

Treating Pain in Children with Medical Fragility-Meeting Recording

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1h 2m 9s

● **Kamat, Deepak M** started transcription



Kamat, Deepak M 0:37

Good morning. It's 7:30 and it's time to start our pediatric grand rounds. Just a quick reminder that please complete your evaluations at the end of the presentation. The CME code is in the chat box and we'll keep repeating it every 10 to 15 minutes. And this presentation has been approved by the UT Health Science Center, San Antonio for one credit of education in pain management and the prescription of opioids. It's my great, great pleasure and honor to introduce this morning's well known speaker, Doctor Rachel Vandermeer.

Who doesn't need any introduction? Everybody knows her here. She's currently associate professor of pediatrics at Dell Medical School at the University of Texas at Austin. She's a pediatric complex care physician at Dell Children's Comprehensive Care Clinic.

Previously, she was the inpatient pediatric palliative care medical director at University Hospital in San Antonio. There she helped develop a perinatal palliative care program which provides palliative care to families expecting a baby with serious illness.

In 2022, she received the Hastings Center Kenneth Dickson Dickson Early Career Physician Award for her work. She completed a degree in biochemistry at Saint Edward's University in Austin and then proceeded.

To medical school at the University of Texas Medical Branch at Galveston. She finished pediatric residency at Dell Children's Medical Center of Central Texas through Dell Medical School at the University of Texas at Austin.

After residency, she entered Hospice Palliative Hospice and Palliative Medicine Fellowship at UT Health San Antonio. The topic for her, the title for her today's presentation is treating pain in children with medical fragility. Dr. Vandermeer, thank you very much for accepting our invitation.

Floor is yours.

VJ Vandermeer, Rachel J 2:40

Well, thank you so much for the invitation to come and join y'all and talking about the care of kiddos with medical fragility. And I'm just really excited to be here with y'all this morning virtually and get to see some of familiar names and faces on camera. So thanks so much for the invitation.

So when Doctor Kamad asked if I would give kind of the opioid presentation for y'all this year, I asked if I could narrow in on little ones with medical fragility and talk a little bit more about my patient population because I I feel like that's.

Where oftentimes we feel the most uncomfortable, right? Most of us feel really familiar with how to manage pain in a completely healthy child who doesn't have anything else going on and doesn't have any other medications on board or any other comorbidities. But when it becomes my patient population and little ones have a long Med list.

And they have other disorders, people get pretty nervous about treating this pain.

And so I figured it might actually be helpful to talk about this population in particular. So our goal today is we're going to review some principles of pain treatment in the general pediatric population and then contrast.

These.

Recommendations for how to treat pain in a medically fragile population. We're going to look at what are the sources of pain in children with medical complexity, and then also think a little bit about how we might develop a pain regimen for those littles. And then I'm just going to share some really practical.

LS Leigh Shapleigh 4:04

OK.

VJ Vandermeer, Rachel J 4:20

Clinical pain management pearls in this particular population. So we're gonna start off with just some basic pain management principles. So this schema just shows the nerve pathways in our body and we're gonna spend some time later talking about the medications that we use to.

Treat.

Pain and where those pain medications. But what I really wanted to focus in on here is pain actually works, right? So when we're thinking about a completely healthy

individual, we're usually thinking about some pain that is occurring in the tissues, whether that's in the extremities because of some type of injury or whether maybe it's an.

Organ like appendicitis, there's some peripheral pain signal that then gets transmitted to the dorsal horn and then there's a synapse there and then it travels all the way up these ascending pathways through the spinal cord to the midbrain where it has some synapses in the midbrain and then it goes through the.

Limbic system and then to the cortex, right. So that's the normal pain pathway when we think about kiddos who have underlying medical fragility. And by this, I'm really kind of talking about that, that, you know, 0.1% of kiddos who have lots of underlying medical illness and many of whom have.

Pathologic impairment, you know, their pain pathways actually look really different compared to a healthy child, right? Because they have ongoing pain on a regular basis. And so that means that those pain receptors aren't actually normal in the tissues, right? Like these are.

Pain receptors that have really been primed to experience pain. The other thing that we know about little ones who have neurologic impairment and who have anatomical brain differences is that a lot of times the structures in the midbrain are not normal and that's where pain is actually processed. And so that means they're not processing pain.

Normally either. And sometimes they can actually get these kind of phantom signals that are happening in the brain because they don't have these normal midbrain structures. And so I especially worry about this in kiddos who have had like anoxic events, right, because we know that watershed damage related to a lack of oxygen. Often.

Sometimes tends to hit the midbrain very, very hard. So things like drownings, big motor vehicle accidents where they had a significant downtime hangings and then even some of the NICU injuries where there was a lack of oxygen around the time of birth. These kids don't have normal midbrain structures.

Oh, just kind of keep in mind that because these kiddos have an abnormal brain, that means that they're going to experience abnormal pain. And that becomes really important when we start trying to manage this pain and agitation in these little ones.

So I also want to talk a little about the medication choices that we have available.

To us, the truth is we actually don't have a whole lot of dedicated pain medications.

And so you kind of have your mild pain medications like acetaminophen and

ibuprofen, or you have an opioid. Kind of classically speaking, a lot of times we're thinking about these opioids as being weak opioids or more potent.

LS Leigh Shapleigh 7:33
Yes.

VJ Vandermeer, Rachel J 7:41

Opioids, I do just kind of want to touch on the fact that all opioids are opioids. So when we think about codeine or we think about hydrocodone, these actually are processed in the body to codeine to morphine and then hydrocodone to hydromorphone. So I think sometimes.

Sometimes we preferentially use hydrocodone because we think it is safer and this is just a reminder that in fact hydrocodone actually becomes dilaudid in the body and but the unfortunate thing about using these.

Sometimes what are called weaker opioids is that they do require metabolism through the CYP2D6 enzyme and not everybody's enzyme is the same. So some individuals are hyper metabolizers, meaning that they metabolize that medication very, very quick, which is where you can see increased side effects from these medications like somnolence and.

Sedation and decreased respiratory rate and respiratory drive or some individuals can also be slow metabolizers, which means that they're not able to actually process that medication into the active drug and then they don't actually get the pain treatment that you desire, so.

These weaker opioids are oftentimes actually less predictable. I would actually advocate for and just recommend that people really think about in this particular population where we already have a lot of drugs on board, where we have a lot of comorbidities that we really stop and think about whether or not we want to kind of. Add in this other layer of complexity and unpredictability. It might actually be better to think about using a more potent opioid, remembering that all opioids are opioids. You're not actually more safe using those weaker opioids, but unfortunately the less predictable opioids.

Are more available. And so in this population, we might not want to necessarily be as dictated by the insurance companies and what they approve, but actually really stop and think about, hey, what's going to make the most sense in this population and argue for that if needed.

So thinking about the safest drugs in medical complexity, again, a lot of times I think there's this fear of using opioids because of the opioid crisis, because we know that there are individuals who become addicted to opioids, that we should at all cost kind of avoid these opioids and we tend to really heavily rely on things.

Like acetaminophen and ibuprofen, but just kind of a quick reminder and we'll talk a little bit more about this later. But ibuprofen is actually associated with GI bleeding, especially in this patient population. We don't really think about that too much in a completely healthy population where they're going to be on this medication.

For a couple of days, maybe a week in the setting of like a post-op circumstance. But in our patient population and children with medical complexity, they tend to require a longer time to recover from any type of illness because their nervous system is not normal to begin with.

So.

They have pain. It takes a long time to recover from pain, which means they might be using these pain medications for a longer period of time. And personally, clinically, I've actually seen way more complications related to ibuprofen use than I have to opioid use because of the bleeding issues. So just something always to kind of bear in mind.

Of course, we do worry about Constipation and sedation and drug-drug interactions when we are using our opioids. Constipation is a really significant issue in little ones who have underlying medical complexity and neurologic injury. So it is something we do have to really think about. I will add though that most of these kids are already on about.

Regimen. And so it's not oftentimes it's not as difficult as we think it's going to be to kind of increase that bowel regimen and kind of account for the opioid since they're already getting daily medications to manage constipation. So things to think about when you're dealing with chronic illness, it does mean that there's going to be chronic pain recovery.

Recovery. So we have to think about what these what these medications do long-term as opposed to just thinking about the short-term effects of these meds where we don't worry as much about kind of big use of ibuprofen and Tylenol.



Amy Quinn 12:05

Big use of ibuprofen and Tylenol.

VJ **Vandermeer, Rachel J** 12:09

All right. I'm not going to spend very much time talking about the math that goes into the use of opioids, but I would just like to remind people that this math exists, right? So there's some real numbers that surround opioid use. A lot of times when we're working with kids who are completely healthy, we heavily, heavily rely.

On the fact that these kids, that these bodies are going, that their bodies are going to recover naturally on their own and we're really just using a little bit of pain medication to kind of help them in that recovery process, but we're not expecting for them to be on these meds for very long.

And every single day, they are dramatically and drastically better. And so we can pretty rapidly wean off of these medications without doing a whole lot of math, right? But unfortunately, in kiddos who have chronic medical illness, that's not necessarily true, right? They might actually be needing more pain.

Medication to begin with. And then we can also expect that it might take them longer to recover, which means that we can't just kind of guesstimate. Oh yeah, they were getting this much IV medication. Why don't I try this oral dose right in this patient population. I would really recommend that you spend some time really look at a.

Opioid conversion chart tally up how much daily opioid they're getting before you decide what their new pain regimen is going to be as you try to wean down those pain meds. So this here is an opioid conversion chart. I'm not going to spend time going over it because that's a lecture in and of itself, but if you don't know how to do.

This and I strongly recommend that you talk to a pharmacist, especially for this patient population. We really do need to think about being very precise with this population so we're not leaving them in pain. The other thing to think about is the duration of action. Again, when we're weaning pain medications and little ones.

Who have underlying normal nervous systems. Most of the time they're not needing nearly as much opioids, but in kiddos who have abnormal nervous systems, they might actually really be relying on that opioid to help address their pain. And if we get make orders like morphine Q6 hours or hydrocode.

Codone Q8. Unfortunately, what happens is then those kids are left hours without pain coverage because the duration of action isn't actually that long. So you just really want to pay attention to that, especially in this patient population where

they're going to be needing probably more pain medication in general.

All right. So the opioid crisis, right? This is why we're actually having this whole conversation, because all physicians need training in this because we're so worried about the negative effects of opioids in our country. So the question is, do I need to actually worry about addiction in this?

This patient population in the general pediatric population. What about in a population of children with neurologic impairment? And I would say, you know, the answer is sort of, right. So first of all, let's review what addiction actually is. So addiction is the compulsive seeking.

Of a drug despite harm, right? And that's not usually something we're really worried about in very young children or children who are developmentally young because of underlying neurologic impairment. They don't actually have the ability to seek out a drug. What we tend to worry.

More about in young children and children with neurologic impairment is the physiologic dependence, where they actually have physiologic changes to their nerve cells. There's changes in receptors, both upregulation and downregulation, and so that puts them at higher risk for withdrawal syndrome if the drug should suddenly be stopped.

I do think though we need to think about addiction in preteens and adolescents and we also need to think about diversion in in parents. You know, is that a risk if we are prescribing long standing opioids? And then of course the physical dependence in more medically fragile children.

So how do we, you know, when should we worry and when should we not worry? And how do we go about screening for this? So it's less concerning if the child is very young, if the child has neurologic impairment, and if the opioid use is really short-term. More concerning, of course, if all the opposite is true, it's an adolescent who's neurotypical and it's going to be a long.

OP.

Prescription. There is an opioid risk tool. This has a lot of evidence behind it and you can rest assured that if that tool it has a low score that you can feel pretty safe using an opioid even for a longer period of time. Things that we don't talk about is how do we screen parents I think.

You actually could screen parents of children if you have worries, right? And maybe it's not even like an official screen, but you know what the questions are on the screen and you can go in and kind of get a better history to really assess if there is a

parental risk of diversion. We'll also say sometimes it's not really a risk.

About addiction or diversion, it's just a risk that someone might accidentally mess the dosing up, right? I definitely have families who are on my panel, families who I've cared for in the past, where they're super, super sweet. They have absolutely no malintent. However, it's just a really chaotic household and I'm really scared that they're going to miss a dose or they're going to accidentally.

Double up on a dose and I just would prefer not to use an opioid in that patient and I think that's a that can there can be some wisdom in that at times.

All right. So those are kind of some of our general pain principles. Now we're going to zero in.

Who have medical fragility. And again, I'm really kind of focusing in on little ones who have some underlying neurologic impairment. So there was a more recent.

Really helpful to look at all of these issues on one slide, right? Standpoint. These kids have spasticity, they have dystonia, they can have movement disorders, contractures, they can have shunt dysfunction. Some of them will have self-injurious behavior.

They can have their eyes can hurt because.

They don't close their eyes the way they're supposed to, and so they get keratitis.

They can have recurrent pneumonias and have chest pain related to that. Their ears don't drain the way they're supposed to, so they can have some ongoing pressure in their ears. Constipation is the number one cause of pain in this population, and oftentimes, you know, we are pretty.

Aggressive about a bowel regimen with these kids, but even with bowel regimens, these kids can very easily get backed up and then become very agitated because of Constipation. They can have reflux, gastritis. Dental disease is another really driving factor for pains in these little ones. A lot of these little kiddos don't tolerate their feet very well, so they.

Enter.

And abdominal distension, which can over time lead to visceral hyperanalgesia, where the gut nerves basically become oversensitized to pain. They can have neurogenic bladders, which means they drain their bladder the way they're supposed to. So the bladder's distended. They get from a musculoskeletal standpoint, they have scoliosis and dislocated hips. They can have.

Pathological fractures. At some point they tend to have stoma irritations. So there's just a lot of reasons why these little ones can have pain, and this is pain that they experience every single day. These are chronic issues. This isn't just one issue at a

time. This is multiple organ systems.

That are really just angry every single day. And so we can understand why these little ones are pretty agitated and it's actually really impressive that they're they're that we don't actually deal with neuro agitation more in this population, so.

The unfortunate thing about having that much pain all the time is that for your brain, pain is like riding a bike, right? So I'm not necessarily somebody who rides bikes routinely, but you know, even if even if someone's not ridden a bike in several years and all of a sudden you're like, hey, let's go for a bike ride, right?

They can pretty quickly get back into the hang of things because your brain has already developed that pathway, right? Once you learn how to ride a bike, you can pretty much always ride a bike. And so unfortunately the same thing happens with pain. So this is kind of my explanation of sensitization.

To families. So if you have a completely healthy kiddo, right, and they're experiencing like true pain for the first time, that pain pathway is like an old dirt Rd. right? It's functional. It can send signals, right? You can have a postman actually carry a signal from.

One end to the other end and that pain signal is going to get there, right? But it may not be super effective and therefore the pain may not be as severe, right? Because that child just doesn't have a well developed pain pathway. Unfortunately in little ones who experience pain all the time.

Our body does the exact same thing that the government does. They build a superhighway, right? So that we can effectively transport those signals from point A to point B, which means that little ones who experience chronic pain actually have. Worsening pain and they actually respond to pain a lot faster and they have tend to have an overreaction to pain because these pain pathways are so well primed to deliver pain signals, right? So you can kind of imagine this is the difference between delivery down and old.

Dirt Rd. and Amazon using a six lane highway, right? Obviously Amazon on the six lane highway is going to be way more effective and a much stronger pain signal than someone traveling down a Dirt Rd.

So in addition to having sensitization to pain, I say that six times fast, these little ones also can have centrally mediated pain. So remember I talked about the fact that these pain pathways actually do go through the middle parts of the brain and there's actually some synapses that occur in the middle.

So.

Brain. Unfortunately, when those mid parts of the brain are damaged, as you know, with a big hypoxic event, whether perinatally or after birth, or even when they're older, that means that the mid parts of the brain don't actually function the way that they're supposed to, which means that sometimes you can get these phantom signals.

Just like you have with seizures, where there's this signaling that's happening in the brain that shouldn't be happening, the same thing can happen with pain, where there might where the pain receptors might be triggered, but there's not actually a pain signal that's coming in from the periphery. It's just kind of these phantom pain voices.

Is that these receptors are hearing and then they're signaling pain, this pain pathway through the limbic centers and out to the cortex. And so these kiddos become really agitated, but there might not actually be a true source of pain, but it doesn't mean that the child's not experiencing the pain and the association.

Agitation that goes along with it. So dysautonomia, this is a term that we throw around a lot in this particular pain population or in this patient population. And So what is it? So usually when we're talking about dysautonomia, we're talking about the dysregulated effects of the.

Sympathetic nervous system. And so it oftentimes it's when the sympathetic nervous system is in OverDrive, right? So these kids have really high heart rates, they have high respiratory rates, they get flushed, they're sweaty, they can become really hypertonic to the point of like ipsetonis, where they're like completely arched backwards. They oftentimes can have high.

Temperatures and they don't manage their temperatures very well and they can be really agitated and crying. So it's sometimes you actually can have true dysfunction of the sympathetic nervous system itself, and then other times it's actually because of disorder in the pain receptors and then that is triggering a sympathetic.

Response. So the way that I talk to this with families is I kind of describe how we might respond to bears. So if you or I are out on a hike and we all of a sudden see a bear, our midbrain understands what's happening before our cortex does, right? So our heart rate.

Going to go up. Our respiratory rate is going to go up. Our blood pressure's going to go up. We're actually going to have increased blood flow to our muscles, right? So we can get ready to run, right? Our midbrain is like, hey, adrenaline rush now because you need to get away from this bear. What happens in little ones who have

underlying midbrain dysfunction?

Function is that they can see bears that aren't really there, or the body can perceive some very mild pain in the periphery as this really big pain response. And so then they themselves become these very agitated little bears and very angry bears.

Because they're responding to a situation that may not actually really exist, and it can be a really unfortunate situation and it can be quite difficult to treat. Actually, one of the things to know about dysautonomia is that it can change over time. So when you have dysfunction in the.

Sympathetic system itself. What tends to happen over time is that at the beginning, though the dysfunction tends to mean that there's a lot of high sympathetic signals and so their agitation and tachycardia and high temperatures and high tone.

But as time goes on, those signals tend to drop out and they and the signals actually start like disappearing. And so then these kids actually have the opposite effects, right? They don't have enough sympathetic signaling. And so then they have bradycardia and they have abnormal breathing and hypothermia and unfortunately these little ones.

Can go back and forth between angry bears and hibernating bears as often as they like, which can mean that it's really hard to actually treat these symptoms because even though you may be, they may be responding and think that there's a bear attack during the day.

They might be hibernating at night, which means that they may be dropping their heart rate down into the 30s and the 40s at night, and then you're having to be really thoughtful about the pain medications you're using because a lot of our pain medications can impact some of the vital signs, and so it can be tricky to really treat these symptoms.

I do want to mention that there is an emotional component to pain. So these pain pathways do go through the limbic system. And so there is some trauma to these little ones who experience pain on a regular basis. And whether that's because of real pain from all of those different sources that we talked about or whether it's just.

From some disordered signaling, there is an emotional component to what these little ones are experiencing every single day. And I think it's important for us to remember that and also to be pretty aggressive about trying to treat agitation in these little ones so that they don't have this kind of learned trauma related to untreated agitation and pain.

So in summary, pain in medical fragility is multifactorial, which means that treatment

should be multimodal. And it oftentimes means that we might need to use more than one drug to actually treat this agitation. Because there's many sources of pain, that might mean that we're using lots of different.

Medications to address those sources, but we might also be using multiple drugs to actually address that central disorder of pain as well. And so a lot of times we're pretty hesitant to engage in polypharmacy. But what I would say is in children with medical complexity, sometimes we are engaged.

Reaching in thoughtful and purposeful polypharmacy for some really good reasons, right? And so we're going to talk a little bit about that as we move forward. So these are the neuroreceptors that are heavily involved in the pain experience in little ones who have underlying.

Psychologic impairment. So when we think about the ways that we want to treat this pain experience, we probably are going to be not just relying on pain medications like ibuprofen and Tylenol and opioids, but we might be leaning into some.

Other pain medications as well, even medications that we don't classically think of as being pain medications. So I'm just going to walk through some of these receptors so that we're just all a little bit more familiar of why we may be picking the drugs that we're picking. So GABA receptors, a lot of times we're thinking about benzodiazepines.

Benzodiazepines with these So oftentimes these are used to treat spasticity and seizures and they're used, but we can often also use them to treat dysautonomia and anxiety. Benzodiazepines work really well to treat dysautonomia and part of the reason why is because when.

One of the big features of dysautonomia in this population is that these little ones oftentimes will become very *****. And so if you can help treat the underlying spasticity that allows the child to relax, which actually kind of decreases the signal that really causes this dysautonomia cycle to happen. So.

It.

Really nice drug to neuro agitation. One of the things that you do really have to be mindful of though, is that we use benzodiazepines as rescue medications for breakthrough seizures. So you really don't want to saturate those receptors. And so if you are using benzodiazepines to help treat neuro agitation, especially if you're. Thinking that, hey, this was started on the inpatient side and we might need to use this moving into the outpatient world and it's going to be more long term. You really want to make sure you're touching base with neurology if that child has seizures

because you want to make sure you're not using so much benzodiazepine that you're not leaving any room for rescue. If these kids have breakthrough seizures, I do think that we should.

Think about using benzodiazepines a little bit more for like pre-procedural anxiety. And these little ones, these kids get poked and prodded a whole lot. And obviously there are some side effects to using benzodiazepines. And certainly we do have to really think about the impact that it's going to have on their respiratory drive. But I also think because these kids.

Already have so much emotional impact because of all the pain they're experiencing that we should be thoughtful about making sure that we're not just poking and prodding them. And because they can't say anything, that we're not just continually coming at them without thinking about their anxiety related to all of those procedures.

Voltage-gated calcium channels. So these are the gabapentinoids. I use gabapentin a whole lot in this patient population and that's because it doesn't tend to have a whole lot of side effects to it. One of the main side effects that you do see is sedation. That sedation tends to get better over a week or.

Two of use and I think that the gabapentin really helps me decrease the other pain medications that I might be using. So if I have a family who comes and says, yeah, like my child just really has a whole lot of agitation, but you know, they respond really beautifully to ibuprofen. So I'm giving them a.

I.

Ibuprofen once or twice a day, every single for children with underlying neurologic impairment who are G-tube fed and really high risk for reflux and gastritis and GI bleeding. Not a super huge fan of using ibuprofen every single just because it can have chronic effects. What I do like to do is add.

Some gabapentin on board and then that might mean that I'm able to use that ibuprofen less, right? So that's kind of that thoughtful polypharmacy. I'm probably not going to get rid of that ibuprofen altogether, but I might be able to decrease the ibuprofen use overall.

So when there's not tons and tons of studies behind gabapentin in this particular patient population, there's no big randomized control trial looking at how we use gabapentin in children with severe neurologic impairment. But there are some good case series that looked at some small. There's still small groups of children, but there is a study out there that looked at like twenty-two children.

Children who had severe neurologic impairment and daily pain. And what they found is that gabapentin decreased that pain by about 50%. And if I can give a child, you know, 50% more good days to me, that's worth it, especially when it doesn't have that many side effects. So I tend to use gabapentin.

A whole lot. And again, it's not because I never promised that the pain is going to go away completely, but my goal is to just give overall more good days. We all are pretty familiar with our opioid receptors and opioids. What I will say is I think we probably don't think about opioids enough. Again, we.

Their.

Is such a thing as opioid addiction. There is a real opioid crisis going on, but that's really not occurring in this patient population, right? We're not worried about 5 year olds with severe neurologic impairment becoming addicted to opioids, right?

However, opioids are really, really nice medication to use and neuroad.

Agitation and that's because it's directly impacting the disordered cells, right? So those midbrain cells that have disordered pain signaling, the opioids are acting directly on those cells. The other thing that I would just like to kind of remind people or you know, I guess teach people is that oftentimes.

You're not really having to use really high dose opioids in this population. I've gotten away with just whiffs of opioids, just really low dose opioids, maybe two times a day, and it really makes a huge difference for these little ones. And it also means I'm not heavily relying on my ibuprofen. I have a.

Increased risk of bleeding, right? And then I'm not getting a whole lot of Constipation from it because I'm not using high dosing and I'm not using it multiple, multiple times a day. So again, kind of thoughtful polypharmacy. Maybe you add in some gabapentin and you add in some low dose opioid and you're not getting a lot of side effects from either one.

Because they're using both of them and they're working together in harmony to help decrease overall neuro agitation A2 adrenergic receptors. So this directly, these directly act on the sympathetic nervous system. So clonidine is an A2 agonist, which is actually part of that negative feedback.

Loop and actually shuts down the sympathetic nervous system. These work. So Clonidine works really, really well in neuroagitation. It probably works. It's probably one of the best drugs for neuroagitation, honestly. And when you can get away with using it, it's really nice. The one thing that you have to think about.

With.

Making though is that because of the way that it works, it does drive down the heart rate. And so one of the significant side effects is that you can get bradycardia when you're using clonidine. Think back to those bears that I showed you earlier. So there are little ones who can be really agitated during the day, but then they can go into hibernation mode at night.

And then they're dropping their heart rate down into the 40s and the 50s, and clonidine then becomes a really tricky drug to use for those little ones because now clonidine's going to further drive down that heart rate. So you have to get a really good history if you're going to use clonidine, and you have to make sure that they have enough heart rate reserve.

Serotonin and norepinephrine. We know that these receptors are involved in chronic pain. We know that they're involved in nerve pain, and there's actually good studies behind using these medications. There's concern for nerve pain. I like to throw them on board when I'm worried that there might actually be some.

From comorbid depression, I don't think we think about depression enough in this population. Just because these kids can't tell us that they're feeling sad or because, you know, they don't actually control their own appetite because they're G tube fed. And so they don't have some of the other signs of depression doesn't mean that they don't actually experience depression.

So if I have a little one who's experienced a big life change, so let's say a parent passed away or a parent moved out, or a grandparent who was a main caregiver passed away. Or let's say there's been a big change in the social structure or the social living environment, or maybe there's been.

A big change in function. So I've definitely have kiddos who have pretty significant neurologic impairment who used to go to school and then something happens with their other medical diagnoses and now they really in school and then these little ones get really, really sad and then they can just get.

Really agitated and it can be helpful then to actually try to treat that depression and see if the agitation improves by adding in an SSRI or an SNRI. As far as a THC, these are usually parents who found some drop that they want to add in. This is not usually something.

I.

And recommending what I would say is that I think we have to be, we have to take a good history and make sure that this medication isn't in play. And then the other thing is to actually try to direct our families to providers who are familiar with what

the resources for these drops and medications are in the community we actually. Here up in Austin, we actually have one of our neuro groups here in town uses some of these supplements and they have like a few select few number of the these supplements that they will actually use and so then they can try to better control and have a better idea of what is actually going.

Into the child's system, as opposed to some of these over-the-counter drops where it's not FDA regulated and you really have no idea what the kid is getting from 1 bottle to the next bottle. And so I don't usually advocate that children use these, but it definitely is something that parents will try and I think we just have to be good at getting that history.

And then if it's a parent who really wants to use this medication, trying to direct them to the right person who has a little bit of expertise in using the supplements in the in that are readily available and which supplements to use and which supplements not to use.

For little ones who have underlying movement disorders or who have a whole lot of self-injury involved, I will think about using Risperdone or ariprazol to help with the agitation in the context of those two underlying comorbid issues.

I didn't list dosing out here because that would take a whole lot more time to go over, but this is a really wonderful guide. It's put out by the Dana Farber Institute and it's updated regularly. It's called the Little Blue Book and it's actually it's a very small thin book. It's only like 2025.

Pages.

And it's organized by symptom. And so you can look at the front at the index or the table of contents, pick out which symptom that you're trying to treat. And then you can go to that page and it lists out all the different drugs and all of the different starting doses and how you titrate those doses. So I strongly recommend this is a resource that everybody kind of has saved on their phone.

Because it can be really helpful when you're trying to manage agitation in these little ones. So I want to end with talking about some of the approaches to pain in children with medical fragility, both in the settings of iatrogenic pain and then also in chronic illness.

So first of all, I think we need to think about trying to prevent pain, right? So what can we do to mitigate pressure ulcers? How do we plan for painful procedures? How do we minimize painful stimuli? Can we combine procedures so that we're not poking these children every other month, right? So if you know the child's going to

be sedated, get labs under.

Sedation. Get vaccines, maybe under sedation, combine those painful procedures. So it's so we're only sending all of those pain signals at once instead of sending these pain signals more regularly. Have a really good bowel regimen in place. We know that Constipation is a really serious issue for these little ones and it tends to cause. A lot of pain signaling and then it primes the system. So then if there's pain anywhere else, it just makes the pain overall worse. So thinking about a bowel regimen as a prevention plan for pain, I think is a really good way to talk to families about the importance of a bowel regimen having really.

Spasticity management is also important, making sure that equipment fits well and that kids aren't having injuries related to, you know, rubbing up against their or their wheelchairs. Also thinking about just environmental factors when they're in the hospital, making sure that they're in a position of comfort, adding cushioning if need be, and then addressing.

Any delirium concerns? Again, this population is really high risk for having delirium and I don't think we think about it enough, but we want to mitigate that as much as possible because it's only going to make your agitation and your pain worse. It is really important for us to think through the plan for painful procedures.

So a lot of the ortho procedures tend to require quite a bit of recovery time for this particular population. And so we want to make sure that we're setting everybody up for success. You know, we are pretty familiar with the meds that we use when they're inpatient and there's a lot of guidelines and there's a lot of kind of regimens that are pretty well.

Well, it's kind of set in stone for what happens after the operations. What we sometimes don't take into account is the fact that it takes these little ones longer to recover, two to three times longer, I think sometimes than we really expect. And then we're all struggling with, Oh my gosh, what do we do? Because now we're having a really.

Hard time getting the kiddo off of the opioid or off of the benzodiazepine. So I would recommend consider starting gabapentin 2 weeks in advance and you're going to ask what is the evidence behind that. So there is some evidence, there's not great evidence and some of that is because we just don't have a lot of.

Of these big randomized control trials that are happening in children with severe neurologic impairment that are getting big hit procedures, right? There are some studies that did look at it and the data is a little bit mixed as to whether or not it

helps. But overall the consensus is we need more studies looking at how we would use gabapentin in a PD.

Pediatric population, specifically in a population of children with severe neurologic impairment. But what we do know from the adult world is that there is evidence that using gabapentin prior to surgery and then after surgery can be helpful and it can be opioid sparing, meaning that when gabapentin's on board, you may still need.

Opioids, but you can use get away with using less opioids when you're using gabapentin. The reason I tend to do this is because again, I'm not trying to decrease all pain and get rid of all pain. I don't think that gabapentin is going to do that, but I do think with some thoughtful, selectful polypharmacy, I might be able.

To decrease the amount of opioids that this kid has to use their procedure and then also the amount of opioid the kiddo might have to come home on, right. So if I and I like to start gabapentin 2 weeks in advance because I like for them to have a good blood level and basically be at steady state before they go into the surgery.

And that helps prevent some of the need for long-term pain management or more like bigger heavy duty pain meds after the surgery. I think you should go ahead and start these kiddos on an H2 blocker or a PPI because we know that one of the mainstays of these.

Big ortho procedures is ibuprofen, right? And it's a it's a great drug to use in this setting. It helps a lot post-op. However, I have seen numerous children over the course of my career who get readmitted with GI bleeds because of prolonged ibuprofen use after big procedures. And so we want to make sure we're being.

Really thoughtful. Go ahead and add that GI protection in early so that we're not kind of kicking ourselves later when this kid gets readmitted. And then we need to have a plan for who in the world is going to be managing these benzos and opioids after discharge. We know that it takes them longer to recover, so.

This.

Let's try really hard not to push them off of the opioid in the benzo by the time of discharge. Let's actually just have rather have a plan for who could actually manage some of these benzodiazepines after they leave the hospital and maybe they do go home with some PRN opioid that might help prevent a rehospitalization.

medication because of uncontrolled pain. So when I am managing these kiddos post-op, I again, I kind of set up the expectation that they may need to leave with some of these bigger pain medications and then have really close follow-ups, right? I'm not saying you just send them out into the world.

I have to have a plan for who's following this. And then usually what I do is I try to have a, you know, whenever they go home that same week, I try to have a telemed appointment and then I'll have a telemed appointment the following week, really checking in on these little ones and then trying to actively wean down the opioids and the benzos. I want to get off of the opioids and then.

1st and then the benzos. I always need gabapentin for last. I actually want kiddos to be off of Tylenol and ibuprofen for a week before I will wean off the gabapentin again, because the gabapentin is actually going to have the least amount of side effects even compared to ibuprofen. So I always wean it off last.

So my kind of summary for gabapentin is be quick to think about it and be slow to stop it. And I'll also say it's a pretty easy drug to come off of. So I think sometimes families are like, Oh my gosh, like, is it going to take a big wean? It really doesn't. It takes about a week to come off of it. It's it's really not difficult to come off of gabapentin.

So what do we do with the really fussy patient? Like, where do we start, right? They might be this little one might be admitted for pneumonia, or maybe they're admitted for a UTI, but they're just so fussy. And that's the main complaint that this family has. And what in the world are we?

Postage.

Do for this patient, right? So first of all, go in and get a really good history. Has the child ever done this before? What medications have helped in the past? Does the child have a history of dysautonomia? The family may not have heard that term, but you can definitely run through those symptoms. So they have episodes where they get really agitated, they have high heart rate, they get flushed, they have some hypothermia.

Right. Or they have increased episodes of tone, right. Also be sure to ask, do they have episodes where they have really low heart rates? Like when they're sleeping, what do we think their resting heart rate is? Because that'll give you some clue as to what medications you can and cannot use. You want to look at the physical exam, you know, do they have signs of spasticity?

Well, well maybe that's one of the first things that we really want to go after. And then we also want to think about what pain triggers the child's at risk for. So we want to go back, look at our list, make sure that we're kind of working this pain up and so we can rule some things out. There are some things that are, you know, highlighted in yellow that are diagnoses of exclusion. So after you kind of go through.

Through the workups for some of these other things, you may find that maybe there really isn't some obvious reason why they're having pain, and maybe you really do think it's just some centrally mediated pain or some visceral hyperanalgesia. So while you do the workup, go ahead and try some Tylenol or ibuprofen if you're going to be scheduling an NSAID.

Again, think about adding in some GI protection. But what if the child is really, really agitated and that's not enough? Well, then we start thinking about our bear sprays, right? So we're out in the woods. This kiddo is seeing bears. They may or may not really be there, right? But we know this child's having a really exaggerated response. So then I'm going to go.

To my bear sprays, right, which tend to be my clonidine, benzos, gabapentin and opioids. Gabapentin is a really good long-term bear spray, right? I tend to use it a lot on the outpatient setting. It's not as helpful on the inpatient setting because it does take a little while for it to work. So on the inpatient side, you might be thinking more about clonidine.

Those.

Maybe using an opioid. First thing to do, go ahead and look at their Med list. Are they already on benzodiazepine? Do they already get some Klonopin for spasticity? Do they already use some Klonidine for sleep? Well, if we if they do, then you know that they tolerate that drug. Could you just add in an extra dose, right?

Know that that their their body responds well to that medication. Why don't we just go ahead and increase that medication and trying to reinvent the wheel. Let's just use their med list to our advantage, right. So that's the first thing that I would recommend. If they don't, if they aren't already on one of these drugs, then you can kind of look at their.

Physical exam and kind of decide what you might use. If they seem to be in really sympathetic system OverDrive, you might go for something like clonidine. If they seem if spasticity seems to be the main feature, then maybe you'd go for a benzodiazepine.

If you really think it's pain that's triggering, then maybe you go for an opioid. Again, just remember you have to get a heart rate history. I've been burned by this, which is why I've mentioned it like three Times Now because these kids come outpatient and then, you know, the home health nurse is like, hey, I'm so their heart rate's like in the 30s and then the family doesn't want to stop the clonidine because it does.

Does work really, really well. And then you're like, yeah, but we can't have our heart

rate in the 30s. So always be sure before you start clonidine, know what you're getting into. So this is just kind of a diagram of the neuroimpairment symptom cycle. And so this is what we tend to see with these little ones. This gets triggered by some type of illness, some type of pain and then all of a sudden.

We have this dysautonomic symptoms, they become *****, they get agitated, then they don't tolerate their feeds and then they get seizures and that just makes them more dysautonomic. And then we just get into this horrible cycle, right? And So what we're doing with these medications here is trying to figure out what is the best way to stop this cycle so that we can help this child be.

Less agitated, just kind of a quick run through drug, drug interactions. You do have to think about it in this population. These kids are on a lot of medications, so you do need to be worried about serotonin syndrome. That is real. I have seen it and I have seen it be missed because it's just not something that we see.

Very often. So these are the signs and symptoms of serotonin syndrome. Most often in this population, what we're going to see is these kiddos be more tremulous and you need to kind of go back and look at the medication list. If they are on an SSRI or an SNRI, then they are high risk for this happening when you start adding in additional medication.

We do need to think about over sedation and vital sign changes, and we also need to think about QTC prolongation. I strongly recommend that you put the med list through a drug interaction checker. This is the one I use. If you actually create an account, you can put like 10 drugs into this interaction checker and it can be really helpful.

You know whether or not you need to get an EKG or whether or not you need to be worried about serotonin. Serotonin can be really tricky. Sometimes it, you know, there are drugs that we don't really think about like ciproheptine or phentylea that had act on the serotonin pathways and we just forget that serotonin is involved. So always be on the lookout.

For that. So just kind of in summary, if kiddos have chronic pain, that probably means when you're adding these pain medications that they may become chronic medications. So we need to really think about those long-term side effects. We need to think about who is going to manage it before we send them outpatient and make sure that everyone is really comfortable with that.

Dosing and with that I'm going to end. There are some additional resources here for you if y'all send out the slides, but I'll take questions if you have any.



Kamat, Deepak M 54:07

Thank you, Doctor Vander Meer, for that fantastic presentation on treating pain in children with medical fragility. Let's see if anybody has any questions, comments.

I'm monitoring the chat box. You can also ask a question directly.

There's a question in the chat box, Rachel. Any experience with the newly approved pain Med sugistregene, the NAM 1.8 sodium channel blocker?



Vandermeer, Rachel J 54:39

I do not have experience with that pain medication. I would have to look more into that. That's not something I've used with my little ones.



Kamat, Deepak M 54:49

Any other questions?

Go ahead and ask your present. Ask your question, please.



patherndon 55:09

Yeah, well, I I I lived in a city and and trained in a city and taught in a city that had a very large African American population. And so we had to have two clinics.

For one clinic for adults and one for children for sickle cell disease. And this can be get to be a really bad problem in terms of stuff and it really opened my eyes the first time I saw a parent.

Correct her child's behavior for drug seeking behavior right in front of the physician. So there's that problem.



Vandermeer, Rachel J 55:53

Yeah.

Yeah, they're definitely, you definitely have to be more aware when you're dealing with those who are neurotypical, right, which is what you usually are dealing with in the setting of sickle cell, right. Sometimes those kiddos do have strokes and so they're not always neurotypical, but usually they are. And so that definitely.



patherndon 56:11

Yeah.

VJ **Vandermeer, Rachel J** 56:14

It's kind of a totally different talk, right? Because you definitely have to be more aware and it's a fine balance, right? Because you want to make sure that you're treating pain, but you also want to make sure that you have all of that accountability, that you're keeping everybody safe and it's it's a very fine line to walk for with that particular population.

P **patherndon** 56:34

Well, what I found was that sometimes the six-year-old kid that was drug seeking behavior, suddenly he's a 20 year old and he has a a a flourishing business. Prescribers giving him opiates or herb. It's a problem.

VJ **Vandermeer, Rachel J** 56:59

It.
Yeah, I mean, these drugs are, they can be very dangerous, right? And as can many other drugs. And I think that, you know, sometimes the opioids, we really focus in on the opioids, but there's a lot of benzodiazepines in these houses. And I have seen benzodiazepines be used inappropriately by family members.

P **patherndon** 57:19

OK.

VJ **Vandermeer, Rachel J** 57:20

More than I have opioids because there tends to be more benzodiazepines in the House of children with underlying neurologic impairment. So I think it's just a good reminder that and then gabapentin can also be misused as well. And so I think it's just a good reminder for us to be thoughtful and to have conversations with families and really the most important thing is that we have.

P **patherndon** 57:26

Yeah.

VJ **Vandermeer, Rachel J** 57:40

Have relationships with these families. We shouldn't just be prescribing these medications and sending them off into the world. We need to be meeting with them frequently. They need to be established in a pediatric home where they're being seen regularly so that we can assess for these things and we can assess for abnormal behavior, not just in the child, but also in the parent.

 **patherndon** 58:00

Well, thank you for this wonderful lecture.

 **Kamat, Deepak M** 58:00

Thank you, Dr.

 **Vandermeer, Rachel J** 58:03

Yeah, need to help.

 **Kamat, Deepak M** 58:03

Yeah, there's another question in the chat box. How quickly are you comfortable to titrating up gabapentin in hospitalized patient?

 **Vandermeer, Rachel J** 58:13

Yeah, so you're gonna actually titrate it up pretty quick. So I usually start out with 15 milligrams per kilogram per a day and you can titrate that up over three days. So I start out with an evening dose, 5 milligrams per kilogram and then go to BID and then TID. So within three days you're.

Really kind of at that 15 milligrams per kilogram dosing, but even like in, you know, later in the week, you could continue to go up. You know it has a pretty large safety window. The thing that you're most worried about with gabapentin is the sedation. So as long as you don't feel like you're getting a lot of excess.

Sedation, then you can continue to go up. Usually average dosing that I'm aiming for is 35 milligrams per kilogram. There are individuals who will really try to push that dose up to like 50 milligrams per kilogram. I've see 5 zero. I've seen, I have seen people really try to.

Push beyond that. I don't think there's much. I don't think that's very helpful. I really try to stay around 3535 milligrams per kilogram. I might get up to 40, but after that then I'm usually looking for some other drug. But I do want to get to that 35

milligrams per kilogram to know.

That I've actually really gotten as much benefit out of that drug as I can. If a kid is already on gabapentin, you know, let's say they're sitting at like 20 milligrams per kilogram, just bump them up. It's pretty easy to you're not really gonna get a whole lot of side effects from it.



Kamat, Deepak M 59:48

Any other questions? There are two comments, Doctor Williams says. Excellent presentation, Doctor Lipsitz. It is refreshing to hear a talk on pain that didn't concentrate on addicted adults.



Vandermeer, Rachel J 1:00:00

Happy to help. Again, opioids, they they are a risk, but they're not necessarily a risk in this particular population. And so we just need to be thoughtful about it and use it when it's appropriate, right? All drugs have side effects and all drugs can have serious reactions.

But that's including all drugs. And as providers, we can know when to use them and not use them and don't necessarily have to be overly frightened and using a medication that might be the best medication for the particular symptom. So thank you so much for having me. It was a real pleasure.



Kamat, Deepak M 1:00:32

OK. There's Rachel, there's one more question, maybe last question. In addition to melatonin proposed sleep, what are you, what are your thoughts on clonidine versus imidipytline versus Trazodone versus Benadryl? Or do you prefer another med?



Vandermeer, Rachel J 1:00:50

Yeah, so clonidine is probably a mainstay. I also use gabapentin a lot for sleep. I don't. I couldn't hear if that was one of the ones that was listed. But gabapentin, because it does cause sedation, it's a really nice medication to add on to help cover for both some chronic pain and some agitation as well as sleep.

I'm not a huge fan of Trazodone because it has some serotonergic activity and it just freaks me out. I think when you start adding in that, it's just a very dirty drug. And so sometimes that's nice, right? In certain populations when you have nerve pain and you have sleep problems and you have some, you know, underlying depression

issues.

Use an agitation like sometimes you're using that dirty all those receptors to your benefit, but sometimes I think it gets just added on and people forget all of the receptors that it hits. And so I tend to prefer clonidine or gabapentin.



Kamat, Deepak M 1:01:44

Doctor Vanderbilt, thank you very much for that outstanding presentation on pain medication in children with medical fragility. Thank you all for attending this morning's grand round. I'm to conclude. Thank you all and we'll see you next Friday.



Vandermeer, Rachel J 1:01:57

Thank you, bye.



Kamat, Deepak M 1:01:59

And.



Kamat, Deepak M stopped transcription