

# Early rehabilitation strategies

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[00:00:04] **Roberta Pesce:** I think we're ready to move on to the next session of the day. Dr. Rajashree Srinivasan is joining us virtually. We're pulling her up as we speak on the screen. And she will be giving a talk on early rehabilitation strategies.

[00:00:26] **Dr. Rajashree Srinivasan:** So, I am speaking about early rehab strategies in AFM. And I do not have any disclosures. I appreciate the SRNA RNDS conference to give me this opportunity to be able to talk even though I am not in the US. And I am currently in India. And to make this possible. So, thank you very much for that. Just a couple of the take home points. And what is important to realize is I am speaking from the early rehab setting, obviously.

[00:01:06] So early intervention of rehabilitation is beneficial and there's a lot of research that has been done to help prove this. And then the functional improvement is the focus of rehabilitation. And education of patients and families to become advocates for themselves and their loved ones is obviously very important. Rehabilitation in AFM is a spectrum. Obviously, it's not just localized to just one part of where the patient is in. So, it begins when the patient is diagnosed with the condition. So, in the medical setting, in the ICU setting and then going on towards rehabilitation.

[00:01:49] And then of course moving to home and the community. And obviously we heard a very wonderful talk from Janet and Paul about how all this was able to be done. With the patients and families being the center of what we do, the medical team obviously consists of your physicians, your nurses. So, the physicians are varied in the sense that they consist of your ICU doctors, you have the neurologists, you have pulmonologists and then you have your psychiatrist or rehab physicians, and of course your nursing staff and respiratory therapy without which we cannot obviously function.

[00:02:38] Just like the social support team consists of a psychologist, child life specialist as well. And then care coordinators, social workers who help support various aspects of the patient care. The care coordinators or case managers are important for helping with finding out about the insurance piece when the patients are in the hospital. And then the social workers obviously help with the integration between providing the support that the patients and the families need. And then of course we have the therapy team consisting of the physical therapist, the occupational therapist, the speech therapist, and sometimes a neuropsychologist

depending on where the situation is in the hospital wherever the patients are. And the three teams obviously would not be able to function without the patient and the families.

[00:03:44] So, I'm just going to talk a little bit about one of my patients who had an AFM. So, he presented on July 4th with just with emesis and decreased appetite. He was seen in the emergency room and then admitted for declining status in the local hospital. And then was life flighted to Houston as he continued to get worse. He was treated with five rounds of IVIG and underwent plasmapheresis. And then, because he had ongoing respiratory insufficiency, he underwent tracheostomy, had a T-tube placement. And then eventually was transferred to inpatient rehabilitation in Dallas where he received physical therapy, occupational therapy, speech therapy, for quite a long time from August of 2016 to February of 2017.

[00:04:39] And at the time of discharge from inpatient rehabilitation he was able to take a few steps with a lot of assistance. He continued to have drooling, was on the ventilator. Excuse me. But he was able to tolerate a passenger valve or a speaking valve. And he had some recovery in the left arm. He went on to do repeated bouts of rehabilitation and has actually recovered fairly well now to where his tracheostomy is out and he's able to take a few steps on his own. And a lot more functional than what he was at the time of the diagnosis.

[00:05:19] So, this is him when he initially came to us in the rehab. And this is during his process of rehabilitation. And this is him now. So, rehabilitation in the ICU obviously as rehab specialists, I'm a rehab physician of course, so as a rehab physician we recommend early rehabilitation which is obviously safe. It has shown a decreased length of stay in the hospital, decreased the disuse atrophy that occurs in the muscles with the muscles not being used. Obviously, the muscles are like dying out and then there's muscle wasting. So, excuse me, the early rehabilitation helps in trying to combat all these issues.

[00:06:11] So, the rehab specialists help provide specific knowledge to the medical team to the patient and families, caregivers, and everybody about the conditions which include spinal cord injury, brain injury, more from a functional aspect. So, we help with the assessment, with the planning, coordination of transition to rehabilitation, and sometimes that's not easy to see, as what has happened to the individual, either the patient or, excuse me, is pretty devastating and hence trying to walk through the entire process is challenging.

[00:06:57] Rehab is involved early in the care and then we help provide education regarding the diagnosis, the prognosis and the various treatment options. Excuse me. We help monitor the condition and institute appropriate therapies. There is a particular weakness pattern that is seen in AFM, which is proximal more than distal. And then the recovery also is like that, where and you see more distal coming back first before the proximal comes back. And then we also are monitoring the stability and the early recovery that is seen with the patients. Oops sorry. So, rehab is involved in various aspects of the patient care.

[00:07:58] We educate the medical team about the various options that are there for rehabilitation and then provide education, the necessary education, that is needed. And we help provide support to the rest of the team and then help provide the therapies which decreases the muscle atrophy. And then obviously helping with the discharge planning i.e., with various recommendations as to what would be most appropriate for the patients at that particular time. And once the diagnosis has been made in the acute care hospital obviously, we would recommend that rehab gets involved early on the thing. The different things that are seen with acute flaccid myelitis include autonomic dysfunction which includes temperature dysregulation, heart rate dysregulation, blood pressure dysregulation. And the rehab psychiatrists are obviously able to help with management of these conditions in addition to the doctors taking care of these patients in the ICU.

[00:09:28] And then the respiratory dysfunction that occurs also needs appropriate planning. So, there's monitoring of the diaphragm function and then possible consideration of mental intervening or possible pacers

as needed. And the recommendations for inpatient rehabilitation, our main based on how the patients are and what the unit that the patient is going into is able to provide for them. So, if I heard all of the questions that the patient had like a low-level responsiveness and then was on the ventilator. So, it is challenging and can be a barrier when all units cannot accept patients on ventilators. So there needs to be a little bit of education to the medical team as well as assistance from the care coordinators or the case managers.

[00:10:31] And then sometimes the social workers also help with finding different entities where the patients can either travel for care, like what Janet said. There's a large variation that is seen with temperature dysregulation. And the heart rate instability also initially is very varied which initially and then later on settles down over 2-3 weeks. And then there is an increase in blood pressure and hypertension that is seen. But when the patient goes to the rehabilitation setting then we see a decrease in blood pressure. And this is because the patient is starting to become more upright and, but because of the decrease in the blood pressure or the hypertension that is seen, they start to become dizzy and then this impacts the weight bearing.

[00:11:29] So, this is something again that we tend to educate the families about to monitor and watch for. And then obviously the rehabilitation team on the inpatient side takes care of the hypertension that is seen with the patients. There is a bowel and bladder involvement that is also seen. However, this is obviously more in the rehab setting that is seen. And pain is another issue that can be seen even early in the ICU setting as well. So, it can be neuropathic pain i.e. coming from the nerve or it could be muscular skeletal, which could be because of the positioning or the fact that there's not enough range of motion and obviously needs appropriate management.

[00:12:24] I'm sorry my slide seem to be advancing themselves. Okay, here we go. Medical concerns that are also seen include your respiratory issues which is accessory muscle atrophy is seen. There is inability to cough. And then of course there is, if the patient's tracheostomy and ventilator is placed then this is impacting communication. And if you are waiting for the ventilator weaning to happen then that delays the therapy. And obviously I cannot say that enough to where depending on where the patients end up going, sometimes the patients will stay in an ICU setting for a longer time and this obviously impacts when the therapy happens.

[00:13:23] Nutrition is obviously affected. Patients have difficulty with swallowing which we call, dysphagia. And then they may be on tube feedings. They have poor appetite and end up having constipation. They're not moving around and hence that just makes it worse. There's poor oral intake and then there's food refusal. Sometimes endocrine issues can occur as well and there's a risk of fractures due to immobility, but this may end up occurring earlier as well. Obviously, anything that happens that is catastrophic in nature. Either with transverse myelitis or acute flaccid myelitis or things like that, it is similar to a traumatic event like a motor vehicle accident. And then there is a tremendous loss of function.

[00:14:17] So, there's a lot of emotional stress that occurs because of this. There is uncertainty about the prognosis and delayed diagnosis sometimes. So hence, providing that support is key and this is something that is also something that is in the wheelhouse of psychiatrists. And then caregiver support obviously is very important, because helping the families cope through the process of grieving the child's change in function is very, very key to ensure that they are getting all that they need, going through the whole process of transitioning from the ICU setting to, if need be, a floor, or to the rehab unit depending on how equipped the rehab unit is to take a patient from the ICU setting.

[00:15:15] And then supporting the family and the child as needed. And then providing the peer support and of course sibling support and interaction as the patients are being cared for and the parents are also being given the support. It's important also to support the siblings, because sometimes the siblings feel that they are not being given the adequate attention that they need and they may start to act out or things like that. And

hence, providing that sibling support is very important. And in our hospital, we have our child life specialists who help with this. Speech and language therapists help with swallowing. Obviously, the swallowing is being assessed and then they are monitoring the safety and progression of the swallow function.

[00:16:10] And that's not the only thing that they do. They also work on helping provide communication options, like I said before. If they have tracheostomy or have a ventilator in place then obviously communication gets affected. And hence, trying to provide different options for communication are important and they come up with different ideas i.e., with communication words, with either yes/no or head nodding if that function is there, or eye gaze and things like that.

[00:16:42] And then speech and language pathologists also help provide breath support when appropriate when that's, more so when they are being weaned from the vent. Physical therapy and occupational therapists, they help with the range of motion, positioning. Sometimes they may need to be prone while on the ventilators if they are medically stable. This helps their respiratory function as well and then helping to provide bracing to maintain the joint position.

[00:17:12] Just because they are laying in bed doesn't mean that we're going to allow them to just lay as they are, because we are prepping them to get better and to maintain their joint position and function when they are medically ready to be able to transition to standing functions and things like that. And obviously, the therapist they are doing a daily assessment. They are looking at how much are they able to do? Do they have the ability to, for instance, even sit up in the bed or out of bed.

[00:17:52] And this is something that has to be coordinated with the ICU team to ensure that it is not impacting when the respiratory treatment is going to happen. Just to make sure that the patient is getting the full benefit of the therapies in addition to all the medical treatments that are also being provided. And then because of the atrophy of the muscles that occurs.

[00:18:19] This is also something that they address. The therapist, in addition to the rehab doctor also helps provide the inpatient rehabilitation recommendations. There's various factors that go into determine the inpatient rehab ability to be able to tolerate that. Whether they are able to tolerate their therapies appropriately and things like that.

[00:18:52] One thing to remember is the lesser the strength lost, the stronger they are while they're starting inpatient rehabilitation. So, to decrease the muscle atrophy we're focusing both on the involved muscles and on the uninvolved muscles as well. So, for the uninvolved muscles you are looking to decrease the loss of strength due to disuse.

[00:19:16] Just because the muscle is uninvolved doesn't mean that it is going to continue to stay healthy if it is not being used appropriately. So, we tend to use a lot of functional activities whenever possible using active range of motion, electrical stimulation, and then the stronger muscles obviously are going to help support the weaker muscles. And then for the involved muscles, you're trying to maintain as much muscle activity and strength as much as possible, trying to get them to do functional activities, electrical stimulation.

[00:19:51] This is just a picture of a Recumbent Functional Electrical Stimulation bike. And this is something that can be used in an ICU setting. And the hospital where I work at, we're very fortunate that we have this to be able to use for our patients. And, like I said before, we collaborate with the ICU team to ensure that the time that we are going to use this is appropriate and that the patient is medically ready to be able to tolerate this. So, it can be done when the patient is in bed. This is called an Xcite electrical stimulation machine. It's

portable with 12 channels and this is different from an FES bike in sense it can be used on smaller children as well because the FES bike has weight restrictions and then height restrictions, whereas this can be used for any age child.

[00:20:57] So inpatient planning is obviously not just a one-person job, it involves a lot of collaboration between the care coordinator or case managers and then social workers. We start talking to the medical team and to the families early in the rehab process as to what kind of things they're going to be needing. And then obviously, we have to check to see if the rehab floor.

[00:21:30] Are they able to take the patient directly from the ICU or is there a need for a transition to the medical step-down unit? And to ensure that the patient is medically stable and then bring them to inpatient rehabilitation, because the worst thing we can do for children is transition them to rehab and then because they are not medically stable, we are hence, shipping them back to the acute side. There's a lot of stress on the patient and the family caregivers as well. And then planning of the admission obviously to ensure that the patients are adequately cared for. And then discussing and addressing any kind of barriers that are there.

[00:22:13] And then when the patients are appropriate for when are they appropriate for rehab? This can be variable depending on the inpatient rehabilitation unit. Do they need to have stable vital signs? And then what is their respiratory status? Are they able to take the patients off the ventilator? Are they getting IV medications? Is pain a huge factor in participation during therapies?

[00:22:41] Because if the pain is impacting therapies then they're not going to get the benefit of being in an inpatient rehab setting. Wherein, all that may need to happen is just addressing that pain and ensuring that the patient has appropriate medications and then they can participate in rehab. So obviously, coordinating with the acute rehab team is important. So, ensuring that there's appropriate handoffs and then bridging that care between acute and the rehab units. And then ongoing collaboration during rehab stay.

[00:23:20] Sometimes in the acute care, the teams may get more of the information which is obviously always passed on to the rehab setting to ensure that information transition is happening appropriately. And then education about long term consequences. This is difficult, because whenever you're talking long term, it becomes an issue of, oh, are you giving up on a child? Or are you giving up on, or is this the best that my child can become? It's not necessarily that.

[00:23:56] It's just educating as to what could happen is what the education process is necessarily just looking at. It's not that you're giving up on anything or you are not able to provide what is needed. Sometimes, so I mean, and again it's each is dependent on the particular families. If they require that education and need that information, then that's provided. But we rarely just push it down and make it a forced education. We try not to do that. This is another one of our patients who also was diagnosed with AFM. And he was 11 years old at the time when he presented. And he now is 15. I was hoping that I would be able to play my videos, but unfortunately, I am not.

[00:25:10] And so, for early rehab strategies, we are basically looking at providing that early information about rehabilitation to start the families and the medical team thinking about it. The process of rehabilitation obviously takes time. When the patient is medically ready and then the referral is made to rehabilitation it may be a little, it takes a little bit of time, because there's a lot of processes that happen. Information is sent to the insurance companies and then we have to get approval from the insurance companies before the patient is transferred to rehabilitation. And then the care coordinators, case managers, are looking into the insurance to see what kind of therapy limitations are there in the insurance.

[00:26:09] Some insurances will provide 30 days of outpatient rehab therapies. And then is it a question of, are you trying to utilize your time for inpatient? Or is it that better for the patient to transition to outpatient? And things like that. Just basically just trying to work out all the details as to what would be the most beneficial and the most appropriate for the patients. And that's all I have.

[00:26:50] **Roberta Pesce:** Great. Thank you so much, Dr. Srinivasan. We really, really, really appreciate you being there. We know it's very late for you there in India. So, thank you so much for this presentation.