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Rural Hospitals Struggle Amid Budgetary Constraints, Reporting Requirements

Hospitals across the United States have their hands full dealing with COVID-19 pandemic-related obstacles that are straining resources and increasing the stress levels of frontline providers. Meanwhile, hospitals in many rural communities are facing added concerns.

Many have seen their already precarious financial health pushed almost to the breaking point while staff struggle to keep up with ever-changing medical advisories and reporting requirements. All this on top of meeting the care needs of their communities in an environment where many patients fear accessing care.

The pandemic is shining a harsh spotlight on America's rural healthcare infrastructure, making it difficult for policymakers to look away from structural and access-to-care problems that have long plagued America's sparsely populated communities.

The rural hospitals of hard-hit Texas are facing unprecedented challenges with the COVID-19 pandemic, but they also are rising to challenges in ways they never have before, explains **John Henderson**, MBA, president and CEO of the Texas Organization of Rural and Community Hospitals.

"Historically, rural hospitals with patients that exceed their capacity refer and transfer patients to the larger urban hospitals," Henderson explains. "That transfer pattern has actually flipped, where rural hospitals are accepting transfer from the urban centers of both COVID and non-COVID patients to help manage bed capacity issues."

These new responsibilities have forced frontline and inpatient providers who work in rural facilities to stretch, Henderson observes. "But most are willing and wanting to be part of the solution, and rural Texas hospitals generally have bed capacity," he shares. "The stressful part is trying to staff [this surge]."

For instance, Henderson notes the CEO of one rural hospital indicated in late July he usually staffs for a med-surge inpatient census of five patients with no ICU beds. However, in that moment, the CEO had to handle 14 COVID-19 patients. "That is at the limits of what that small hospital can do," Henderson

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reports. "[The rural hospitals] are happy to do it, and I think they are meeting the need and will continue to do that, but fatigue is a factor."

Another limiting factor is the reality that many rural hospitals have no ICU capacity, which means they cannot support patients requiring ventilators. "That is not realistic for most of the rural hospitals in Texas," Henderson says. "Some have ICUs, and some have patients with ventilators, but that is probably the minority of rural hospitals in Texas."

Certainly, EDs are feeling the pressure, and clinician recruitment has been an issue for rural hospitals in the state since long before the pandemic, Henderson notes. "The hospital in Anahuac, TX [near the Gulf of Mexico] called me, and they generally have a very low-volume ED that they cover pretty easily with a single physician," he observes. "They've gone to two physicians 24/7 in their ED to handle the surge in patients."

One facility that has weathered more challenges than most is the hospital in Rio Grande City. In late July, providers in that border town experienced a "worst-case scenario." Not only was the facility filled to capacity with COVID-19 patients, staff were caring for victims of a tropical storm that recently swept through the area. "It was like a double-whammy," Henderson says. "They haven't buckled yet, but they are struggling."

The state has responded to the workforce shortages, sending thousands of nurses to the Rio Grande Valley. "That was certainly helpful. The reaction, though, has been staffing requests from all over Texas that the state is struggling to respond to," Henderson shares.

A silver lining of the pandemic response in Texas has been the progress on telemedicine. "Most rural Texas hospitals have embraced telemedicine; if not before the crisis, they have now accelerated their deployment and implementation [of telemedicine]," Henderson says.

One good example of how telemedicine has facilitated effective care involves a hospital in Dumas, TX, located in Moore County in the Panhandle where a COVID-19 outbreak at a meatpacking plant occurred. "They were able to lean on intensivists and hospitalist-type physicians who were not on site to manage these complicated, respiratory patients and keep them in house," Henderson explains.

Perhaps the biggest challenges facing rural hospitals in their efforts to battle the pandemic are their enduring budgetary concerns. "Before the pandemic, 44% of rural Texas hospitals had negative operating margins, making them very vulnerable," Henderson relates. "In April, I was getting calls daily from those that were truly on the ropes and couldn't make it through another payroll cycle."

Many of these facilities had maxed out their credit and were in real trouble. There were three hospitals in bankruptcy when the pandemic began. "I was worried we were going have another round of closures," Henderson says.

However, the Coronavirus Aid, Relief, and Economic Security (CARES) Act, which became law in March, funneled $10 billion specifically to rural hospitals and clinics, helping these entities avoid dire financial consequences, at least for now. Henderson says by early May, Texas facilities began enjoying the benefits of the CARES Act.

What should hospital administrators and policymakers learn from the pandemic experience?

"One [thing] is the importance of access to care and hospital capacity. Some of the rural Texas hospitals that closed [prior to the pandemic] — I know we wish we had that capacity today," Henderson explains. "The healthcare system ... probably hasn't performed as well as we would like in a country that spends $4 trillion a year on healthcare. I think it is fair to expect a better result than we have seen."

Lisa Davis, MHA, director of the Pennsylvania Office of Rural Health, notes rural hospitals in her state did not struggle to activate their emergency plans, ramp up, or make any changes they needed to make in their facilities. However, she notes the administrative burden has been crushing. "All the activity within the federal agencies ... as well as our Pennsylvania emergency medical agencies — suddenly, everyone is on high alert. All of the agencies are reviewing all of their policies, procedures, and regulations and trying to get them aligned to address a pandemic," Davis explains. "All of those pieces are interrelated. One of the big issues that we saw with policy and regulation was just an enormous amount of communication coming out."

Particularly in the early days of the pandemic, a lot of the information would change from day to day, making it difficult for small, rural hospitals to keep up. "The reporting that needed to go to the federal government was really on the demand side: how many beds you are using, how many respirators are you are using, how much PPE you are using, and so on. Those reports needed to be submitted by 5 p.m. every day," Davis notes. "On the state side, they were really looking at the supply component: how much PPE do you have available, how many respirators do you have available, and how many beds do you have, what kind of staff do you have ... and those reports needed to submitted three times a day."

Unlike many rural hospitals in Texas that saw volume spikes, most rural facilities in Pennsylvania have experienced significant volume declines, particularly in the early weeks of the pandemic. "Emergency departments were essentially empty. People were not coming to the ED, even when they should have, whether or not [the issue] was COVID-related," Davis says. "Rural hospitals were not seeing a large number of COVID patients in general ... for those patients they were seeing, only a small percentage needed to be hospitalized. The rest were sent home to self-quarantine and recover there."

By mid-summer, elective surgeries resumed, but volume in the EDs of rural hospitals remained well below normal levels. As with the Texas hospitals, CARES Act funding helped tremendously in helping offset lost revenue. Still, rural hospitals struggled with properly accounting for all the funds. "The chief financial officer of one of our critical access hospitals said he was petrified to spend any of this money because he only has two people in the hospital's accounting office, and they have never had to deal with something like this," Davis relates. "The concern was being able to bring the funds in, spend them appropriately, and assure that the funds were not duplicating other pandemic funding or being used to support non-eligible types of services or expenses [for which] the hospital would then later be penalized."

Another problem is that some CARES Act funding was earmarked specifically for fee-for-service or traditional Medicare patients. "We have some hospitals that have no traditional Medicare [patients], just Medicare Advantage," explains Davis, noting Pennsylvania has one of the highest penetrations in the country of Medicare Advantage plan coverage. "They were seeing enormous deficits coming to them because what they estimated would be their funding

EXECUTIVE SUMMARY

The COVID-19 pandemic response has pushed many rural hospitals to the brink, placing added strains on skeletal workforces that have long struggled to meet the healthcare needs of their communities. While some smaller facilities are pitching in to help larger, urban centers manage capacity, others have seen their patient volumes dwindle as fear keeps patients from accessing needed care. Most conclude the pandemic is highlighting the need for change in the way healthcare is delivered to rural communities.

- In Texas, the traditional transfer pattern has flipped: Many rural hospitals are accepting patients from large, urban facilities that are overrun with COVID-19 patients.
- Rural hospitals in Pennsylvania have faced hurdles trying to keep up with ever-changing policies and an avalanche of reporting requirements from state and federal agencies.
- Patient volume is way down in hospitals throughout rural Colorado, even as they strive to be ready for any potential spikes in COVID-19.
- A bright spot for many rural hospitals is the advancement of telemedicine. However, broadband limitations continue to hinder expansion in some areas.

from [the CARES Act] did not materialize."

Some rural hospitals in the state have faced shortages of testing supplies and PPE. "One hospital administrator whose hospital is very close to the New York state border ... went up to Binghamton, NY, knocked on doors, and got PPE up there because he wasn't able to get it in [Pennsylvania]," Davis recalls.

As with Texas, the relaxing of regulations regarding telehealth has been hugely beneficial in expanding access to care to residents in rural parts of Pennsylvania during the pandemic. Of particular importance to the state is the expanding definition of telehealth to include phone encounters. "We are one of the states that is having real problems with access to broadband and internet across the state, especially in rural communities, so that has helped tremendously," Davis explains. "Also, commercial payers have stepped up to cover more telehealth services. That has been really helpful." Davis cautions that telehealth cannot deliver all the forms of care people require. "It is not a panacea ... but it sure does help," she says.

Currently, while Pennsylvania is experiencing a bit of a breather from spikes in COVID-19 patients, the state is working with rural hospitals to help them assess what worked well from their emergency plans and what did not. That way, any adjustments can be made before potential surges occur.

Unlike in Texas, rural hospitals in Pennsylvania have not been called on to help manage capacity overflows from urban facilities. However, there is growing concern about potential COVID-19 outbreaks as many urban dwellers flee to the country to escape the virus and students return to campuses. "My office is at Pennsylvania State University. We have 23 campuses, many of which are in rural communities. We also have a state system of higher education that has 14 universities, all of which are in rural communities," Davis explains. "There is only a guess as to what this is going to mean for transmission of COVID-19 ... and the expectation is that this is not going to be good."

Rural hospitals in Colorado are struggling to combat public fear about accessing care. "We have definitely struggled with getting patients back in. Volumes in the ED continue to fluctuate in most of our [facilities]," observes **Michelle Mills**, CEO of the Colorado Rural Health Center in the State Office of Rural Health. "Some days, [volume] is close to what pre-COVID experiences were; on other days, it is way, way down."

Consequently, hospitals have been working with the communities they serve to help people understand that it is safe to come back and what procedures have been put in place to protect patients. The biggest concern is someone who is experiencing an emergency may not come in because he or she is afraid, Mills says.

It is true many rural hospitals in Colorado lack ICU capacity, but Gov. Jared Polis moved quickly and proactively to address the issue. "The state set up three separate locations to be able to help with overflow should additional ICU beds be needed," Mills says. "One [ICU overflow site] is in metropolitan Denver. There is one in the north part of our state and another site that is over on the Western Slope."

While many EDs in rural hospitals have used telehealth for stroke patients for a long time, other parts of the health system, such as rural health clinics, have faced challenges in "standing up" telehealth capabilities. For instance, there have been many questions about how to bill for telehealth visits and how to spread the word out about telehealth. "Those things are continuing to be worked on right now. I think there are still some barriers in terms of acceptance by the community of that type of care," Mills says. "Of course, we continue to have some broadband issues as well that have made telehealth a little bit harder."

Rural hospitals in Colorado currently have sufficient supplies of PPE, but potential shortages of important supplies remain a concern. "Our state numbers [of COVID-19 cases] are starting to tick up again. There is some concern about whether there are going to be shortages again," Mills says. "There definitely was a difficult time at the start [of the pandemic] in getting PPE, but our state has been great about setting up a way for people to be able to work together to obtain [needed supplies] from each other."

Mills says the pandemic continues to highlight the vulnerability of rural hospitals. "We have been very fortunate in Colorado that we haven't had any rural hospitals close, but I think this pandemic has really heightened [that concern]," she says.

To shore up support, Mills wants to see passage of the "Save Rural Hospitals Act," a bill that, among other things, would facilitate funding for rural hospitals and enable critical access hospitals to transition to a new type of delivery model in communities that cannot support a hospital. "It would essentially look like a 24/7 ED with a clinic attached to it so that [the community] would still have primary care and emergency care," she explains. "Hopefully, Congress will work to make sure that [people] continue to have access to care in our rural communities." ■

CHART Model Offers Two Tracks to Shore Up Rural Healthcare

Recognizing that the way healthcare is funded and delivered in rural communities needs an overhaul, the Centers for Medicare & Medicaid Services (CMS) has unveiled a new approach it hopes will provide a roadmap for how to do just that.

The Community Health Access and Rural Transformation (CHART) model provides some new avenues and funding that rural providers can pursue to redesign and improve systems of care.

First, for rural communities, CMS has created a Community Transformation Track in which up to 15 rural communities will receive funding to pursue "delivery reform, provide predictable capitated payments, and offer operational and regulatory flexibilities" to build sustainable systems of care. For example, communities may take steps to expand the use of telemedicine, enable some outpatient clinics or EDs to be paid as if they are hospitals, and enable participating hospitals to waive cost-sharing for some part B-services.

CMS says it will begin the selection process for community participants in early fall; winners will be announced early next year. Implementation of the CHART model at the selected sites is set to begin in the summer of 2021.

Second, for rural providers, CMS has unveiled a new Accountable Care Organization (ACO) Transformation Track. This approach will deliver upfront investments to improve outcomes and quality for patients. Under this ACO track, providers will participate in two-sided risk arrangements as part of the Medicare Shared Savings Program.

Up to 20 rural ACOs will be selected to participate in this track, with implementation set to begin in January 2022. CMS anticipates applications to participate should be available to interested providers in spring 2021.

CMS says both tracks are designed to provide financial stability and remove regulatory burdens to healthcare providers, and to enhance both access and quality for patients who live in rural communities.

More information about the CHART model is available online at: https://bit.ly/2D94VMQ. ■

Analysis Uncovers Gap in Emergency Physician Availability in Rural Communities

Hospitals in rural areas are experiencing a shortage of emergency physicians (EPs), a situation that is expected to worsen in the years ahead, according to the authors of a recent analysis.[1]

Of the 48,835 EPs who practice in the United States, 92% work in urban areas and just 8% practice in rural communities. This is down from the 10% of EPs who reported working in rural areas in 2008.

The analysis revealed EPs working in rural areas tend to be older than their urban counterparts. More than 70% completed their medical training more than 20 years ago. The authors reported the median age for an EP working in a large rural community is age 58 years; that age climbs to age 62 years for EPs working in smaller rural communities. Conversely, the median age for an urban emergency physician is age 50 years.

Nonetheless, the analysis shows the training pipeline to be robust. There are 7,940 residents in 247 programs today, up from 4,565 residents in 145 programs in 2008. The key is where these new EPs will choose to work.

Considering that one in five Americans lives in a rural community, the American College of Emergency Physicians says action is needed to address the workforce challenges facing rural emergency care.[2] The organization says its "Emergency Medicine Workforce Task Force" will help identify best practices, site supervision requirements, and funding mechanisms to support further research and training programs focused on rural emergency care. ■

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Study: Considerable Room for Improvement in Telemedicine Adoption

For all the reports regarding how much telehealth has advanced during the COVID-19 pandemic, it may have gone without notice that robust telehealth capabilities still are not deployed on a large scale in the United States. Some regions and states are much better equipped and experienced in this arena than others.[1]

Investigators from Florida Atlantic University (FAU) scoured through 2017 data from the American Hospital Association, Area Health Resource Files, and Medicare cost reports. They wanted to identify factors that predicted telehealth and e-ICU capabilities at U.S. hospitals. They found that larger hospitals and facilities that are part of a system are more likely to possess telehealth and e-ICU capabilities than their smaller and independent counterparts.

Beyond those factors, region seems to play an outsize role. Hospitals in the West North Central region tended to be well-equipped with telehealth capabilities. Meanwhile, facilities in the East South Central region and West South Central region were less likely to possess these capabilities. In particular, the researchers found coastal areas that were hit hardest by the initial wave of COVID-19 had the lowest prevalence of rural telehealth capability.

Overall, only 27.4% of hospitals had telehealth capabilities and just 14% had e-ICU capabilities, showing considerable room for improvement in this area. However, multiple barriers to adoption remain, with cost at the top of the list.

"It takes millions of dollars to actually install telehealth capabilities. To not get any payment out of it, why would any hospital invest in these capabilities?" observes **Neeraj Puro**, PhD, lead study author and assistant professor of management programs and health administration at FAU. "Until [the pandemic], the internal enlistment for telehealth capability was not enough because insurance would not pay for telehealth or a telemedicine consultation."

Scott Feyereisen, PhD, study co-author and assistant professor of management programs and health administration at FAU, adds there is a general impression that telemedicine is more widely available in hospitals than it is. However, the funding and motivation for adoption have not been there.

"Different states are more involved in terms of providing the funding and the incentives [to provide telemedicine], but [adoption] has been very low," he says. "We did have some of the data from 2018 that was most recent. We didn't really see any trend toward additional diffusion [of telemedicine] at that point. I think it is really just coming to the surface now just because of the pandemic and people realizing ... this is a really valuable tool."

Puro and Feyereisen note states like Minnesota, Iowa, South Dakota, North Dakota, Nebraska, Missouri, and Kansas lead the way in telemedicine use, while New York, Florida, California, and Washington lag. However, both investigators are hopeful there is impetus now to enact the regulatory changes needed to make telemedicine more widely available. ■

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Another Outbreak of Acute Flaccid Myelitis Could Complicate COVID-19 Response

As if frontline providers do not have enough to worry about with COVID-19, the CDC warns 2020 could be another peak year for cases of acute flaccid myelitis (AFM), the frightening polio-like condition that primarily affects children.

Since an outbreak of the neurologic condition in 2014, the illness has tended to reappear in higher numbers in an every-other-year pattern, making 2020 an "on" year for another outbreak.

This prediction is consistent with what epidemiologists believe is the primary cause of the illness: enterovirus D68 (EV-D68), an illness that has been making a more pronounced appearance in the United States in recent years, following the same every-other-year pattern of AFM. The vast majority of children who contract EV-D68, or one of the other viruses that have been linked with AFM, will not go on to develop the serious neurologic symptoms associated

with AFM. However, those who do develop AFM may require ventilator assistance. Many face permanent disabilities.

By the end of July, the CDC reported it had confirmed more than a dozen cases of AFM in 2020, and dozens more were under investigation.[1] But the peak season for enteroviruses, and likewise for cases of AFM, is August through November, noted **Robert Redfield**, director of the CDC, during a Vital Signs news conference on Aug. 4 during which he cautioned clinicians to be on the lookout for potential cases.[2]

"Clinicians need to remain vigilant for AFM and promptly evaluate patients even as frontline healthcare workers, family physicians, and other medical professionals continue to work under the constraints of the ongoing COVID-19 pandemic," he said. "While phone and telemedicine can be used for initial evaluations, AFM is a medical emergency that requires immediate medical care and monitoring as this condition can progress rapidly to respiratory failure."

Redfield added that clinicians should not delay in hospitalizing patients with suspected AFM.

"We don't know how the COVID-19 pandemic and the social distancing measures may affect the circulation of enteroviruses or if COVID-19 will impact the healthcare system's ability to promptly respond to AFM," he said. "[Cases of] AFM may be fewer this year or the outbreak delayed ... but AFM is a public health priority."

There has been a national increase in AFM cases every two years since the CDC began surveilling the illness in 2014. The third and largest outbreak occurred in 2018, **Thomas Clark**, MD, a pediatrician and deputy director of CDC's Division of Viral Diseases, noted during the Aug. 4 press briefing.[2] In that year, the CDC confirmed 238 cases from 42 states, with most cases occurring in young children.

"Most patients with AFM had a fever or respiratory illness about six days before limb weakness onset," Clark shared. "Once they developed limb weakness, it was common for them also to have difficulty walking, neck or back pain, limb pain, and fever."

Clark noted many of these patients sought care within one day of developing limb weakness, with most presenting to the ED.

"Overall, 98% of these patients were hospitalized, 54% were admitted to intensive care units, and 23% required ventilation," Clark reported.

While most patients were hospitalized quickly, Clark observed 10% of these patients were not hospitalized until four or more days after they developed limb weakness.

"This could indicate delays in recognition of AFM and present an opportunity for improvement in patient outcomes," he explained. Although some cases of AFM were associated with other enteroviruses, EV-D68 was the most common one detected in patients with AFM. These cases tended to be more severe, with patients more likely to require treatment in the ICU and ventilation.

"[The] CDC urges clinicians to consider and promptly recognize AFM symptoms, to hospitalize patients immediately, to collect specimens early, and to report all suspected cases to their state or local health department," Clark said. "The CDC is prepared to respond if an outbreak develops this year, and we will continue to learn about AFM, its risk factors, treatment, and patient outcomes."

Janell Routh, MD, MHS, medical officer and AFM team lead at the National Center for Immunization and Respiratory Diseases at the CDC, shared more information about the illness with clinicians during a presentation on July 21.[3] She noted there have been more than 600 cases of AFM confirmed in the United States since 2014.

EXECUTIVE SUMMARY

If previous patterns hold true, there could be an outbreak this year of acute flaccid myelitis (AFM), the frightening polio-like condition the CDC has been studying since 2014. Public health experts advise frontline providers to be particularly attuned to patients presenting with the hallmark limb weakness, and to report such cases promptly to their state health department.

- Outbreaks of AFM have been occurring in the United States every other year since 2014, with the largest number of confirmed cases occurring in 2018.
- Based on the cases seen in 2018, the illness primarily affects young children (average age = 5 years).
- In most cases, the onset of limb weakness occurs about a week following a non-distinct illness associated with respiratory symptoms and fever.
- Management of AFM primarily consists of vigilant supportive care, with about one-third of patients requiring respiratory support.

Routh noted that during the 2018 outbreak, there was no apparent geographic clustering.

"The median age was 5.3 years, and 94% of the cases were pediatric," she explained. "Of those cases with complete data, 53% identified as white, 20% as white or Black Hispanic, 9% as Black, and 3% as Asian."

Routh noted the AFM hallmark, limb weakness or paralysis, can progress rapidly in patients with AFM. In the cases confirmed during the 2018 outbreak, 87% showed an increase in the number of cells in their cerebrospinal fluid (CSF), a median white blood cell count of 94, and a lymphocyte predominance, she explained. "The number of limbs affected was variable, with over a third [of patients] presenting with one affected limb, and about a quarter presenting with all four limbs affected."

Routh added that in the 2018 cohort of cases, there was a predilection for limb weakness in the upper extremities, with 47% of cases exhibiting only upper extremity involvement and 16% showing only lower limb involvement. Ninety-seven percent of cases featured some combination of symptoms that were consistent with a viral illness.

"Acute flaccid myelitis patients generally start with a respiratory illness and then develop fever just shortly before weakness onset," Routh explained. However, she noted that a relatively small number of specimens return a positive result for a viral illness, making it difficult to conclusively determine a cause for the illness. For example, in the cases identified during the 2018 outbreak, only two CSF samples sent to the CDC returned a positive result: one for EV-D68 and the other for EV-A71. Stool samples revealed a viral illness in 13 samples, and respiratory specimens delivered the highest yield, with 71 delivering a positive result for a viral illness, the most common of which was EV-D68. Overall, less than half of the specimens returned a positive result, Routh reported.

Interestingly, investigators found intriguing information when they examined cases of AFM in peak years in comparison to non-peak years.

"We compared cases in 2016 and 2018, the two years we have complete data for, with [cases from] 2015 and 2017, our non-peak years," Routh shared. "Peak year cases do appear different. These [patients] were significantly more likely to have [CSF] pleocytosis, a greater proportion with only upper limbs affected, preceding respiratory symptoms prior to weakness onset, and enterovirus or rhinovirus isolated from any specimen." Routh added that only cases in peak years tested positive for EV-D68.

The cases of AFM identified in non-peak years were significantly more likely to be older, to feature lower limb weakness, and to be more severe than cases in peak years, according to Routh.

"We defined a case as severe if [the patient] had weakness in all four extremities, required mechanical ventilation, and had symptomatic cranial nerve involvement," she explained. "These data suggest that something different is occurring in peak years that may be driving these clinical distinctions."

Routh noted the higher detection of EV-D68 in peak years is striking, and adds evidence for an association with AFM during those years. She also said patients diagnosed with AFM in 2018 were more likely to report fever and respiratory or gastrointestinal symptoms before weakness onset. Further, Routh shared there were more cases testing positive for EV-A71 in 2018, which she attributed to an isolated outbreak of AFM in Colorado that year.

"[That] reminds us that many enteroviruses do have the capability to cause AFM. It is important to continue to conduct broad clinical and enterovirus surveillance to understand this full spectrum," she stressed.

Still unclear is what clinicians can expect to see of AFM this year, considering the COVID-19-related push for physical distancing, masking, and improved hand hygiene practices.

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"These practices may result in decreased circulation of other viruses, including enteroviruses, and therefore either a decrease or delay in AFM this year," Routh offered.

It is important for clinicians to understand and recognize the four stages of AFM, beginning with the prodromal illness that often precedes the neurologic symptoms by about a week, according to **Kevin Messacar**, MD, MPH, who also spoke during the July 21 presentation.[3]

"This is typically a non-distinct illness that, in over 90% of cases, is associated with fever and respiratory symptoms such as cough, congestion, sore throat, and sometimes asthma-like symptoms such as wheezing and shortness of breath," said Messacar, a clinical researcher and associate professor of pediatrics at the University of Colorado. "Gastrointestinal symptoms such as vomiting and diarrhea are seen less commonly in around one-third of patients."

Messacar added that in cases that are associated with particular enteroviruses (e.g., EV-A71), there also may be distinctive lesions on the palms, the soles of the feet, and the back of the throat that are characteristic of hand-foot-mouth disease.

After five to seven days, on average, the second stage of AFM, the onset of neurologic symptoms, generally begins, Messacar noted. At this point, many patients report their prodromal symptoms have resolved or are improving. But once the neurologic symptoms start, fever may return or rise, and there may be meningeal signs such as headaches, which lead to vomiting, neck stiffness, and back pain.

"In older patients, many complain of pain in the limb that ultimately goes on to become paralyzed," Messacar shared.

Not long after the onset of neurologic symptoms, the third stage of AFM (rapid, progressive neurologic injury) begins with the acute onset of flaccid limb weakness, which is a hallmark of the illness.

"The weakness tends to be asymmetric, affecting one side of the body more than the other. Unlike polio and Guillain-Barré syndrome, it tends to affect the arms more than the legs," Messacar explained. "The proximal or more central muscle groups, such as the shoulder girdle, are more affected than the distal muscle groups in the forearm and the hand."

There is a wide spectrum of illness severity that can occur in patients with AFM. For instance, Messacar noted some children are profoundly affected with weakness in all four limbs, while others may experience only mild weakness in just one limb.

"Cranial nerve dysfunction is seen in addition to limb weakness in around one-third of cases. This can present as abnormal eye movements or double vision, asymmetric facial droop, or, most important to recognize, bulbar weakness," Messacar said, adding that indications of bulbar weakness may require rapid interventions to secure the airway.

The fourth stage of AFM, which can last for weeks to years, is rehabilitation. For any case presenting with acute limb weakness, AFM should be considered in the differential diagnosis. Messacar noted AFM is commonly mistaken for a musculoskeletal injury, with the limb weakness attributed to a recent, unrelated trauma. He also said when the asymmetry and focality of the findings are not appreciated sufficiently, AFM symptoms may be incorrectly attributed to fatigue.

To accurately diagnosis AFM, Messacar said it is important to conduct a careful history, noting when limb weakness occurs following a preceding illness with fever, and to complete a neurologic exam to ascertain strength, tone, and reflexes.

Further, once limb weakness has been identified, MRI of the brain and spinal cord and lumbar puncture are recommended to assist in the diagnosis of AFM.

"On MRI, most AFM patients will have a distinctive longitudinal lesion in the spinal cord," Messacar observed. "Particularly in those with cranial nerve deficits, focal non-


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enhancing lesions in the brain stem and cerebellum may be present."

When CSF from the lumbar puncture shows pleocytosis with a normal glucose level and normal or mildly elevated protein, that is supportive of an AFM diagnosis. Messacar recommended collecting biologic specimens as early as possible in the course of disease. These should include CSF, serum, stool, and respiratory sampling.

"It may sound counterintuitive to look in the respiratory tract or GI in a patient presenting with neurologic symptoms, but many of the viruses associated with AFM are not found in CSF or blood at the time of presentation," Messacar stressed. "Sampling these sites is necessary to detect where the virus may still be shedding."

Additionally, every suspected case of AFM needs to be reported to the state health department.[4]

"It is essential to surveillance to understand the burden of disease, and biologic specimens are necessary to further our understanding of how to better diagnose, treat and prevent this disease."

Management of AFM largely consists of vigilant, supportive care. "Due to the risk of respiratory decompensation, it is recommended that all patients be hospitalized during the stage of progressive neurologic injury," Messacar said. "Respiratory status should be assessed through examination of the gag reflex, ability to protect the airway, and measurement of negative inspiratory flow to assess respiratory muscle function."

Messacar added that about one-third of patients with AFM will require respiratory support, with some needing intubation and ventilation for respiratory failure. More common complications in AFM patients include autonomic dysfunctions such as constipation and urinary retention. These may require preventive bowel regimens and catheterization.

"Those with bulbar dysfunction may need enteral feeding tubes to provide hydration and nutrition support," Messacar added.

Unfortunately, it is unclear which therapies are most effective in treating AFM. Messacar noted most patients receive immunomodulatory therapies such as intravenous immune globulin, which may contain antibodies against potential infectious agents.

Further, high-dose IV steroids are recommended if there is spinal cord edema leading to upper motor neuron signs due to cord compression. Currently, there are no FDA-approved antiviral therapies against the enteroviruses associated with AFM, Messacar reported.

What has been shown to help AFM patients is early, aggressive, and continued rehabilitation. This may include physical, occupational, speech, respiratory, and psychological therapies.

"More recently, nerve transfer — splitting and moving functioning nerves to muscles paralyzed by AFM without functioning nerves — and tendon transfers have led to functional improvements, and may be an option in selected cases," Messacar explained.

While long-term outcomes in patients with AFM remain unknown, the patients followed since 2014 have displayed some functional improvements with distal, less-affected muscle groups.

"Most of the recovery occurs early, in the first few months. However, continued rehab is important because patients will show slow but steady improvements even a year after onset," Messacar said. "In total, around 75% of patients will have persistent motor deficits one to two years from onset."

For clinicians newly confronted with a suspected case of AFM, it may be beneficial to seek added input from neurology and infectious disease experts with experience in managing the disease.

One option available is an AFM Physician Consult and Support Portal offered by the Siegel Rare Neuroimmune Association.[5] Here, clinicians can request a peer-to-peer consultation with a neurologist that specializes in AFM. ■

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Natural History Study Focuses on Unlocking Mysteries of Acute Flaccid Myelitis

Non-polio enteroviruses have been suspected as the primary culprits causing acute flaccid myelitis (AFM).

However, it is clear now that other viruses can cause the illness, noted **Emily Erbelding**, MD, MPH, director of the Division of Microbiology and Infectious Diseases at the National Institutes of Health (NIH) during a July 21 CDC-sponsored presentation on AFM.[1]

Erbelding noted there is evidence to suggest many, if not most, cases of AFM detected over the past few years were caused by enterovirus D68 (EV-D68).

"We don't understand whether the virus damages motor neurons directly or whether the host immune response causes this damage," she said. "We also don't understand why some children are uniquely vulnerable to this condition if they become infected with EV-D68 and whether there is some genetic susceptibility."

These are some of the key questions investigators are seeking to answer in AFM-focused research studies. One notable example is an NIH-funded AFM natural history study coordinated by the University of Alabama Birmingham.[2]

"The study will allow a large number of sites to collect the standard set of specimens and clinical data according to a common protocol," Erbelding explained. "It will also support specimen collection in household contacts. This will allow for researchers to define why some children are vulnerable to AFM when their siblings who might also be infected with the same virus do not suffer the same consequences."

NIH researchers anticipate approximately 40 sites in four different countries will be participating in the study. About half these sites have been activated already, according to Erbelding.

"The sites are diverse in geographic location, and that will allow for a collection of specimens over time so that research can describe the evolution of the virus and also any genetic mutation that might evolve," she observed. The NIH also is in the early stages of developing a vaccine for EV-D68, according to Erbelding. She noted the agency has been actively collaborating with organizations like the CDC as well as academic investigators and members of affected families to strengthen AFM research efforts.

"There is much more to do in this area," she said. "We have ongoing efforts to develop and improve animal models for AFM, to improve our diagnostic tests, to develop possible therapeutics such as monoclonal antibodies, and to continue with EV-D68 vaccine development." ■

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CME/CE QUESTIONS

1. **There is evidence to suggest that many, if not most, cases of acute flaccid myelitis detected over the past few years were caused by:**

   a. an as-yet unidentified norovirus.
   b. enterovirus D68.
   c. a genetic disease.
   d. a blood disorder.

2. **The Centers for Disease Control and Prevention recommends clinicians avoid hospitalizing patients with suspected acute flaccid myelitis for as long as possible.**

   a. True
   b. False

3. **Before the COVID-19 pandemic, what was one factor already hindering rural hospitals in Texas?**

   a. Negative operating margins
   b. Severe workforce shortages
   c. Limited access to telemedicine
   d. Dwindling patient volumes

4. **In acute flaccid myelitis, what often precedes neurologic symptoms by about one week?**

   a. Dysphagia
   b. Severe headache
   c. Prodromal illness
   d. Low back pain

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