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## Juvenile Idiopathic Arthritis and the OT Role Recorded July 28, 2020

Presenter: Cameron Van Oort, BSc, MSc, MScOT, CHT  
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- [Fawn] The course today is juvenile idiopathic arthritis and an OT role. Our presenter today is Cameron Van Oort. Cameron began his academic endeavors in kinesiology, completing both an undergraduate degree and a master's degree in the field. During his master's degree, he performed research on the effects of physical activity in children with juvenile arthritis. Subsequently, he went on to complete his master's degree in occupational therapy. He currently practices as a certified hand therapist in multiple private practices, treating a diverse range of conditions and injuries. Welcome, Cameron, so happy to have you.

- Thanks, Fawn. Yeah, so we'll go ahead. We're going to talk about a juvenile idiopathic arthritis today and our role as occupational therapists. Just kind of a brief overview. So previously it was called juvenile chronic arthritis or juvenile rheumatoid arthritis. And now the name has become juvenile idiopathic arthritis, just to have a common name just so that we can all have a basic understanding of juvenile arthritis and refer to it under a common name. Sorry, I just gotta advance my slides. So, no disclosures on my end. No financial disclosures or relationships to disclose, aside from the honorarium from OccupationalTherapy.com And the learning outcomes of today are to first discuss the disease process of juvenile arthritis and then recognize the various impacts and sequelae of JIA. And then finally, to identify some interventions for children with juvenile idiopathic arthritis. So kind of first to discuss synovial joint structure. So as we know, we have three types of joints in our body, fibrous joints, for instance, in the skull, cartilaginous joints, for instance, in your spine, and then synovial joints, which are found all over the body and very affected by arthritis.

So as you can see here, it's kind of where two bone ends meet. And then right over top of that bone, we have our fibro cartilage, which is a bit more dense. And then over top of that fibro cartilage we have what's called hyaline cartilage and it's a bit softer and provides more cushion to the ends of the bone. And then kind of on the surrounding area we have our articular capsule and on the outside we have what's called their

subintima and that is a bit more dense and provides a bit more structure. And then the intima, which secretes the synovial fluid into this joint and that also provides cushion as well as nutrition to the joint. And then we have our ligaments, intracapsular ligaments as well as extracapsular ligaments and intracapsular ones are within that joint capsule and the extracapsular ones are outside of that joint capsule. So in terms of arthritis, comes from kinda the root words and Greek words, being arthro, meaning joint, and then itis meaning inflammation. And so, and when we think of the adult population typically we think of two main forms, one being osteoarthritis and then the other being rheumatoid arthritis. And with osteoarthritis it is such that the bone rubs on kind of the other end of the bone as we use our hands or use our feet, knees, whatever body part, and the bone ends rub. And then that leads to wearing down of that cartilage that we spoke of. And as that wears down it creates some inflammation. As that inflammation occurs it stretches out those ligaments and then as those ligaments stretch out the joint is less stable. And then there creates more rubbing in that joint, which eventually leads to joint laxity as well as obstructive bone growth.

So there's a bit of extra bone growth because it's bone rubbing on bone. And that's what you'll typically see when individuals have nodules kind of on the back of their interphalangeal joints or nodes on the back of their interphalangeal joints due to extra bone growth. And it ends up being obstructive because it limits the amount of movement. And then in terms of rheumatoid arthritis, it's the autoimmune disease where the body attacks itself and creates inflammation within a variety of joints as well as other body structures, including the heart and potentially the eyes. And so we'll get into juvenile arthritis in terms of various subtypes and how those kind of relate to this. So juvenile idiopathic arthritis is definitely a heterogeneous group of diseases. So it's not all the same. And as you can see here, there's seven different subtypes, which can vary greatly depending on the subtype, as well as depending on the child. It is an autoimmune disease diagnosed in kids under the age of 16 and the symptoms have to last for a greater than six weeks. In terms of those seven subtypes the most severe,

also the least common, is systemic JIA. And that is kind of a full body. The joints are inflamed, as we spoke of the synovial joints, but also you can get pericarditis or myocarditis where the heart also has issues. And then we look at kind of oligoarticular, also called pauciarticular arthritis, or juvenile arthritis. And that's when less than five joints are involved and you have extended oligoarticular arthritis, which initially is less than five joints and then progresses to five or more. Or you have persistent oligoarticular arthritis, which it remains kind of less than five joints. In terms of the next two, there's polyarticular rheumatoid factor positive, and polyarticular rheumatoid factor negative. And those are five or more joints.

Obviously, the one being where the client has rheumatoid factor positive and the other being where the client is rheumatoid factor negative. And then we have enthesitis related and enthesitis related is the joints themselves are inflamed and affected, but also the insertion of tendons into the bone, as well as the insertion of ligaments into the bone. So if those extracapsular ligaments become inflamed and where they insert into the bone is also inflamed, as well as the tendons around the area, then it's typically labeled enthesitis related JIA. And then we have psoriatic juvenile arthritis or juvenile idiopathic arthritis. And with that, there's the sort of concept of arthritis, but then there's also psoriasis that comes into play. And typically with these kids, you'll see uveitis as well, so inflammation in the eyes. And then finally, undifferentiated JIA is where they don't fit into one subtype. So it's multiple subtypes or they just don't fit into any of those subtypes and the rheumatologist still believes it is juvenile idiopathic arthritis. However, all that being said, the International League of Associations of Rheumatologists, or the ILAR, is currently going through a next step to make different subtypes. Basically grouped into four different subtypes.

So these groupings may change within the next five years. So if we look at kind of common symptoms of JIA, we have arthritis, which as we know, is inflammation of the joints. We have arthralgia, which comes sort of hand-in-hand, pain within the joints.

Uveitis, as I said, which is inflammation within the eyes. Obviously these kids, if it's in the knees or ankles, there's going to be some limping involved, especially if it's significantly painful, as well as fever, skin rash and abdominal pain. And there's numerous other also symptoms that can present. And so the etiology or the cause of the disease, we still label it idiopathic meaning that there's no known cause, however, the research is definitely advancing in terms of what comes into play with juvenile idiopathic arthritis. And so there is genetic factors. There's a greater prevalence between siblings and twins. And then if we look at kind of a what's called HLA, or human leukocyte antigen, that's been the most researched gene type and genetic research, and it definitely has a role in terms of juvenile idiopathic arthritis. There are other gene complexes as well, but that one has been the most researched. And then environmental factors definitely also have a role in terms of that various pathogens, bacterial infections, viral infections, also leading to kind of juvenile idiopathic arthritis.

So you may hear parents of the kids you treat say that, initially, their kid had some sort of infection or fever and then after that they've developed this juvenile arthritis. So as I briefly spoke of before, the diagnosis occurs in children less than 16 years of age and the symptoms have to last for greater than six weeks. Typically it's done by a rheumatologist or better yet, a pediatric rheumatologist and you have to kind of exclude other conditions. So it can't be septic arthritis where there's an infection in a joint and that's the reason why the joint is inflamed. It can't be trauma related, as if the kid fell and the joint or joints are inflamed because of that. Fibromyalgia will have to be ruled out as well. And then hematological conditions also have to be ruled out. And the difficult part about diagnosing JIA at least is that there's no kind of one litmus test which you can diagnose things off of. So it takes into account the clinical presentation and then also various laboratory tests, including C reactive protein and erythrocyte sedimentation rate, as you see there, CRP and ESR, so those are blood tests. And then also standard radio graphs with x-rays as well as ultrasound to see the joint and potentially see the tendons if it's enthocytis related and then MRI potentially to have a

better image of that joint. In terms of the epidemiology, so the average age of onset is 4.8 years and this is based off kind of the most encompassing research that I saw based off a systematic review. Incidents rates, so as we know, incidents rates are how many new cases are diagnosed per year. And that's 5.7 out of a 100,000 children for boys and 10 out of a 100,000 children for girls. And then prevalence rates how many people have that condition at that specific time. And it's 11 per 100,000 for boys and almost 20 per 100,000 for girls.

So it is more common in females. However, all that being said, there are differences geographically. So lower vitamin D levels living further away from the equator does play a role. It's more typical to have the condition if you do live further away from the equator. Racially also plays a role. And then depending on the subtype, some are more common in certain Caucasians or people from various parts of the world. And then in terms of gender, as I stated here, it definitely plays a role in terms of how common it is. So, kind of diving in a bit further into the epidemiology, oligoarticular JIA, or less than five joints involved, is the most common subtype. It definitely is a good thing because it's the least severe subtype of juvenile arthritis. And then the most common joints involved are the knees, the hands and the feet. And in terms of kind of the most recent research, it continues into adulthood in about 30% of patients. So not every patient who has juvenile arthritis will have that for the rest of their life. And it is a good sign cause it can give hope for parents and the child, especially in terms of them growing out of the condition. So if we look at the physical impact of the disease, obviously edema or swelling in the joints is a symptom and a physical impact. That in turn can cause reduced physical activity because of that swelling and that pain and kind of the research now isn't 100% sure if it's the disease causing a reduction in strength and range of motion and function, bone marrow density, or if it's the fact that the swelling in the joints is causing reduced physical activity and that reduced physical activity is causing these kind of further sequelae.

So previously years ago, the thought was always to kind of go ahead and do bed rest until it gets better. And now, as more research comes out, bed rest is not the prescription for these children. You do definitely want to have them stay active within reason, but yeah, definitely stay active because otherwise the condition worsens and it's much more difficult to kind of get them back to being, quote unquote, a normal kid. So that's the physical impact. There's also psychosocial impact. So, obviously, pain as it lasts longer and longer becomes chronic. And so these kids have increased pain sensitivity as well as hyperalgesia, meaning that a noxious stimuli or something that would be painful for you and I, is more painful for these children. As well as allodynia, so something that shouldn't be a noxious stimuli, just say, touching the joint, is now painful for them. So that is common in juvenile arthritis.

And, as everyone's probably experienced, when you're in pain it's more difficult to sleep, so these children definitely experienced sleep disturbances. As well as reduced leisure activity because of the pain. And it can also affect their schooling if they have to miss school or just, yeah, because the pain is kind of preventing you from focusing as well as you could be able to. And then reduce quality of life because you can't do everything as a normal kid. Furthermore, with the psychosocial impact these kids sort of show internalizing behaviors as well as externalizing behaviors. So when we're speaking of internalizing behaviors, we're speaking of things where the child feels that inside, but it's less shown us phenotypically on the outside. So emotional difficulties and reduced mood is one of them. Low self esteem, distorted self image and especially these kids, especially if you get it when you're young, you're grappling with why is this kind of happening to me? And then anxiety and depression can definitely occur in these children, especially if the condition is more severe. And then externalizing behaviors, you can see aggressive behaviors and rule breaking behaviors if these kids are in pain a lot. Yeah, it can lead to kind of a short temper, as I'm sure we can all appreciate.

So in terms of the number one goal with treatment, it is a remission. So if they go see the pediatric rheumatologists or even family doctor, the number one goal is to get this condition into remission. Otherwise, the joints can wear down the cartilage as well as the bone. And for these kids who are growing the physis, or the growth plate, can also be affected. And so yeah, there can be growth disturbances and the joints confuse and then you'll lose that motion. And furthermore, there can be malalignment if things become very inflamed and those ligaments stretch out, as we said. There's not as much stability in those joints and they become malaligned. In terms of remission types, we speak of three main types. There's clinically inactive disease. Meaning that at that one point in time, there's no markers of the disease occurring. And then there's remission on medication. And so that means that for the previous six months there can't have been any signs of the arthritis occurring. And then there's remission off medication. And as opposed to six months, it's now you have to be 12 months off medication and there can't be active signs of, of the disease. And so one thing that, knowledge-wise, that we can help parents and the child with in terms of remission is that there is a positive correlation between disease duration and remission frequency. So the longer the child has the disease, the more likely they are to go into remission and experience more remissions.

Now that's not to say that everyone is that way, but it can help in terms of encouraging parents and patients to feel hopeful. So now we'll kind of discuss the OT role and how it interplays with treating kids with juvenile idiopathic arthritis. And the first thing to mention is, typically, you won't see, or at least in Canada specifically, you won't see the kids who are much less severe. It'll be those kids with systemic JIA or a more severe condition who we'll be treating. Assessments, I definitely believe they're the key to developing an effective intervention. So I'll just go through a few different ones and some disease specific ones that we can kind of discuss and you can kind of determine which ones you may use for your specific client. So we have the, just to start general assessments, the COPM, or the Canadian occupational performance measure, where



you can kind of discuss with the child and the caregivers main goals in terms of what they're hoping with occupational therapy and having you there. And in terms of research, self report assessments, or assessments with the child that have them engage with you, they can be done as young as four years of age, but you just need to tailor the questions appropriately. And then Can Child, out of Ottawa, Ontario in Canada, they developed what's called the F-words of childhood disability.

So it's six different words that start with F and they can kind of help the child group various goals and come up with various goals. And so those F-words are function, family, fitness, fun, friends, and future. And so they develop a goal for each of those words. And then they state a reason why they feel that goal is appropriate for them. Another option is the peds quality of life questionnaire, which kind of has various components, including physical, emotional, social, and school functioning. And it is appropriate for kids two to 18 years of age, obviously with the two year olds though it's done by proxy through the parents. Then we have more disease specific assessments specifically developed for juvenile idiopathic arthritis. And so one of them is the CHAQ or the childhood health assessment questionnaire. It has a disability index that is gleaned from the questionnaire and related to function, obviously. And then a discomfort index related to pain and then a health status index. And again, one to 19 years of age, if it's kind of under eight years of age, it is done by proxy through the parents. And it's free for research purposes, no materials needed sort of thing. And then we have the POSNA pediatric musculoskeletal functional health questionnaire. POSNA is the Pediatric Orthopedic Society of North America.

So a variety of surgeons developed this questionnaire, which encompasses sort of disability, pain and health. And it's free and there's no materials needed and can help you glean where the child's having issues in terms of function, as well as pain, and how they're coping with the disease. A few more are the JAFAR, as well as the JAQQ. The JAFAR is just a variety of functional tasks and the child's just ranking them in that

they're able to do them independently, they're able to do them sometimes independently, or they're rarely able to do them. And then you can kind of glean with what tasks they may need help with. And they're very common kind of household tasks and it's appropriate for seven to 18 years of age. And then the JAQQ is a bit more encompassing in that it assesses motor skills, psychosocial functioning, general symptoms, as well as pain. And it does have a wider age range, but again, it's a questionnaire style. The JAFAS, or the juvenile arthritis functional assessment scale, there's 10 tasks that the child is assessed doing.

So it's a bit more objective of a measure. It's free to use. And then you can glean what issues functionally the child is having and develop interventions from there. And then finally, we have the JASI, or the juvenile arthritis functional status index. I think they tried to make it like a nice name so they eliminated the functional and just said J-A-S-I, but it's a functional ability assessment for eight to 17 years of age. And there is a cost, but there's no materials needed because it is more of a questionnaire style again. So in terms of physical assessment, that's kind of what we gleaned from questionnaire based, and there was one physical assessment in there, But to augment that you can definitely just have the child list which joints and how many are painful, swollen, involved, in their condition. With systemic it's obviously going to be a lot more. With all the oligoarticular it'll be a bit more focused. And then you're going to want to assess range of motion, especially for the affected joints. And so for those of you who don't do this often, what I typically teach, if I have students, is kind of ballpark the range that it's at.

So if we're looking at the proximal interphalangeal joint kind of ballpark, okay, that's about 45 and then put the goniometer, sorry, and then put the goniometer on and kind of read that number from there. Because there is sort of two numbers with each. And so just to not confuse yourself, yeah, you do want to kind of ballpark it first and then put the goniometer on and it'll be easier to not confuse yourself with the range motion

that you're getting. And then in terms of strength you can do manual muscle testing, obviously, as well as dynamometry. So you can use a grip strength dynamometer or a pinch strength dynamometer and see how they're doing if their hands are involved in the condition. And then swelling, you can measure it circumferentially with a measuring tape or a figure-of-eight depending on the joints you're measuring. And then the third option is volumetric. So basically use what's called an edema gauge and it's basically a flask fill with water and the child would submerge their extremity in that. And there'd be kind of a spout out of the end and that water would pour the end into cup off to the side, a measuring cup, and then it would show you differences based off how much water was displaced. And they are very accurate if done correctly.

So if it's something you feel like would be appropriate for your client definitely look into that a bit more. In terms of psychosocial assessments, so we have pain, obviously. Kind of first thing being a visual analog scale. Just having the child mark on that line where they feel their pain is, from one end being no pain to the other end being worst pain imaginable, and they mark on that line and then you measure from kind of center point. Usually you'll do about a 10 centimeter line and then you'd measure where they marked on that line. One that's probably more appropriate, and with faces, is what's called the numeric rating scale. And so from zero to 10, again, those anchors are no pain or worst pain imaginable, but the faces also help, from a smiley face to a very sad face, in terms of helping that child describe their pain in terms of severity. And then you can also use the McGill pain questionnaire for kids, teenagers 13 and over. Or you can use the adolescent pediatric pain tool, which we'll go through further into the presentation and the case study. And then two other options are the child behavioral checklist as well as the Connors early childhood. And both of those can kind of help you understand if they're having issues with problem behaviors at all or anxiety, depression, some of those internalizing and externalizing behaviors. Both of those can help you understand that. However, there is a fee for use with those. So in terms of interventions, this is the other portion of the meat and potatoes and what we want to

know. All that being said though, it is difficult in terms of the condition being very heterogeneous. And so one kid is not going to present like the next kid and your interventions will definitely vary based on the child.

So just to start, and not that we're prescribing pharmaceuticals at all, but just to have kind of an awareness level understanding of what these kids may be going through with pharmaceutical intervention, we'll discuss a few here. So there's nonsteroidal antiinflammatory drugs, over the counter things like ibuprofen, naproxen, indomethacin and then there's intraarticular corticosteroid injections. And so those are similar to a synthetic cortisol and they basically get injected into the joint. And the goal with that is to suppress the immune system and bring down the inflammation. And then you have prednisone, which is an oral corticosteroid, which can help. And then we have disease modifying anti-inflammatory drugs, including methotrexate as well as the leflunomide. And then we have biologics, which are relatively newer. The most common one you'll see is etanercept or the brand name for that being Enbrel. So a lot of times what you'll see in JIA is methotrexate used or etanercept. And this is typically injected every couple of weeks with a child. If their juvenile arthritis is severe, they'll go to the doctor every couple of weeks and have that injected.

So exercise definitely plays a big role. And as I kind of discussed before, the initial thought with these children was, okay, have them go through bedrest, let things feel better, and then let them go play again. But that's definitely not the case now. And as more and more research comes out, a lot of it from Holland actually, it discusses kind of the options in terms of exercise. It's still not fully determined what the right dosage and frequency is, but in terms of what the research is discussing right now, low impact for 30 to 50 minutes at a time, two to three times a week and a focus on strength, balance, and flexibility is kind of the best at this point. They've done research so far on a aerobic exercise, like having kids jog, ride a bike, those sorts of things. The evidence isn't as strong as exercise that's focusing on strength, balance and flexibility,

especially if these children's joints are stiffening and they're having that muscle atrophy. So as kinda, you guys understand, it'll definitely improve fitness, strength, function and then it also improves self-efficacy and quality of life. 'Cause these kids can play with their peers a bit easier and it actually reduces the disease activity.

So it's something to educate parents on as well as a child. If it hurts a lot, obviously at that time, you want to get the pain down, but exercise is definitely a good thing. Sitting and not doing anything is not the best option. In terms of orthotic interventions, and as occupational therapists we may know this area well, years ago, before biologics and disease modifying anti-rheumatic drugs, orthotic intervention was more commonplace. Now that pharmaceuticals are working a lot better for these children, orthotic intervention isn't as necessary in a lot of cases. All that being said though, the splinting research is somewhat conflicting. So some of the research has shown splinting after a cortisone injection to be beneficial for reducing inflammation, improving function and improving pain. And then other research has shown somewhat of increased stiffness and increase pain after splinting. So if I were to recommend what you would do as a therapist, I would say discuss it with the child, discuss it with the parents. If the child's feeling like I'm not going to wear that anyways, then obviously it's a moot point and you don't need to spend the time making a splint. But if you feel it will be beneficial definitely monitor them regularly and see, okay, do we need to change things? Is the splint working for them? Is it not? Older research in terms of serial castings, so where you'd cast for this research, it was the proximal interphalangeal joint.

So you'd cast it and try to straighten it out because it's very contracted. It did work well. Not as common, will you see that now. Just because we know more about the disease, pharmaceuticals are better. And so, the goal is not to allow that, those joint contractures to occur. In terms of adaptive aids, so one of the goals with adaptive aids is to reduce the pressure on the affected joints and ideally shift it to larger joints or more joints so that there's not as much sort of pressure on that individual joint. The

other goal is to kind of make things easier. So if there's a reduced range of motion at the shoulder then we may not want the child to have to lift as high. So maybe we have them on a step stool or maybe we lower whatever they're reaching up to, be it a clothes hanger in their bedroom, maybe you want to lower that just so that they don't have to reach up as high. So a variety of options and we probably all know these, but extended comb handles if they can't kinda reach as high or if it's painful to do that in the mornings. Adaptive eating utensils where they don't have to make as tight of a fist. Shoe horns where they don't have to kind of bend over at the waste as much. Velcro, as we know, will make it a bit easier, especially if their hands are affected. Elevated toilet seats, obviously, if the knees are an issue to kind of go into more and more flexion. Wheelchairs, which are rare, but may be necessary, even if it's for intermittent times where they're going longer distance. Just so they don't have to walk as long if they're with family or friends. And then writing aids, as we all know, to not have them have to grip as hard or in as tight of a fist. And Dycem, very similarly, just to make things a bit grippier and a bit easier. So in terms of psychological interventions for juvenile arthritis, there is conflicting evidence as well for this. But better outcomes are shown in children who are affected more by the disease.

So it is somewhat of a ceiling effect in that if a child doesn't really have many issues, psycho-socially, then an intervention is not going to be as necessary. Whereas those kids were a lot more effected a psychological intervention may be more necessary and it obviously should help them more. There's also better outcomes with peer support groups. And so you'll hear a lot of these kids describe that they don't have as many friends and they don't know many people with the condition. And so it's important to them to meet people or meet other children with a condition and kind of feel more normal. The types of interventions research have in mind, body interventions like yoga, meditation, cognitive behavioral interventions, trying to reframe cognition, and how the child's thinking about things, which in turn should influence their behavior. And then peer support interventions, which as I said, are typically described as important for

these children. So now we'll get into a case study. And so yeah, the person we're going to discuss is a made-up person, obviously. So Liam is an eight year old boy. And as I said before, this is kind of how these kids present a lot of times, especially if it's systemic JIA. They may have a significant fever at some point and then the condition kind of develops from there. So he had a significant fever, 18 months ago, it persisted. And then he began getting significant pain, as well as fatigue and reduced function. He kind of went through the process, finally got to a pediatric rheumatologist and was diagnosed with systemic juvenile idiopathic arthritis, about a year ago. And currently he's doing biweekly injections of Enbrel, or etanercept, it's also known as etanercept, and he takes oral naproxen twice a day, or Aleve twice a day.

So in terms of my assessment for Liam, I kind of picked four different assessments. Majority of intervention will be based off a client centered approach. So what he decided where his kind of six areas that he wanted to improve on, but I also think it's still important to do your due diligence and also measure with kind of various other assessments. So as you can see here, Liam decided his goal for function, and you can grab this off the website. It's translated in a variety of other languages as well. So it does make it easy if you're having kids who English is their second language or families doing this it's their second language. You can still develop client centered goals with them. So the first one function, he wants to be able to do his schoolwork with less pain and because he wants to get good grades. In terms of family, he wants to be able to travel with his family a bit easier without getting as tired. In terms of his fitness, he definitely wants to get stronger. He's a hockey player and so he wants to improve his strength. In terms of fun, he wants to be able to play video games with his friends without as much pain because he finds after playing for a bit his hands are hurting. And so he can't play with his friends as long. And in terms of his friends, he wants to meet some new friends with juvenile idiopathic arthritis because he doesn't know anyone yet who has the condition. And then looking into the future, he wants to be able to ride a bike. His parents sort of said, don't ride the bike right now because

his joints are inflamed and he's in pain, but that's definitely his goal, is to be able to ride that bike. So this is the JAFAR. It may be a bit hard to read. I had to kind of take it off their publication. And they gave me permission to do that, but it has 23 different functional tasks. And then the child basically says, can I do these all the time? I'm able to do them sometimes. Or is it almost never? And so anything from taking his shirt off a hanger to getting into bed, walking up five steps.

So there's a variety of functional tasks. And I find this useful just because it can help you glean how can I set up the environment differently to allow this child to succeed? And so if they're only having issues with a few of these then you only have to focus on a few of them. For Liam, due to his condition being more systemic, he may have a bit more problems with more of them. And so yeah, looking into adaptive aids or setting up the environment a bit better just so that he can function a bit easier and a bit more independently. As he gets a bit older he definitely, one of his goals was to function more independently. Range of motion, kinda as I discussed before, ballpark what you think the movement is at and then measure from there, especially if these children are having stiffness. If there's no issues with stiffness then it can be as simple as kind of talking to the child, talking to the parents and observing the joints. It's also important to note kind of when, at what range the child is having pain. So if they're, as simple as the PIP joint, if we're discussing that, if they're straightening and they're getting pain there and then as they go past that it's becoming more painful. It's important to note that and give strategies accordingly.

So maybe do a bit of long duration stretching just to allow the ligaments to stretch out a bit more with a bit less sort of quick movements. And then also heating it up beforehand. So a lot of prescription for these kids is to bathe them in the morning to loosen up the joints and then have the child go through various range of motion exercises. And then for the day they have a bit more movement with less stiffness. As we know, heat kind of loosens the joints and so that can be one of the strategies for



these kids. In terms of pain, so the adolescent pediatric pain tool can be used. And on one side of it you have a image of the body front and back and the child can select where their pain is. So showing the location of the pain. They can also select the intensity on that numeric rating scale. And the quality of pain, there's a variety of descriptors that they can choose to describe their pain. And then there's the temporal pattern to pain. So is it all the time? Does it come and go? And those are various descriptors in the assessment as well that can just help you understand what this child's feeling. As well as help you understand pre-post or mid intervention. Okay, are they feeling better now? Is the pain less severe? Is it less often? So I find this to be a good measure for kids who are age appropriate to use and just to see how your interventions are helping them.

So, as I said before, kind of basing our interventions off of the F-words. So the first one Liam decided was, for function, was to improve it at his schoolwork. So an option there could be speech to text as well as kind of scheduling breaks and allowing more time for his assignments. So it could be talking to the school and organizing like an independent education plan for that child to allow them more time or speech to text when kind of he feels is appropriate. Just so we can give his hands a break. A computer can also be helpful just so he doesn't have to write repeatedly. The traveling with family goal, so bathing in the mornings, as I said, to kind of warm up, loosen up the joints, stretching, and then allowing adequate time for activities. Not having Liam be rushed from one activity to the next can definitely help him. As we know, kinda in the adult population with arthritis, spacing things out is definitely appropriate. And that's part of our joint protection principles. And so the same applies with these kids as you want to give them enough time. And then the third option is if they're walking long distances, is something like a wheelchair. Just for those long distance walks where he could sit down and they could still kind of participate in, whether it's going to Disneyland or whatever the case is. In terms of interventions, further for gaining strength. I think a lot of our role is education that exercise is not harmful to these

children and it definitely is necessary. So yeah, definitely educating the parents as well as the child on, okay, doing activities where you're targeting kind of strength, flexibility, balance will be beneficial for these kids. I mean, plyometrics, something where these kids jumping, is not going to be the most beneficial, but activities like swimming, like biking can definitely be beneficial to increase strength, flexibility, and balance.

And then in terms of his next goal, he wanted to be able to play video games with friends longer. So X-Box or Microsoft makes adaptive controllers and that can be something to look into with him. As well as kind of varying the styles of games that he's playing. So if he's playing something that's a bit more gross motor, like a Nintendo Wii, and then doing games that are a bit more fine motor and varying and back and forth. It'll be more beneficial for him than doing the same thing repeatedly, putting a lot of load on certain joints repeatedly. So the next goal of his was to kind of meet friends or new friends also with juvenile idiopathic arthritis. And so that would be kind of up to us to look in the area and determine if there are peer support groups. Also, the rheumatologists may be recommending certain peer support groups that they know of. You can also educate the parents and the child on various camps. And if we can play this video, you guys can see one of the camps that's based in Ontario, as well as Minnesota. And it's specifically for kids with JIA.

- Jessica, it's time to get up. You wanna go have some breakfast?

- Okay.

- [Jessica Voice-Over] Having arthritis means like your joints will hurt. I had it since I was two. It's hard sometimes.

- [Mom] Jessica's illness doesn't define who she is. It might add an extra obstacle, but it doesn't stop her from doing what she loves.

- [Jessica Voice-Over] Sometimes my wrists, my knees and my hands hurt. To get rid of the pain I put this cream on and I have pills I chew up sometimes. Because of my arthritis they think I can't run, but I can. I like Camp Cambria because I got to see all my friends and there was all arthritis people. I was scared that I was the only one. And then I went to camp and I saw so much people with arthritis. And now I know I'm not the only one.

- [Children] Bananas, go bananas.

- [Girl Voice-Over] I really thought I wouldn't be able to do it so I was really nervous, but on my third try I got it. And it feels great to do stuff that other kids can do as well. I can water ski

- [Jessica Voice-Over] Everyone's special their own way. To the little girl that has arthritis I would tell her, I don't care what they say, she's like everyone else and she could do things actually.

- Okay, so I hope you guys enjoyed the video. Yeah, it's definitely important to have these kids know that they're kind of not alone and there are a variety of options in terms of them meeting other children with a condition and also experiencing a full life. And then finally, Liam's last goal was riding a bike. So definitely continue with the strengthening and balance and flexibility. 'Cause it will be beneficial for helping him to be able to ride a bike. Again, educating the parents that activity's not going to harm the child and adaptive aids if necessary to help the child ride a bike. So if he has issues at his low back and can't kind of bend as far without pain, maybe I raise the handlebars. If he can't push as hard through the pedals without pain and issues, maybe I start with an electric bike. Thicker handlebars is definitely an option if the child can't make as tight of a fist. And yeah, you can go through the kind of gamut of options in terms of

helping them to be able to ride a bike. Yeah, so that's kind of the presentation. Just to wrap up, it is a very heterogeneous condition, as I said, kind of at the start. So you have to definitely base treatment off the child and as OTs we definitely know that. We're holistic and client centered. So you definitely want to be basing things off the individual, but yeah, especially when you get referrals for patients with JIA. You definitely have to look into kind of what subtype it is, what OPIs or occupational performance issues they're having and what goals they have kind of with treatment. So that's it. If anyone has any questions, you can type it in the Q and A and yeah, we can go from there.

- [Fawn] Thanks, Cameron, for a great talk. We're waiting for people, as we're waiting for people to type in, I'll just read. There's a couple of comments here. One person really liked the video. Thought it was very well done.

- Wasn't mine, but yeah, thank you.

- [Fawn] I have a question while people are typing in. Have any of your clients gone to that camp?

- No, I do not have any. The camp is based in Ontario and I work on the other side of the country, out in British Columbia. So yeah, I have not had any clients go there. When I was doing my research I was in kind of the middle of the country as well, in Saskatchewan, above North Dakota area. And it's still a bit of a distance, so I didn't have any kids go to that specific camp.

- [Fawn] Okay, here's a question coming through here. What is the positive correlation between disease duration and remission frequency?

- So I just drew the graph just cause it was, I didn't want to find a copyrighted graph, but it's basically that the longer the child lives with the disease, the more likely they are to go into remission, whether it's once or a second time. So early on, if the child is diagnosed with the disease, they are less likely to experience remission. But the more that time goes by, they're more likely to experience remission. And it's hopeful for parents as well as the child because it doesn't mean they're going to for sure live with the disease forever and there's greater likelihood that things will improve. All that being said though, some people have the condition for the rest of their life. So it's not 100%, but it's definitely a positive correlation.

- [Fawn] Okay, we have another comment. Great presentation, thank you. I don't see any other questions coming in so, oh wait, we have one coming in right now. Let me read that. How do you recommend promoting and advocating for OTs roles in JIA? From personal experience, rheumatologists are more likely to refer clients for PT services than OT services.

- Yeah, I definitely agree on that end. I mean the exercise role is where a lot of the research comes in. So definitely I can see pediatric rheumatologists or rheumatologists referring to PT. But, I mean, in terms of adaptive aids we know it well. In terms of kind of an all encompassing approach as well. Because it would be something to discuss with rheumatologists and doctors in that these children aren't just effected physically. There is also the psychosocial components and we are likely more apt to treating that and helping with that. So, I mean, advocating-wise, it would be something to try to discuss with rheumatologists and try to discuss with doctors for the OT role. I know in Canada, at least we have, or in my area, we have what's called the Mary Pack Arthritis Center. And so they do have a PT and an OT on hand. And things are somewhat divided weird in the sense that the upper extremity goes to the OT, the lower extremity goes to the PT, aside from the feet. So if you're in those settings, you can advocate a bit better. If you're not in those settings then, yeah, I would just say kind of discussing

with people in your community, rheumatologists, what your role could be and how you could help would be a good option. And then as you are helping those children, as they're going back and saying, yeah, it was beneficial. It's definitely going to be somewhat advocating for OT roles, but I mean, it's hard in a lot of practice settings to advocate for us. So I think we just have to keep doing it. And yeah, kind of go from there.

- [Fawn] Okay, we have one last question that came in. We'll take this and then we can wrap up. What is the difference between polyarticular rheumatoid factor positive and negative?

- Yeah, so polyarticular is five or more joints, as I said. As opposed to oligoarticular or pauciarticular. In terms of rheumatoid factor positive and negative, it's a blood test. And does this child demonstrates that the rheumatoid factor positive or are they rheumatoid factor negative? So if there's more than five joints involved and their blood work doesn't show anything then they're going to be grouped under that polyarticular rheumatoid factor negative. Whereas if there's more than five or more joints involved and they are rheumatoid factor positive then there'll be grouped under that. But again, those are changing a lot.

- [Fawn] Thank you so much for a great talk today. There was one last question coming in, but for time I'm going to wrap and have that person please email you. There's the email there. And if any other people have questions that they're thinking about or were in the process of writing, please do so as well. So thank you so much.

- Thank you.

- [Fawn] I'll go ahead and wrap up by saying thank you everyone for joining us today on Continued and OccupationalTherapy.com. Hope you join us again. Thanks very much, everyone.