

RAPS: Rehabilitation for Amplified Pain Syndrome

Amplified pain syndrome (APS) is a condition in which the child's perception of pain is increased due to the abnormal firing of nerves which sense pain and control vascular tone. Amplified Pain Syndrome (APS) can include: Juvenile Primary Fibromyalgia Syndrome, Complex Regional Pain Syndrome (CRPS) (formerly Reflex Sympathetic Dystrophy (RSD)), and other types of nerve-related pain.

Treatment is as unique as the condition itself: intensive exercise, physical and occupational therapy; relaxation techniques; stress-management training; and music and therapeutic art.

Cara Hoffart, DO is here to explain how the RAPS program (Rehabilitation for Amplified Pain Syndrome) at Children's Mercy is one of only a few treatment programs in the country and has attracted patients from as far away as Lima, Peru.



Featured Speaker:

Cara Hoffart, DO

Cara Hoffart, DO, is a pediatric rheumatologist and Director of Rehabilitation for Amplified Pain Syndrome at Children's Mercy, and Assistant Professor of Pediatrics at the University of Missouri-Kansas City School of Medicine. Dr. Hoffart received her medical degree from the Oklahoma State University Center for Health Sciences. She completed her residency in pediatrics at Children's Mercy and a fellowship in Pediatric Rheumatology at The Children's Hospital of Philadelphia. Dr. Hoffart's research interest is in defining predictors and risk factors of development and refractoriness of pediatric amplified pain syndromes.

[Learn more about Cara Hoffart, DO](http://www.childrensmercy.org/templated.aspx?id=3589&doc=486)

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Transcription:

Dr. Michael Smith (Host): Our topic today is rehabilitation for amplified pain syndrome. My guest is Cara Hoffart. She is the Director of Rehabilitation for Amplified Pain Syndrome at Children's Mercy and she's also the Assistant Professor of Pediatrics at the University of Missouri Kansas City School of Medicine. Dr. Hoffart, welcome to the show.

Dr. Cara Hoffart (Guest): Thanks so much for having me. I appreciate the opportunity to discuss this somewhat unknown condition in pediatrics.

Dr. Smith: Sure. Why don't we start there? What exactly is amplified pain syndrome?

Dr. Hoffart: Amplified pain syndrome is an umbrella term that actually includes juvenile fibromyalgia, complex regional pain syndrome, localized pain, neuropathic pain, central sensitization syndrome. It's more of a catch-all term that refers to conditions where children's perception of their pain is increased due to the abnormal firing of nerves which sends pain into a control vascular tone.

Dr. Smith: So, hence the word amplified, right?

Dr. Hoffart: Correct.

Dr. Smith: What age group are we looking at mostly here for amplified pain syndrome?

Dr. Hoffart: The range that we typically see in our clinic is about age 10, which is definitely on the young side, but age 10 to 17 or 18 years old. The majority of our patients, though, are about age 13-16. That's where most fall and about 80% of patients are female.

Dr. Smith: Right. That's about what we see in the adult population, again, for a lot of these pain syndromes.

Dr. Hoffart: Correct.

Dr. Smith: Any recent research highlighting some of the causes of these pain syndromes? Anything new out there that you find interesting?

Dr. Hoffart: These pain syndromes really are a result of a very complex biopsychosocial model. Definitely, in both animal models and in human research, showing basically an overactivity of the nervous system that's firing--specifically the sympathetic nervous system--sending too many pain signals and they're too great in severity also affecting vasculature as well. Basically, that pain signaling is also influenced by genetics. We have found that there are genes associated with chronic pain. It's not unusual to find chronic pain run in families. We know that the hormonal system is involved and often we see the emergence of these pain syndromes as our patients are hitting puberty. A lot of my female patients notice that every month when they have their periods that their pain is much worse around that time with those hormonal fluctuations. Research is showing that there are even changes in the immune system long-term in patients who have chronic pain. Basically, there is no system that is not affected by pain and we know that there's this physiologic and nerve and blood vessel component. Ultimately, with the blood vessel piece, it's hypothesized that the blood vessels actually will clamp down, which increases lactic acid in the body, which decreases oxygen delivery, which further sends additional pain signals to the brain. Because of that, you get autonomic symptoms with pain such as dizziness, swelling, color changes—a lot of interesting symptoms that patients will complain of. Then, on top of that, we also talk about the fact that as much as this starts out as a true nerve and blood vessel issue and there's a lot of passive physiology that we know about – we don't know everything – but, in addition to that, being in pain, of course, is a very emotional experience. No one is actually created to endure pain all the time. So, being in pain all the time increases stress. Stress further increases pain, which further feeds into that loop. Being in pain, of course, increases feelings of sadness and anxiety and depression and nervousness. A lot of those things start to emerge in our patients, as well. Most of my patients, because their pain has become so severe and so disabling, they're not in school anymore. They don't do the sports they love. They're not doing things with friends and family. Their lives are very altered. Not to mention the fact that the families, usually, are searching for the country for a diagnosis. They're searching for treatments using to no avail. It's very frustrating. Just even the stress of that further increases their pain. So, just a very vicious cycle.

Dr. Smith: Obviously, treating this is going to be very challenging just based on the fact that there is a multifactorial etiology going on. Before we get there, what's the role of the primary care pediatrician in

all this? At what point do they need to realize, “Okay, I’ve got to send this on to a place like Children’s?” Or, what do you do for the primary care physician? Are there workshops, educational opportunities for them? What role is Children’s Mercy playing in that?

Dr. Hoffart: I think that’s a fantastic question because I think the primary care providers have a huge role in this and, sadly, there is a lack of education about pain, in general, even in our medical training. I actually didn’t have a single class on pain when I was in medical school.

Dr. Smith: I’m not sure that I did either, now that I think about it.

Dr. Hoffart: Right. I just happen to stumble upon a mentor who is doing this in Philadelphia. I loved it. I saw how disabled these patients were and they can actually get all the way better. Most pediatricians just aren’t armed with the knowledge and the education to know what to do with these families. On top of that, our medical system isn’t really meant for pediatricians to get to spend a lot of time with their families anymore. The amount of time that I spend with these patients on a new visit – I usually spend an hour and a half to two hours with the family. But, that being said, I’m building a rapport with them and I need to get that time for the medical history. The benefit that the pediatricians have is that they have established a relationship with these families already over time. While it’s really important to work up pain adequately and make sure we’re not missing an inflammatory condition or an orthopedic condition, the reality is a lot of these kids have probably a little too much medical work up. Which further can continue their pain cycle and over medicalize them and even make them worse long-term because of the continued fear and worry about what is happening can actually make this worse. So, there comes to a point where pediatricians – if all the labs are normal, if the imaging is coming back normal and there’s still a lot of pain and the pain is just out of character and just greater than you would expect for what you’re finding with your work up. Then, it’s probably time to talk about these types of conditions. We definitely have a lot of resources on our website available for pediatricians through our pain management and RAPS website. I have been talking with the AAP for the last two years – actually, this will be my third year coming up – to discuss amplified pain syndromes and what the general pediatrician can do. We’re actually in the works to develop an educational seminar, hopefully next spring, here at Children’s Mercy that will be open to area pediatricians as well.

Dr. Smith: I’m speaking with Kara Hoffart. She is the Director of Rehabilitation for Amplified Pain Syndrome at Children’s Mercy. In preparation for this, Dr. Hoffart, I came across an interesting statement from Children’s Mercy about the treatment of APS. It says that ‘treatment is as unique as the condition itself’. Can you explain that for us?

Dr. Hoffart: Sure. That’s incredibly true. This is a confusing condition, first and foremost. Every patient looks different from the next. Some patients look different day to day. So, it’s confusing to medical providers. These kids can be hard to diagnose and they go a long time without diagnosis and without a treatment plan. The way that we treat this, because this is a nerve and a blood vessel condition, of the over firing of the sympathetic nervous system and all the down trail effects from that. This is not an issue with bones or muscles or other types of organic causes in the body. We treat this a little bit differently. Normally, when someone has pain due to an illness or an injury we tell them “You should rest. You should take it easy. Don’t do that anymore.” But when you have pain from amplified pain syndromes and these nerve-related pains, we actually go very different and our mantra is “If it hurts to do something that’s what you should do.: You actually have to start working through your pain and

working on function because function comes back before pain goes away. What that basically means is that you need to be able to walk a long time, do your sports, go play with friends, be at school all day every day. That's function. You actually have to be functional for pain to go away, which is completely unfair. Ideally, your pain would go away and then you would be functional. But, that's not how this works because you actually have to retrain your nerves and blood vessels to know what normal is again and train your brain to see what normal is. As I tell my patients, if it hurts when you start walking and it hurts a lot yet your bones are healthy, your muscles are healthy. Those nerves are sending an alert system saying there's danger with walking. If you're walking and you stop walking because of pain, you've basically just told your nerves they did a good job by firing that pain signal. The next time you start walking, they'll be sure to fire that same signal again but bigger, better, louder. The key is that if you continue walking despite pain because you know you're not injuring your body you actually send a signal to the nerves that walking is not dangerous and it will cause the nerves to – what I tell my kids – get bored and stop firing because they'll recognize that's not something dangerous and there's no reason for them to fire. You actually have to work through your pain and do things that are really hard.

Dr. Smith: That's very interesting. Tell us a little bit about this specific program that you have at Children's Mercy--the rehabilitation for amplified pain syndrome. What's the typical office visit for the patient?

Dr. Hoffart: The RAPS program itself is actually a more intensive day program for patients who have failed traditional outpatient therapies. I first evaluate patients in our multidisciplinary pain clinic where they see myself, a pain psychologist, social work and also get some additional teaching from nursing. It's a pretty lengthy first visit. They're there typically an entire morning just learning about the different ways that we need to work on their pain, both physically and emotionally. Based on that visit, we determine if a patient is eligible for the RAPS program which is our intensive pain rehabilitation program. Every patient who leaves our clinic, for the most part, leaves with a recommendation of a four-pronged approach to getting better for amplified pain. Number one is intense exercise therapy. That's at least 45 minutes a day of aerobic activity, which means heart rate up and sweating. Number two is desensitization. A lot of these patients have pain to touch or ogloszenia. Basically, if it hurts to touch something, rub something, massage something. That's what you should do. They have to do that several times a day as well. It does not feel good. They basically have to inflict some pain upon themselves but it retrains their nerves to recognize normal. We also talk a lot about addressing the emotional side of pain. We typically recommend counseling for the majority of our patients to work on stress management skills so that stress does not show up as pain. We also teach them relaxation breathing and talk about a variety of other relaxation skills. Most of my patients are Type A perfectionistic pleasers and they don't know the first thing about relaxation. So, we really start trying to teach them those things. A lot of patients can actually get better out patient – doing those therapies on an outpatient basis. For kids who then fail outpatient therapies and by the time they get to my clinic, I usually see the most severe kids and they often need the RAPS program, which is basically the outpatient paradigm on a much larger scale. The RAPS program typically lasts 3-4 weeks in duration. Patients are here Monday through Friday from 7:30-4:30. They get 5 hours a day of intensive physical and occupational therapy to really push on that functional piece, build their confidence, build endurance, build strength. They also get individual and group-based talk times of counseling throughout the week. We also teach them a lot of relaxation techniques through yoga, guided imagery, relaxation breathing, aroma therapy. They also learn expressive coping with art and music as we have child life resources available as well. The goal is to get patients functional in a relatively fast period of time. Like I said,

most kids are here 3-4 weeks and you have to be functional, basically, is what we work on – to leave the program. I don't promise that you leave pain free and some people even leave with pain exactly where it was but they leave here functional. When our patients leave here, they can typically go back to school full time. They go back to their sports. The goal is to get them back into life, into being a normal teenager. When that happens we continue to see pain decrease and go away over the following, usually, 3-6 months.

Dr. Smith: That is amazing. You must develop some wonderful relationships with the patients as well. Huh?

Dr. Hoffart: We have really unique relationships with our families. It's really neat. The program has been in existence for about 3 years now. It's neat. We get a lot of updates from kids that were here from three years ago that are doing fantastic.

Dr. Smith: Oh, nice.

Dr. Hoffart: We have amazing success stories and it's very gratifying.

Dr. Smith: That's great. Dr. Hoffart, I want to thank you for the work that you're doing and thank you for coming on the show. You're listening to Transformational Pediatrics with Children's Mercy Kansas City. For more information you can go to ChildrensMercy.org. That's ChildrensMercy.org. I'm Dr. Michael Smith. Thanks for listening.

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