported to undergo an MRI (99/100, S2), injury was primarily localized in the spinal cord grey matter (82/86, 95.4%, S2); but some injury to surrounding white matter was also reported (20/58, 34.5%, S2). Almost one quarter of children (20/82, 24.4%, S2) required tracheostomy. Mean duration of tracheostomy was 15.3 months (median [SD] = 12 [13.2]; S2, N=15). Some children were able to wean the ventilator after about 6 months, but, for example, of the 36 children who were ventilator dependent in 2014, three remained dependent in 2018.

Table 1. Demographic characteristics of the acute inpatient phase.

	Survey 1	**Survey 2**	**Surveys combined**	**CDC 120**[15,37]
Demographics				
Age (median (SD)) [age at survey]	*7 (6.14)*	*7 (5.78)*	*7 (5.91)*	*7.1 (0.4-20.8)*
Gender		*N=104*		*N=120*
Male		*63 (60.6%)*		*71 (59.2%)*
Female		*41 (39.4%)*		*49 (40.8%)*
Race	*N=62*	*N=105*	*N=167*	*N=95*
Asian	*0 (0%)*	*3 (2.9%)*	*3 (1.8%)*	*8 (8.4%)*
Black/African-American	*1 (1.6%)*	*2 (1.9%)*	*3 (1.8%)*	*7 (7.4%)*
Caucasian	*47 (75.8%)*	*87 (82.9%)*	*134 (80.2%)*	*79 (83.2%)*
Mixed ancestry	*11 (17.7%)*	*8 (7.6%)*	*19 (11.4%)*	*NR*
Other	*3 (4.8%)*	*5 (4.8%)*	*8 (4.8%)*	*NR*
Symptoms at Nadir	*n=58*	*N=101*	*N=159*	*N=120*
Vision	14 (24.1%)	19 (18.8%)	33 (20.8%)	NR
Face	15 (25.9%)	31 (30.7%)	46 (28.9%)	18 (15.0%) ^
Swallowing	21 (36.2%)	46 (45.5%)	67 (42.1%)	14 (11.7%)
Neck	26 (44.8%)	60 (59.4%)	86 (54.1%)	NR
Right arm	34 (58.6%)	74 (73.3%)	108 (67.9%)	NR
Left arm	38 (65.5%)	64 (63.4%)	102 (64.2%)	NR
Either arm	45 (77.6%)	85 (84.2%)	130 (81.8%)	92 (76.7%)
Both arms	27 (46.6%)	53 (52.5%)	80 (50.3%)	NR

Right leg	42 (72.4%)	66 (65.3%)	108 (67.9%)	NR
Left leg	40 (69.0%)	71 (70.3%)	111 (69.8%)	NR
Either leg	46 (79.3%)	81 (80.2%)	127 (79.9%)	79 (65.8%)
Both legs	36 (62.1%)	56 (55.4%)	92 (57.9%)	NR
Sitting up	37 (63.8%)	77 (76.2%)	114 (71.7%)	NR
Walking	44 (75.9%)	78 (77.2%)	122 (76.7%)	NR
Respiratory difficulties	31 (53.5%)	53 (52.5%)	84 (52.8%)	95/118 (80.5%)
High blood pressure	13 (22.4%)	33 (32.7%)	46 (28.9%)	NR
Infection **	14 (24.1%)	21 (20.8%)	35 (22.0%)	NR
Pain ***	39 (67.2%)	67 (66.3%)	106 (66.7%)	61 (50.8%)
Other (e.g., meningitis, fatigue) ****	10 (17.2%) [check this]	14 (13.9%)	24 (15.1%)	NR
Bowel and bladder incontinence	--	43 (42.6)		NR
Numbness, tingling *****	--	35 (34.7%)		NR
Joint pain or laxity	--	34 (33.7%)		NR
Treatments received	*N=56*	N=95	*N=151*	*N=120*
Intravenous immunoglobulin	41 (73.2%)	81 (85.3%)	122 (80.8%)	88 (73.3%)
Plasmapheresis	17 (30.4%)	36 (37.9%)	53 (35.1%)	18 (15.0%)
Steroids	38 (67.9%)	79 (83.2%)	117 (77.5%)	65 (54.2%)
Antivirals	19 (33.9%)	25 (26.3%)	44 (29.1%)	NR
Fluoxetine	-	24 (25.3%)	-	NR
Other (e.g. gabapentin, antibiotics, pain medications)	22 (39.3%)	15 (15.8%)	37 (24.5%)	NR
EV-D68 Testing	*N=44*	*N=87*	*N=131*	
Positive	9 (20.5%)	28 (32.2%)	37 (28.2%)	11/56 (20%)
Duration of acute inpatient stay (days)	*N=54*	*N=97**	*N=151*	*NR*
Mean	49.9	48.6	49.1	NR
Median	23.5	22	22	NR

SD	62.5	79.9	74.0	NR
Q1, Q3	8, 60	10, 50	9, 60	NR
Range	2-292	0-671	0-671	NR

* N=3 were still hospitalized at the time of the survey, have not been included in N=97
** Infections in the acute settings included aspiration pneumonia, urinary infections, and persistent upper respiratory symptoms/sinusitis. *Clostridium difficile* infection was reported in one child.
*** Pain included both radicular pain with onset prior to the paralysis (e.g. neck pain when cervical spine/roots affected), as well as pain shooting down the legs, typically behind the knees. Both responded to gabapentin/pregabalin; other treatments included opioids, benzodiazepines and muscle relaxants, ibuprofen and acetaminophen. Parents also reported some allodynia and hyperesthesia.
**** 'Other' symptoms reported included headaches, 'induced coma', iatrogenic complications (e.g. gastric bleeding from steroids), and other symptoms of autonomic instability (hypotension, variable heart rate, high temperature with persistent sweating episodes).
***** Sensory changes included paresthesias, loss of sensation, and hyperesthesia/allodynia.
^ Facial weakness and numbness

Acute and chronic rehabilitation trajectories.
For the children going on to inpatient rehabilitation after their hospital stay, mean (SD) duration of stay was 42.3 (SD:67.6, range 0-500) days (S1+S2, N=128). Thereafter, a majority continued with outpatient therapy (**Table 2**). Median number of hours weekly in the first six months was 6-11 hours, and this decreased to 0-5 hours thereafter (**Supplementary Table 2**). Parent-reported benefits of physical and occupational therapy included direct gains in walking, balance, strength, confidence, independence, stamina; guidance regarding orthotics, bracing, and ambulatory assistance (wheelchairs, walkers, etc.); administration and guidance for functional electrical stimulation; maintenance of bone and muscle integrity; prevention and treatment of spasticity in children with white matter injury. Parents did not report as much ongoing utility of speech therapy except in specific cases of severe dysphagia. Aquatherapy was noted to be particularly useful.

Nineteen percent of children had undergone nerve transfers at the time of the survey (28/145, S1+S2), at a mean (median, SD, range) of 91.0 (67.5, 91.6, 0-413.1; N=18, S2) weeks since onset of AFM. The majority of parents considered the transfers successful (87.5%, 14/16, S2), reporting recovery noted within 6 months (29.4%, 5/17, S2), after 6 months (47.1%, 8/17, S2) and 4 were too soon to tell (23.5%, 4/17, S2). All parents (17/17) did recommend the procedure.

Table 2. Overview of rehabilitation care received.

	Survey 1	Survey 2	Surveys combined
Duration of initial inpatient rehabilitation program (days)	*N=43*	*N=85*	*N=128*

Mean	39.9	43.5	42.3
Median	7	22	21
SD	61.9	70.6	67.6
Q1, Q3	0, 56	1, 50	0-56
Range	0-275	0-500	0-500
Types of outpatient therapies received	*N=46*	*N=91*	*N=137*
Physical Therapy	44 (95.7%)	87 (95.6%)	131 (95.6%)
Occupational Therapy	40 (87.0%)	77 (84.6%)	117 (85.4%)
Speech/Swallow/Language Therapy	28 (60.9%)	47 (51.6%)	75 (54.7%)
Other Therapies	23 (50.0%)	40 (44.0%)	63 (46.0%)
Use of Braces/Orthotics	*n=50*	N=96	N=146
Yes *	36 (72.0%)	59 (61.5%)	95 (65.1%)
No	14 (28.0%)	37 (38.5%)	51 (34.9%)
Use of Electrical Stimulation	*N=50*	N=96	N=146
Yes	32 (64.0%)	70 (72.9%)	102 (69.9%)
No	18 (36.0%)	26 (27.1%)	44 (30.1%)
If yes:			
Frequency at least 4 times a week		31/60 (51.67%)	
Median duration (minutes)		30 (SD = 20.3, range: 8-120)	
See nerve fire during stimulation? Respond “yes”		32/61 (52.5%)	
Use of functional electrical stimulation (FES) bicycle?		N=66	
No		36 (54.5%)	
Yes, at home		9 (13.6%)	

Yes, in rehabilitation		22 (33.3%)	
If yes, helpful?		N=30	
Yes		15 (50%)	
Maybe		13 (43.4%)	
No		2 (6.7%)	
Nerve Transfer performed?	*N=49*	N=96	N=145
Yes	8 (16.3%)	20 (20.8%)	28 (19.3%)
No	41 (83.7%)	76 (79.2%)	117 (80.7%)

* Orthotics included: ankle-foot orthotics (AFOs) due to weak plantarflexion (n= 47), bracing for scoliosis (n=21), other knee and leg orthotics (n=27), shoulder bracing to prevent subluxation (n=14), hand, wrist or elbow bracing (n=14), neck bracing (n=12), shoe inserts (n=6), among others.

While a number of parents persisted with ongoing rehabilitative care beyond the initial diagnosis, the neurologist's role diminished. Only 23.0% saw the neurologist more than twice a year (17/47, S1; 11/75, S2), and 29.5% less than once a year (8/47, S1; 28/75, S2). Responses regarding their utility appeared to reflect neurologists' interest in, access to information about AFM and outlook. When this was poor, responses included "Horrible – knows nothing and is zero help"; "She told us to accept what we have and we've not been back. Her role is Dr. No"'. When neurologists were more familiar with AFM, responses were more favorable: "She helps u understand the low-level causes, and keeps up with national developments"; "Dr. [AFM expert] – encouragement and direction"; "Were [sic] only 3 months out but she recommended nerve transfer right away and has been very accommodating and spoke on the phone with me numerous times"; "My son was originally diagnosed with Transverse Myelitis. Once we saw [AFM expert] two months after he was discharged he changed it to AFM due to his MRI and clinic observation. He also referred him for nerve transfer."

Current status of recovery and child development

Mean duration since onset at the time of the survey was 2.37 years (median: 1.34, SD: 3.41); 77.1% (128/166, S1+S2) of all affected children were at least 6 months since onset. Following the acute phase, recovery was mostly poor, and most children were left with sequelae, with only 2.4% parents reporting their child had fully recovered and 14.6% parents reporting barely perceptible deficits (**Table 3a**). The most common specific residual deficits, each affecting >50% of children, were weakness in either arm, weakness in either leg, walking impairment, and fatigue. Developmentally, limb length discrepancy and osteoporosis had occurred in one quarter of children (**Table 3b**). Encouragingly, for children who were at least 6 months out from onset of AFM, 80.4% parents (41/51, S2) reported ongoing, even if subtle, improvements in function, including new regions activated, and increased strength or bulk of recovering muscles, range of

motion, or balance. Additionally, about 50% of children were able to participate in some form of athletics (including adaptive sports) (63.9%, 23/36, S1; 42.3%, 30/71, S2).

Table 3. Persistent deficits in children affected by AFM at a mean duration of 2.4 years since AFM onset. (a) Patient assessment of child's overall functioning at time of survey (Survey 2 only). (b) Current deficits at the time of the survey (Surveys 1 and 2).

		TIME SINCE ONSET				
	ALL N=82	**<6M (N=26)**	**6-12M (N=2)**	**1-2Y (N=4)**	**2-4Y (N=26)**	**4+Y (N=24)**
Completely back to normal, no deficits	2 (2.44%)	0	0	0	0	2
Some deficits, hardly perceptible unless you look	12 (14.63%)	4	1	0	3	4
Deficits continue to limit their ability to do what they would like	37 (45.12%)	14	0	0	12	11
My child's ability to participate in daily activities has changed dramatically	31 (37.80%)	8	1	4	11	7

	Survey 1	**Survey 2**	**Total**
	N=46	*N= 83*	*N=129*
Symptoms			
Vision	4 (8.7%)	10 (12.0%)	14 (10.9%)
Face	6 (13.0%)	10 (12.0%)	16 (12.4%)
Swallowing	5 (10.9%)	15 (18.1%)	20 (15.5%)
Neck	11 (23.9%)	27 (32.5%)	38 (29.5%)
Right arm	19 (41.3%)	48 (57.8%)	67 (51.9%)
Left arm	23 (50.0%)	39 (47.0%)	62 (48.1%)
Either arm	34 (73.9%)	63 (75.9%)	**97 (75.2%)**
Both arms	8 (17.4%)	24 (28.9%)	32 (24.8%)
Right leg	20 (43.5%)	40 (48.2%)	60 (46.5%)
Left leg	20 (43.5%)	43 (51.8%)	63 (48.8%)
Either leg	26 (56.5%)	51 (61.4%)	**77 (59.7%)**

Both legs	14 (30.4%)	32 (38.6%)	46 (35.7%)
Sitting up	4 (8.7%)	23 (27.7%)	27 (20.9%)
Walking	32 (50.0%)	43 (51.8%)	**75 (58.1%)**
Pain (in location of onset, e.g. neck or hips; and back of the knees)	21 (45.7%)	30 (36.1%)	51 (39.5%)
Respiratory difficulties	7 (15.2%)	21 (25.3%)	28 (21.7%)
Legs that are different lengths	17 (37.0%)	19 (22.9%)	36 (27.9%)
Fatigue	28 (60.1%)	40 (48.2%)	**68 (52.7%)**
Arms that are different lengths	12 (26.1%)	15 (18.1%)	27 (20.9%)
Osteoporosis	14 (30.4%)	17 (20.5%)	31 (24.0%)
More infections	10 (21.7%)	18 (21.7%)	28 (21.7%)
Other (e.g. subluxation, scoliosis, muscle atrophy, heat intolerance, depression)	16 (34.8%) *no scoliosis incl.	50 (38.8%) *scoliosis is 29 of 50 here	66 (51.2%)
Bowel and bladder incontinence	--	24 (28.9%)	--
Joint pain or laxity	--	24 (28.9%)	--
Numbness, tingling	--	0 (0.0%)	--
No sequelae	0 (0.0%)		

Persistent challenges beyond the acute setting

In mixed qualitative and quantitative responses, parents described a number of challenges to their child's recovery. Uncertainty regarding the cause of their child's deterioration persisted as an emotional burden for parents, as did the loss of their child's former 'normal' existence. While most of the children were reported to be functioning at average or above average academically (64/67 (95.5%, S1+S2), they experienced behavioral sequelae such as anxiety, emotional outbursts, and challenges navigating their peer or sibling relationships. With respect to care, parents' general experience can be summarized with "I have encountered so many uninformed emergency medicine doctors, pediatricians, neurologists, rehab specialists. This is not unexpected because AFM is an emerging disease, but it absolutely needs to be addressed and has not been." Lack of literature on rehabilitation was one reason for poor insurance coverage of ongoing rehabilitation needs. Relating to longer time frame of recovery, parents mentioned high burden on them in terms of changes in employment, income and time allocation to accommodate and pay for their child's recovery. For example, 81.4% reported at least one caregiver needing to

take at least 1 month off work (S1+S2, N=84: 4.9% no time; 23.5% <1 month; 28.4% 1-3 months; 13.6% 3-6 months; 6.2% 6-12 months; 3.7% >1 year; 6.2% switched to part-time; 13.6% quit work permanently) (**Supplementary Table 3)**.

DISCUSSION

Almost seven years after the initial description of a concerning increase in the incidence of AFM in the United States, a number of encouraging initiatives have been developed including a dedicated CDC task force, a dedicated clinical working group, and a dedicated foundation (afma.org). During these intervening years, however, geographically disparate pockets of parents navigated the care and development of severely affected children with a dearth of available information or clinical expertise. In this setting, the current social media group filled a number of important gaps, rapidly disseminating information across states and even countries, and synthesizing information so that new members of the group were more able to access the 'best of' prior posts. This information could also improve approaches used by health professionals in developing, improving and evaluating social support systems for parents/caregivers.

In the current manuscript, we first evaluated the demographic and clinical characteristics reported for the affected children. We identified several discrepancies relative to published clinical cohorts, likely reflecting survey biases. For example, few children were included from the Colorado outbreaks, suggesting that the Colorado parents were either better guided through their local clinic and therefore less reliant on social media, were more apprehensive about social media, or, experienced survey fatigue given the more extensive data capture at their site. Children's ages were also lower than previously reported, possibly pointing to greater need for support or information for younger children whose dynamic developmental needs might be more challenging.

We also identified some other interesting differences. For example, respondents described specific symptoms, hypertension and bowel/bladder symptoms, that were not published in the larger case series and may have been under-ascertained in prior research. Second, one in five children underwent nerve transfers, indicating the role that rapid dissemination of information can play when medical standards of care have yet to be established. Finally, we saw some evidence of improvements in clinical awareness, evaluation and care of AFM in more recent years: while challenges to diagnosis were still reported by a large proportion of parents, there was significant improvement between children with AFM onset 2014-2016 (69.1%) and those with AFM onset after 2016 (45.7%) (Fisher's exact, $P < 0.01$).

Without a definitive reference cohort or information about the families choosing not to respond to the survey, it was not possible to fully evaluate for response biases. Our survey did have low overall response rate, as well as variable response to specific questions. These biases could have included individual parental or familial factors, such as (1) lower socioeconomic status or literacy in the household, resulting in decreased time for or ability to access social media; (2) access to emotional, social and medical support in their families and communities vs. online; as well as (3) variable concerns about online activity, including privacy or more general reluctance to 'speak up' and expose themselves to others' comments. Literature from online social support and information groups, suggests that the benefits of participation permeate from the active users

to the more prevalent (45-90%) 'silent majority' of passive "lurkers" who post occasionally or not at all, but are known to read the group's postings regularly and to benefit in similar areas compared with active members."[33] Response biases could also have included child-related factors. For example, parents with more severely or recently affected children might use the site both more often to access critical information, and over a longer duration when recovery was incomplete; or conversely less often, given a more substantial caregiver burden. As national and international cohorts are developed, it will be possible to gauge which of these factors might have biased the current responses.

The benefits of participating in online social support and information groups, especially pertaining to stigmatized conditions, include anonymity, freedom of expression, control of when/how much support to receive, expanding social network, increased self-efficacy and empowerment.[29] These benefits have been well described for parents of children with other conditions requiring specific approaches or care, such as Autism Spectrum Disorders (ASDs).[34] Risks include exposure to misleading information or to greater uncertainty about clinical trajectory, and to negative comments from others.[35] Beyond their typical established roles in managing membership (including blocking inappropriate members) and managing the discussion (to help participants to feel at ease, establish the goals and boundaries of the discussion, and rule setting),[36] the group moderators played a further expanded role by specifically establishing working groups to collect data, organize advocacy, and interface with clinical groups.

The overall picture of long-term outcomes is that the most children were left with persistent deficits that included not only walking but also significant numbers of children with other sequelae such as pain, and bowel and bladder dysfunction, with persistent albeit slow improvement in function. The results also highlight a severe burden of parental care, family impacts, and unmet needs. Awaiting more complete, rigorous and clinically validated data, the current observations may serve to foster greater awareness regarding specific areas for improvement in the acute clinical management of affected children (including performing a neurological examination in children presenting with weakness), focused parental guidance regarding rehabilitative interventions including nerve transfers and electrical stimulation, and the long-term challenges and opportunities in the care of children.

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Supplementary Table 1. Qualitative responses regarding challenges in diagnosis reported by respondents to Survey 2.

INITIAL DIAGNOSES: NEUROLOGICAL SYNDROME NOT RECOGNIZED
"It took a full week for a diagnosis--he kept being treated as a kid with strep even though he was losing strength and not responding to anything"
"They kept trying to tell us our kid had croup and was just lethargic. She went into respiratory failure later that day and was diagnosed until 2 days later"
"Was admitted straight away in a local hospital but was there for 3 days with suspected pneumonia. Only when I said this didn't feel right did they consult another hospital and then when my son deteriorated we were transferred. There he then received steroids, IVID, and PLEX without issue"
"Went to 4 doctors in one week. Last time at the emergency room the ER Dr. had the foresight to do an MRI. Pediatrician neglected to do a neurological exam even though we told him my daughter's arm did not work."
"Discharge from ER with fatigue, pneumonia diagnosis. Admitted in respiratory failure due to 'pneumonia', neurological eval not done until day 3 of paralysis"
"No one knew what our daughter treatment took longer than what it should have I feel that if they would have treated her sooner it wouldn't have got to her losing 50% of her body to begin with within the matter of 20 minutes she had lost her arm and her leg and nobody had bothered to start steroid treatment I literally had to push an emergency bunted to get nurses to help me help my daughter"
"At the ER, they told us the reason his arm wasn't moving was [because] of an injury which we knew was not the case. After X-rays showed nothing, they did not want to investigate further and told us to go home and see how he was doing in the morning. We then pushed to be admitted to the children's hospital. Once we got there, they did CT to rule out infection (active ear infection at the time) and then became concerned about AFM and ordered MRI. Diagnosis came as he was coming out of MRI."
"Dismissed by pediatrician and first ER visit. Diagnosed with pneumonia and fatigue/ dehydration although was paralyzed from C2 down and in early stages of respiratory distress."
"My child first went to an urgent care facility; from there was flown by helicopter to the ER at the big children's hospital; she was ignored for 6 hrs and sent home to "get better." Obviously had to return to the ER the next morning. UGH"
"Went to the ER spent all day was told he was just dehydrated sent home went back the next morning when he was worse. More tests done again they were thinking just dehydration but wanted to admit him to watch him that's when I said no I want transferred to children's hospital. Spent 2 weeks testing before AFM diagnosis but he was the first in Colorado so it wasn't known yet"
"Went to ER with tingling hands and feet with stiff neck. Diagnosed with sinusitis and a lulled muscle from coughing."
"Told it was likely a stomach bug then HFM then a movement disorder, all while symptoms were getting worse but before paralysis. Went to ped office 1x and urgent Care 3x before getting moved to children's hospital."
"Sent home from urgent care after IV fluids. Diagnosed with Strep, mono, GBS."
"Toxic hip. Toxic neuropathy"
"No one wanted to diagnose or test for anything. The health department here in town said that they didn't want the hospital wasting time and money on testing for a diagnosis for an enterovirus."
INITIAL DIAGNOSES: NEUROLOGICAL SYNDROME RECOGNIZED

“Multiple ER and specialist visits. Because AFM was so new, they weren't sure how to diagnose or treat.”
“The hospitals in the U.K. Do not recognise AFM, we have arrived at this diagnosis through our own research. Our official diagnosis is a mixed picture of Transverse Myelitis and Guillain Barre.”
“At the children's hospital doctors didn't know what it was, they didn't give a us a diagnosis until the 4th day (ATM) We have to see another neuro in other hospital and finally got AFM diagnosis. 1st hospital was very pushy about the IVIG treatment but they didn't know it it was ok or not for what they thought she has.”
“In the netherlands there are only 2 kids [with AFM]. the doctors don’t know what to do.”
“In our case, the Dr. had no clue this existed as well as the hospital. [Our child] is technically still diagnosed with ADEM”
“Neurologists correctly diagnosed AFM but then said, "nothing to do, supportive care" based on CDC guidelines. If I had not reached out to others to hear about east coast protocols and pressed for treatment, she would not have gotten Prozac and IVIG.”
“We saw our pediatrician, who suggested we would need an MRI, but couldn't get us an appointment for at least a month. He insisted it wasn't urgent and sent us home. Went to urgent care (it was a weekend) a little later and they sent us home as well. That night, he spiked a fever and began to cry uncontrollably, so we took him to the ER where he was finally admitted.”
“My child was actually born in 1984 and got the virus in 1992. She was not diagnosed until many years later because no one knew what she had”
“They did a spinal tap and decided it was viral meningitis. They were preparing to send him home when we noticed he couldn't move. We had to push the doctors to relook at him many times. I was not leaving the hospital until someone could answer why he couldn't move. It wasn't until we got the infectious disease dr to look at him that she knew something else was wrong.”
“Transferred to Denver 2 wks later got true diagnosis”
“Took him to hospital and they tried to send him home saying it was spinal meningitis and that he was not moving because he was choosing not to, we insisted he be transferred to BBCH where he was immediately treated and diagnosed a few days later”
“We've gone to two hospital emergency rooms and have seen her pcm where they all diagnosed her with nursemaids elbow or dislocated shoulder.”
“Sent home from PCP, first time just a bad cold - didn't do the Lyme test I suggested. Week after this lyme negative, must be growing pains then - sent home again. My son broke his right arm prior to onset - it was our ortho that sent us to the ER”
“At first they thought it was trauma caused by abuse, or that she had ingested chemicals, but it was ruled out. We had a lot of trouble with insurance until I had her doctors add the diagnosis of transverse myelitis, but that was before AFM was coined.”

“1 dx - nursemaid's elbow; 2 dx brachial plexus injury; 3 dx parsonage turner syndrome; 4 dx AFM. We went to urgent care at time of onset, 8-21-16, then were referred to ER so went and were discharged following morning with no answers except negative for nursemaid elbow and potentially something neurological. Follow up appt 8-25, possible brachial plexus. Follow up 8-31, possible parsonage turner syndrome, finally admitted to hospital that day, then 9-1 dx AFM”
“The ER we went to wanted to send us home for follow up with our pediatrician the next day. They were determined it was an injury and advised against a spinal tap even though he complained of neck pain. We refused to just go home and asked to be transferred to the children's hospital.”
“We were sent home twice 2 days in a row from the same ER saying they had no idea what was wrong with him. We finally went to CHOP our 3rs time and finally got the care and diagnosis we so desperately

needed."

"Attended local hospital A&E as [he] was vomiting, unable to keep down any liquids, had been delirious over night, uncontrolled temperature, not passing urine, unable to stand, viral rash and not eating. He was admitted for one night given IV fluids and discharged the next day, despite being unable to stand. We returned a day later, as he was unable to hold himself in a sitting position, his neck had slumped and he could not roll over. We were rushed by ambulance to the nearest Children's hospital as they suspected EV68. The paralysis and pain set in rapidly from that point"

"Saw doctor all week before and then was cleared from followup. Was discharged while paralyzed, from our local ER with a diagnosis of 'fever with illness.'

"During treatment of meningitis, child began having severe pain in legs and continued pain in neck. Was told it was due to length of illness and inactivity. Child was not able to hold self up or walk at time of discharge. Continued to question weakness. Policy to see specialist was referral from primary physician and wait for return call to set up appointment. Much time was lost waiting for referrals between specialists. Final diagnosis was over 1 month later."

"We were sent home from the ER twice and almost a third time. Upon discharge, was told that it was most likely NMO. A few weeks later, we got the AFM diagnosis."

"Visited ER twice and pediatrician x1, dx'd with mono second ER visit and given IVF then sent home."

"We first went to urgent care for the viral symptoms. They could not find anything and prescribed antibiotics. The next day we took her to our towns hospital because paralysis had began and they didnt believe she could not use her arm and then diagnosed her with a sprained shoulder. We then drove 160 miles to take her to the ER at the childrens hospital and she was properly tested and diagnosed there."

"She started with a fever and her right arm and neck affected. Day 1 no one at our loacal ER had a clue. Day 2 they diagnosed her with a rare tonsil issue. Then her left arm went and they sent her to a different hospital and they were unsure. About 5 days later they diagnosed transverse myelitis and 2 days after that AFM."

"She had right arm paralysis. Went to the doctor, they said it was a pulled elbow and sent us to the children's hospital. At the hospital they said that she probably slept on it funny (Monday night). Went back to the hospital Wednesday morning, the doctors seemed more concerned and wanted neuro to come see us in the emergency depepartment, neuro wouldn't come and made an appointment for the Friday. Once at the appointment (5 days post onset) it as finally taken seriously. She did not have an MRI until Monday (1 week post onset) and was given treatment the following day. She was not diagnosed for almost 6 weeks post onset and I brought them the info about AFM and asked if this was what she had and they said yes. They did not discuss or mention AFM until then."

"He was seen in urgent care on the first day but then sent home"

"Sent home unable to walk from Children's hospital in Columbus after ct scan of abdomen fluids and pain meds
Doctors appointment Friday before onset neck pain ear infections and fever"

"Took to ER with facial paralysis, fever, couldn't walk. They tested for strep. It was negative. They sent us home, said it was just a virus."

"He was first diagnosed with Transverse Myelitis."

"Took 2 days for full MRI brain/spinal cord to be completed and AFM diagnosis to be given.
Due to CDC "recommendations" of supportive care only, neurologists at our hospital did not want to offer any treatments."

"Adult, so hard to diagnose. NMO, TM, and 100 or so tests for all kinds of things (GBS, West Nile, Lymes, etc.)"

“Doctors treated her like a patient with Transverse Myelitis, but told us from the beginning that her MRI images looked different from other TM cases because of the gray matter and told us it looked similar to polio. The treatments had little impact on her, so the doctors knew it was something more.”
“Initially diagnosed as TM by primary pediayattending service. The consulting neurologist acknowledged AFM as the more appropriate diagnosis. On day 4 of admission, after 2 doses of IV methylprednisolone, his symptoms worsened. The recommendation was to start PLEX, but I had to aggressively advocate to start it the same day. The PLEX doctor and the general surgeon (needed to place central line) were not in agreement/support of starting the same day. I demanded a face-to-face meeting at my son's bedside to hash out the plan with ALL necessary parties. He went to the OR within the next hour (5 am) and had 1st PLEX completes by 9pm.”
“Diagnosed as: Spinal Stroke, Guillian Barre, ADEM, TM then AFM”
“Our son was initially diagnosed with pediatric onset MS. We spent a year chasing that diagnosis. That was essentially ruled out in 2017, leaving us with AFM. We had pretty much settled in that one prior to MS being ruled out.”
“We were originally diagnosed with AFM and then they changed his diagnosis to stroke with possible AFM. Communication with his neurologist was very little and he never explained why they changed his dx. My son had zero genetic markers for stroke and had no signs of stroke on his MRI's. After unsuccessfully trying to communicate with his neurologist here, we decided to make the trip to Dallas to see Dr. EXPERT who immediately told us after looking at his MRI'S that it definitely was AFM. We just got confirmed today!”
“Said it was Transverse Myelitis
“They weren't sure of what was wrong. They considered Guilliane Barre, but said he was presenting atypically. They were not convinced he had Guilliane Barre and after researching and comparing research to CHILD'S bloods and mri results they concluded he had AFM”
“Spinal stroke and TM”
“firstly GBS after a EMG it was AFM. then they say sort it out your self we have not enough people to help you.”
“Didn't know what it was. Gave steroids but dr was afraid to give plasmathesis because of possible side affects. When plasmathemasis was finally given rage of disease started to slow down.”
“Went to one ER that did lots blood test cat scan of mri of neck but not spine sent to another Hosptial (children's) where the messed up first mri that they put her under for 2 hours and the. Had to do another mri for 2 hours of brain and spine.”
“CHILD presented with sudden onset paralysis, in the ED she was Dx spinal stroke and GBS, later she was Dx TM and then possible TM and AFM combonation with a possibilty of spinal stroke, we are still unsure of correct Dx despite seeing many specialists.”
“Initial diagnosis was brachial Neuritis. 8th day in the hospital,after the 3rd MRI it was changed to AFM.”
“No one knew what it was we had to go to children's hospital 12 hours away from family to get any diagnosis.”
“The doctors had never saw this at the hospital we were at, They kept saying they don't know, was trying different Antibiotics in high doses of steroids that cause him to have several stomach bleeds”
INITIAL DIAGNOSES: PSYCHOSOMATIC
“Our children's hospital said it was psychosomatic and didn't want to treat my son at all, except recommend names of psychologists/psychiatrist. My son was in a wheelchair, they didn't even help me get him into my car (it was just me and him for the 3 day hospital stay) and wouldn't give us a Rx for PT.”

"At onset we went to urgent care and were immediately flown by helicopter to the ER at CHOA. We spent six hours there with a dr doing nothing. We were sent home with Dx of conversion disorder. She awoke the next day paralyzed neck down. Went by ambulance back to the same ER. Was diagnosed with TM after an MRI later that day. Subsequently - years later - Dx changed to AFM.

"She tested negative for the tests they gave her (they focused on head injury because of her soccer). They also looked for GB, Meningitus, etc. - all negative."

When they couldn't confirm those common diagnosis they told her she was just being emotional. We heard this from the first three neurologists. Finally we pushed for an EMG (4 months) and it showed nerve damage in half the nerves in her lower right arm and lower right leg."

"Son was first tested for everything but then it was stated that it was Lyme's and didn't search for further answers until Lyme's test was negative. (3 days time) No neurologist was advised to take part in any of this until after previous thoughts and test were unfounded. As further neurological symptoms progressed, was told it was all in his head and that he was responding to prevent further pain. Not that it was a true flaccid paralysis was occurring."

"He was diagnosed with a respiratory infection, was told he was having 'displaced pain' (this was when he said his legs were heavy), and told basically told over and over it was just a bad cold"

"We were told his neck pain was only in his head or related to a possible ear infection (although they didn't see evidence of an ear infection), he was denied care at an ER, then at another hospital we were told he had TM"

"Despite me telling the ER doctors that my son was running a fever the afternoon even collapsed and that I had given him Motrin for fever and hip pain, they discharged him from the hospital after 3 days stating that it was psychosomatic and that it wasn't viral he cause there was no fever. In fact, which there, they kept him on Rx Motrin for a severe spinal headache after a LP, so of course he didn't present with a fever. As we went home I told my son that I wasn't going to give him any kind of pain meds/fever resudicers for a few hours to see if he had a fever and within hours he had one."

"3 different hospitals, claimed she was not walking due to stubbornness with potty training"

Supplementary Table 2. Parent-reported number of hours spent in rehabilitation therapies weekly (Survey 2).

MILESTONE AFTER ONSET	0-5 hours	n	6-11 hours	n	11-15 hours	n	16-20 hours	n	21-25 hours	n	26-30 hours	n	31-35 hours	n	36+- hours	n	Total N
1 month	36.6%	34	**26.9%**	**25**	16.1%	15	11.8%	11	2.2%	2	3.2%	3	1.1%	1	2.2%	2	93
3 months	39.0%	30	**29.9%**	**23**	15.6%	12	6.5%	5	3.9%	3	1.3%	1	1.3%	1	2.6%	2	77
6 months	48.4%	31	**28.1%**	**18**	14.1%	9	7.8%	5	0.0%	0	0.0%	0	1.6%	1	0.0%	0	64
1 year	**56.7%**	**34**	30.0%	18	6.7%	4	3.3%	2	0.0%	0	0.0%	0	3.3%	2	0.0%	0	60
2 years	**60.7%**	**34**	26.8%	15	5.4%	3	1.8%	1	1.8%	1	1.8%	1	1.8%	1	0.0%	0	56
3 years	**79.3%**	**23**	17.2%	5	0.0%	0	0.0%	0	0.0%	0	3.5%	1	0.0%	0	0.0%	0	29
4 years	**86.4%**	**19**	9.1%	2	4.6%	1	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	22
5 years	**100.0%**	**8**	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	8
6 years	**85.7%**	**6**	14.3%	1	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	7
7 years	**100.0%**	**5**	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	5
8 years	**100.0%**	**5**	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	5

Supplementary Table 3. Areas of greatest challenge reported by parents in the chronic phase.

CHILD'S SOCIAL BEHAVIOR	
Anxiety	"She has anxiety and cries a lot and gets upset around people"
	"[Our child has] anxiety and depression. She has lost her independence."
	"She is terrified of strangers, the trach has made her in verbal for the most part but she's trying to learn to talk again."
Dysregulation	"Some issues with executive functioning such as dealing with emotions - can sometimes get upset/angry at the drop of a hat, more so around us"
	"...she is more prone to disproportionate outbursts than she was prior to onset. Every once in a while she seems to find something to latch onto to justify why she is mad or acting up and I think in the end it is just a way she has to get her frustration out."
	"He acts younger than stated age at times"
	"emotional breakdowns are common due to frustration and weariness over his inability to walk and use his right arm."
Social discomfort	"since her face has had droopiness it it's hard for her to look at people in the face for fear that they will look at her differently or laugh"
	"The one challenge I've seen is that since he is a teenager sometimes a few of his old friends don't really know how to interact with him, almost like they are nervous or don't know what to say. It hurts. This part where he isn't able to go do things on his own with friends is the most painful. I'm hoping that at least with us getting back to therapy soon he will get some of the social part of life he needs so much."
	"She was very young when she got sick so doesn't really have a lot of 'friends'"
Impact on siblings	"She is a lot more aggressive towards her sisters especially her youngest she almost bullies her which we have tried and are working on breaking this habit."
CHALLENGES TO MEDICAL CARE	

Lack of qualified rehabilitation	“Our home is not wheelchair friendly and we can not afford to change that. He is at the age where he asks us why he can not ride the bus with his brother instead he is on a seperate bus. We all really can't go anywhere as a family because we all + chair will not fit into the car. We can’t get approved through our insurance for pediasure so that takes a toll. The list goes on and on...
	“Doctors said they did not know what it was and did not prescribe rehabilitation. We did it on our own.”
	“We tried to get her into inpatient but the only inpatient rehab in Az wouldn't take her on a ventilator” “We believe she could be doing so much more if she had better therapy. She's on a ventilator and is working on sprinting but it makes it hard to travel.”
	“Rehab as an inpatient was excellent, but ongoing therapy now that we are outpatients is very limited.”
	“Physical therapy [was a challenge]... so we moved states. Literally anything was hard to get him, besides them making sure he was stable.”
	“It's really hard to find therapist who have any knowledge or understand this disease. I travel 4 hrs to a Dr. Appointment for specialists. “
	“Finding a rehab facilty that can appropriately treat CHILD has been out biggest issue. We live in Rhode Island and our resources for therapy are slim. We travel to Baltimore where CHILD may not get therapy year round but it is appropriate therapy. Now that she is 18 we have begun to run into issues with approvals.”
Lack of insurance coverage	“It has taken insurance over 10 months to approve her wheelchair or stander she has NO equipment. We've called every week since this happened”
	“Support from health insurance company is partial, spotty, and insufficient. This has lead to out of pocket expenses for things like wheelchairs, braces, FES bike, etc etc. It's a heavy burden.”
	“We took out a second mortgage on our house and we’re very strapped financially”
	“The provider specified by ins [urance] is a nightmare. 4 months after being discharged we do not have his wheelchair (he is paraplegic). They have lost his paperwork, forgot to include doctors Notes... endless list. Combination problems with insurance and provider.”

	"We lost both our jobs because we don't fit in any system that can help us."
	"Insurance feels it's not medically necessary"
	"We had exhausted all ot pt for the year, even after a major surgery for a muscle transfer our insurance wouldn't cover surgical rehab without a hearing which would've taken up to 15 days. We couldn't wait for that he needed therapy now. Luckily we have Medicaid with a waiver so they are supposed to cover. How does a major surgery on a child not a medical necessity for therapy? So frustrating."
	I was angry, and sort of embarrassed to say so, that just because our child didn't have cancer, we did not qualify for certain services or housing in some cases - I think people need to know that rare illnesses need services and attention too - and we should not be limiting services or charities to specific diagnoses - because AFM like other diagnoses isn't any much better in many cases, and in many cases is worse.
PARENTAL CHALLENGES	
Emotional processing	Our children will have life long struggles, and denying treatment or claiming treatment of any sort is medically unnecessary is unjust. Especially since they have no idea what AFM is or what treatments will be helpful. This process would be a lot less stressful for our family if we didn't have to fight insurance about every single treatment."
	"this is a marathon, and there is no step by step playbook - and that no two kids with AFM have it exactly the same way in most cases. I didn't even know that a virus could do something like this to a person […] and while I don't want people to panic since it is rare, people need to know these things are out there - and that not every kid in a wheelchair or with an apparent disability was born that way - that for us- all our kids were playing in the yard like any other kid 2 days before hospitalization. So the trauma and shock is huge- and now we plan a new course while we let go of what we thought would be, because even though these kids may have some major physical limitations than what they were born with - they are still ok and fine - and to accept anything less than that is like saying they aren't good enough as they are.
	"It's a lonely diagnosis especially when we didn't have the FB group. It's a roller coaster and the only thing I can say for sure is that when she is good, I am good. When she is upset and frustrated or angry - I am not good - so I just try to make it good no matter what - but some days it's impossible and I am too tired so I just cry. I was never someone who cried before and I think I cry almost every day still- not even sure why sometimes. I don't know how I would have done this as a single parent.

	“Physically demanding for me to be doing continuous home therapy. It's exhausting and depressing.”
	“It is extremely difficult being the primary caregiver of a teenager with AFM - who should be becoming very independent but who needs me for everything everyday.”
	“[A]ll the dr appointments and therapy appointments are more than what a child should have to endure. also you feel guilty for making them do all of these therapies, e-stim, stretching that no child should have to endure. it has been awful and painful for me.”
Employment	“we hardly ever have a nurse and dad had to take time to help me we have 3 young kids and I was mentally physically and emotionally exhausted.”
	“I her mother have been unable to go back to work because I have to stay home to take care of her and her dad lost his job a week into her being diagnosed and stayed home to help for 10 months”
	“I, her mother, took a year off after coming home from the hospital. Therapies were happening up to 6 times a week.”
	“my husband goes to work at 6 in the morning to get her to therapy at 3:30 in the afternoon”
	“I stay at home full time with my son now because of all his appointments and medical care. Recently he started school and one of our biggest challenges is making playgrounds, classrooms, and sports programs accessible for a preschooler in a wheelchair. It takes a lot of advocating and energy.”
Uncertain etiology of AFM	“It keeps me up at night wondering what caused it, could it come back and could it affect my other daughter who is now 1 year old.”
	“Yes there are times that the not knowing if it was enterovirus D68 that caused this but in all reality does it really matter anymore? She will be handicap the rest of her life and we struggle with the fact that one day we will not be around to take care of her”
	“I get worried that if she got it once, she could get it again and I can feel the anxiety building whenever she gets sick and especially as we head to the one year of her diagnosis.”
	“I have asked numerous medical professionals all over the US for an explanation. None given. Idiopathic. It drives me nuts. I want to know what the heck happened to my child.”